Divided We Stand: The Collaborative Work of Patients and Providers in an Enigmatic Chronic Disease

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In chronic conditions, patients and providers need support in understanding and managing illness over time. Focusing on endometriosis, an enigmatic chronic condition, we conducted interviews with specialists and focus groups with patients to elicit their work in care specifically pertaining to dealing with an enigmatic disease, both independently and in partnership, and how technology could support these efforts. We found that the work to care for the illness, including reflecting on the illness experience and planning for care, is significantly compounded by the complex nature of the disease: enigmatic condition means uncertainty and frustration in care and management; the multi-factorial and systemic features of endometriosis without any guidance to interpret them overwhelm patients and providers; the different temporal resolutions of this chronic condition confuse both patients and providers; and patients and providers negotiate medical knowledge and expertise in an attempt to align their perspectives. We note how this added complexity demands that patients and providers work together to find common ground and align perspectives, and propose three design opportunities (considerations to construct a holistic picture of the patient, design features to reflect and make sense of the illness, and opportunities and mechanisms to correct misalignments and plan for care) and implications to support patients and providers in their care work. Specifically, the enigmatic nature of endometriosis necessitates complementary approaches from human-centered computing and artificial intelligence, and thus opens a number of future research avenues.

CCS Concepts: • **Human-centered computing → User studies**; • **Applied computing →** *Health informatics.*

Additional Key Words and Phrases: illness work; patient-provider partnership; enigmatic disease

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1 INTRODUCTION

Patient-centered care has emerged as a prominent framework for delivering care, especially in the context of chronic conditions. It establishes guidelines for providers to engage patients and their caregivers in accessible, coordinated, well-informed care [57]. At the same time, self-management has become a necessary part of caring for chronic illness [93].

A rich body of research in interactive technology has established the value of technology and data for supporting providers at the point of care [9, 108] and patients in self-managing their condition [17, 37, 56, 60, 86, 96, 101]. Patient-generated data can facilitate a data-driven workflow of clinical encounters [23, 65, 121]. Some research has focused on understanding and designing for patient-provider collaboration in care [46, 84, 100, 103], and recent work highlights the importance of reflection [12, 49, 72], context [18, 92, 121], and personal narrative [4, 55] in managing chronic illness, with some focus on collaborative reflection between patients and providers [80, 87, 94].

Yet, in practice, many gaps remain in the project of designing tools to support care for chronic conditions, namely to incorporate and focus on domains of everyday life beyond medical aspects and to design for collaborative care [91]. Furthermore, conditions that are enigmatic, or poorly understood scientifically, require substantial effort to understand a patient's illness, work in partnership with a care team, and make decisions about care and management. Our study focuses on endometriosis, an inflammatory chronic, multi-factorial, and systemic condition estimated to affect 6-10% of women of reproductive age [128]. Despite recent research interest, endometriosis remains enigmatic: it has no biomarker for diagnosis, no cure, no standard treatment guidelines, and patients experience unpredictable responses to treatments [2]. To design tools to support the collaborative effort of caring for patients, we must understand the dynamics of the work of patients and providers in this enigmatic chronic condition.

In this work, we utilized qualitative methods to engage endometriosis providers from various clinical specialties and endometriosis patients actively engaged in care. We aim to understand how women living with endometriosis care for their condition, on their own and in partnership with providers. We ask the following research questions: **(1)** In the work of patients and providers when caring for endometriosis, what aspects of their work pertain specifically to such a complex condition? **(2)** What role does technology play in facilitating the partnership and the success of endometriosis care, and what opportunities are envisioned?

We contribute to the HCI and CSCW literature by extending prior research on personal informatics tools to support collaborative work of patients and providers in the context of an enigmatic chronic condition. Overarching themes suggest that caring for endometriosis does not create new work, but rather intensifies every aspect of patient and provider work, as well as complicates their relationship. While some technology solutions exist and are used by both patients and providers, they fall short of supporting them in dealing with a condition with no established medical guidelines nor enough knowledge to produce reliable treatment plans. We identify three opportunities for design along with the design implications of dealing with this complex condition: considerations to construct a holistic picture of the patient, features to reflect and make sense of illness, and mechanisms to correct misalignments. We argue that the enigmatic, complex, and ambiguous nature of endometriosis necessitates complementary approaches from human-centered computing and artificial intelligence, opening numerous avenues for future research and design.

2 BACKGROUND AND RELATED WORK

We provide background on enigmatic chronic illnesses and endometriosis, our disease of focus. We also review HCI and health informatics research around patient-provider collaboration and the work involved in care.

2.1 Enigmatic chronic illnesses

We refer to chronic conditions as enigmatic when they are not well understood scientifically, have unknown etiology and pathology, and when symptoms are often unexplained, biologically undetectable, and seem to vary widely from one patient to another. Care and management for patients living with these conditions are complex, uncertain, and often ineffective. Thus, the illness experience can be frustrating, exhausting, and overwhelming, resulting in emotional toll often compounded by healthcare providers discrediting their symptoms or suggesting psychological origins [117]. There are a surprisingly large number of enigmatic chronic conditions despite today's medical advances, including chronic fatigue syndrome, rheumatoid arthritis, migraines, and irritable bowel syndrome (IBS). The difficulty of diagnosis and the extensive diagnostic delays create a need for the patient to advocate for themselves. This need for advocacy becomes part of the patient's identity, but also carries an emotional burden [75]. HCI research on enigmatic conditions to date has largely focused on eliciting aspects of the conditions from patient reports to design personal health informatics tools [37, 82, 102], to characterize sensemaking [124], and to engage patients in self-experimentation with self-tracked data [61, 62]. Research on tools to identify triggers in diseases with high uncertainty, e.g., for migraine [102, 104] and IBS [23, 24, 61, 103], give key insight into supporting the collaborative use of self-tracking tools, but do not address the additional challenges entailed in caring for a multi-factorial disease, or in aligning the medical expertise of patients together with those of providers.

We focus our inquiry on the enigmatic disease endometriosis, an inflammatory, estrogen-dependent disorder defined by the presence of a tissue similar to uterine endometrium located in physiologically inappropriate body locations leading to chronic, cyclic, and persistent or progressive symptoms [2, 128]. Pain, frequently but not limited to the pelvis, is a hallmark of endometriosis, along with infertility. There is a long tail of symptoms which range widely in description and severity and include gastro-urinary symptoms, dysmenorrhea, and pain associated with sex. Diagnosis and treatment remain problematic and no reliable biomarkers, imaging techniques, or symptom profile sufficient for diagnosis yet exist [118]; the gold standard remains laparoscopic surgery, thus leading to lengthy delays in diagnosis. Additionally, no cure exists although symptoms may be managed and surgery to remove diseased tissue may alleviate symptoms [1, 16, 48]. Symptoms can be debilitating and impact activities of daily living [99], and patients described additional struggles and losses associated with their disease and lack of support: women identified health professionals who trivialized and dismissed their symptoms as most distressing [33]. Findings across the literature support the problematic nature of receiving a diagnosis and care for endometriosis, with a substantial burden of stigma [73]. On the other hand, when patient-centered endometriosis care was implemented, patients reported increased quality of life [3, 35]. Tools that enable patients and providers to work together to understand and manage this enigmatic chronic illness have the potential to improve care, and could be extended to other complex, poorly understood conditions.

2.2 Patient-provider partnership and collaboration in care of chronic illness

Patient-centered care reconciles the traditional biomedical-only frame of disease with care "that is respectful of, and responsive to, individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" [57]. Key to patient-centered care is shared decision-making, which supports patient-provider collaboration and negotiation in approach to care, where both providers and patients have relevant expertise and perspectives [8, 20]. Providing access to clinical documentation has been linked to higher perceived shared decision-making among patients and insights into their own care and self-management practices [47], but patient portals still lack functionality to allow patients to fully participate in care decisions [50]. Patient-generated data can also facilitate shared decision-making, for example, one study with Parkinson's patients found that graphical summaries of sensor data helped to guide collaborative conversation [84].

Beyond the clinical encounter, **patient self-management** is a fundamental component of coping with chronic illness [13], especially in the context of an enigmatic illness, where treatments are not reliably effective at mitigating symptoms. While health professionals consider self-management a routine element of a patient's medical regimen, patients think about self-management as a process to facilitate day-to-day normalcy and structure, often through trial-and-error, working through the emotional toll of illness, and challenging the medical dominance over their illness experience [69]. Patient experience and expertise are not consistently acknowledged in the current medical model or the traditional role of the patient, but are in fact key to patient empowerment and enable pragmatic handling of uncertainty in the intricate day-to-day contingencies of self-management [110]. Patients engage in problem-solving to transfer insights from past experiences onto current self-management situations [53]. Self-tracking tools have been shown to support patients coping with incurable illness by facilitating problem-solving and coping with detrimental emotional reactions [86]. Furthermore, patient expertise allows patients to integrate clinical knowledge into self-care practices and enables finding common ground with providers, supported by incorporating data beyond clinical documentation into care tools [111].

Common ground, as introduced by Clark [26], is the process of building shared knowledge, beliefs, and assumptions which evolve through time in a partnership. The more common ground, the more successful the communication between actors and the better the collaboration; when common ground is lacking, misalignments abound. Coiera [28] expanded on the idea of grounding, suggesting that effort required to ground conversations could happen ahead of time or at the time of an interaction. **Pre-emptive grounding** is best suited for information-focused tasks where information is stable, repetitive, archival, or critical but rare and that may be worth formalizing. On the other hand, **just-in-time grounding** is best suited for communication-focused tasks where new knowledge is exchanged, information is informal, local, personal, or rare, and prediction of what needs to be shared is difficult. Conversations with substantial common ground shared between patients and providers can be succinct, but poorly grounded conversations must be supported with information exchange and often rely on artifacts to facilitate communication, align perspectives in care, and make sense of uncertainties together. For providers, technology has been explored to facilitate common ground in a clinical setting (handoffs in the ICU) with high complexity due to high data volume and coordinating across multidisciplinary care teams [29, 30], but these studies are limited to collaboration within clinical teams, rather than across patients and providers.

Care for chronic illness requires **collaborative and ongoing efforts** to align perspectives and attend to the embodied complexities of illness, beyond treatment and self-management, particularly in situations with substantial uncertainty. Empowering patients and including them as partners in their care is important, but autonomy and independence are not universal ideals. Patient choice does not always lead to better outcomes, with limits on the controllability of disease and the potential for this responsibility of choice imposing burden on patients [88, 89]. Relying on patients for self-management and involvement in medical care has both benefits and downsides [106]. While patients asserting their expertise and questioning medical dominance can help them understand and manage their condition, patients who are not doing everything they can to mitigate or actively seeking to cure their disease may be blamed or deemed a personal failure. Individual responsibility in the absence of a patient-provider partnership may do more harm than good. In fact, patients are not generally looking to be autonomous in their care [38, 39], but rather to partner with providers for decision-making [21]. The role patients play and want to play in their care fluctuates (within and across individuals) and depends on context [66] and trust in the patient-provider relationship [68].

Boundary negotiating artifacts can be used in complex knowledge-sharing tasks to exchange information, negotiate roles and expertise, and establish and align perspectives within multi-disciplinary collaborative teams, like patients and providers [70]. These tools facilitate crossing and pushing boundaries in dynamic, context-dependent situations where expertise are shared and misalignments are common. Chung and colleagues [23–25] argue that using self-tracking in patient-provider collaboration can be conceptualized as a dynamic process of navigating tensions between the patient and provider scope of expertise through creating and using boundary negotiating artifacts. Piras and Miele [95] also explore applying self-tracking implemented by patients to set boundaries and reaffirm independence in self-management. Based on their own understanding of their bodies and patterns, prior research has shown, patients may utilize strategies of noncompliance to further their personal self-care goals or values, based on their own experience and expertise [93, 105]. Widespread use of mobile phone apps for health management suggests opportunities to leverage patient-generated data and health informatics tools to support clinical encounters and meet healthcare needs [13]. **Personal informatics tools**, that enable both collection and reflection of personal health data (e.g., behaviors, symptoms, treatment progress, and general health) [43, 71], can support patient self-discovery independent of their providers and when shared with providers can enable negotiation of roles and facilitate patient-provider communication, support diagnosis and personalized treatments, and enhance motivation, accountability, and engagement with tracking and the treatment plan [23].

2.3 Work across the illness trajectory

In designing for patient-centered, collaborative care, we apply the **patient work framework** that extends design focus beyond a singular biomedical lens of illness by "attending to the embeddedness of patients' health management in larger processes and contexts and prioritizing patients' perspectives on illness management" [119]. By understanding the efforts entailed in care and the dynamics of getting this work accomplished, we can design technology that is responsive to and supportive of the lived experience, local context, and work activities of caring for chronic illness.

Patients with chronic illness and those who provide care for them dedicate substantial effort, time, and resources to care and management. The "illness trajectory" describes the experience of living with the illness, the related work, and the impact of the illness and work on those involved across the course of illness [114], and involves various lines of work overlapping and interacting dynamically over time [31]. **Illness work** (diagnostic, treatment, and symptom management activities) and **everyday life work** (daily or regular tasks to keep up personal and home life) are regular, ongoing activities to facilitate patients' day-to-day lives with their illness [31]. Existing technology often supports illness work, and designs are beginning to incorporate context-aware solutions [123].

Biographical work entails understanding and reconstructing identity and life meaning in relation to one's illness and social history. This effort to understand one's life and identity across the illness trajectory overlaps with the largely implicit and unacknowledged **sentimental work**, necessary towards both humanistic and pragmatic ends [114]. Effort in communication and relationship-building can provide comfort, satisfy social norms (e.g., active listening), and help get back on track after a negative patient-provider interaction. Building trust between patients and providers is critical to establishing a collaborative partnership and can also help motivate patients in their care regimens. One study documented how providers' emotions are used to coordinate care in the ER (e.g., to facilitate a shared mental model about a situation, or to communicate concern as a call to action) and how they are represented (or not) using technology or in paper documentation [85].

Across the illness trajectory, projects or "arcs of work" comprised of tasks (or clusters of tasks) must be coordinated amongst actors varying in experience, skill, knowledge, training, and social location [112]. **Articulation work** is the complex interplay of mostly implicit work that organizes and coordinates tasks and actors, enables tasks to be carried out, and "gets things back on track" after unexpected contingencies [31, 51, 112, 113]. Articulation work has been extensively studied in CSCW, particularly with medical records [10, 11].

Information work is pervasive across the various arcs of work, including articulation work, wherever information is given, received, or exchanged [19, 32]. Patients engage in other forms of information work to facilitate care of chronic illness. To understand their illness experience, patients can produce and reflect on self-knowledge (e.g., symptom self-tracking, diabetes self-monitoring) to gain insights by searching for patterns and linking past information to inform current or anticipate future situations. Artifacts of this **reflexive work** could reduce the cognitive load required, and insights from reflection could mitigate the stress associated with managing illness. Self-monitoring may also enable a process of (re)discovery and (re)learning about one's illness experience through experimenting [81]. Personal informatics tools can facilitate reflection. Work in HCI suggests strategies and tools to support self-reflection and communication, which may allow patients to correct misalignments with providers and articulate their values, self-care approaches, and how these intertwine [72]. Tools with prompts to steer reflection are promising to minimize burden and enable control over disclosure [12]. Beyond the expertise gained from reflecting on one's own lived experience, patients with chronic illness also build lay expertise by consulting online resources, researching established literature, and connecting with online health communities to discuss their unique case and brainstorm broader solutions to fill in gaps in knowledge. This **work of becoming an expert patient** [106] and the responsibility to self-manage can empower patients and reduce stress associated with illness. But while these self-tracking technologies have the potential to empower patients, they also risk adding stress related to the tracking or the illness and may magnify surveillance or pressure for patients to be "disciplined" in their involvement [81, 106].

3 METHODS

All study procedures were approved under our institutional review board.

3.1 Provider interviews

Providers were recruited from large institutions that provide endometriosis care and through recommendations from patient advocacy groups. Eligibility criteria were self-reporting endometriosis expertise in their practice. Semi-structured interviews lasting one hour probed providers about their approach to a typical visit with endometriosis patients, perspectives about shared decision-making in practice, attitudes towards using patient-generated data at the point of care, and use of technology to support care. Preference when recruiting participants was given to provide diversity in clinical specialties and to cover a

***Providers** (N=10)*	***n (%)***	***Patients** (N=21)*	***n (%)***
Gender		Age	
Female	7 (70)	*Younger than 30*	7 (33)
Male	3 (30)	*30 or older*	14 (67)
Years Experience		Years Diagnosed	
Less than 5	3 (30)	*Less than 5*	12 (57)
5 to 10	3 (30)	*5 to 10*	6 (29)
10 or more	4 (40)	*10 or more*	3 (14)
Specialty		Race or Ethnicity	
Gynecologist	2 (20)	*White*	14 (67)
Surgeon	3 (30)	*Black*	5 (24)
Physiatrist	2 (20)	*Latina*	2 (10)
Pelvic Phys Therapist	2 (20)	*Asian*	1 (5)
Pain Specialist	1 (10)		

Table 1. Participant characteristics. Patients could select more than one race; race and ethnicity were asked separately.

wide range of experience (three to 24 years, mean of 9.7 years). Interviews were conducted until we reached information saturation, resulting in 10 interviews. Provider characteristics are detailed in Table 1.

3.2 Patient focus groups

Following best practices of ethical research, our work is anchored with patient advocacy groups and follows citizen science principles [74]. Patients were recruited for the focus groups using social media and flyers hung near clinics. Eligibility for participation were English-speaking adults with a diagnosis of endometriosis, having experienced symptoms in the past three months, and having received care for endometriosis in the past year. Patients were compensated with a $25 pre-paid card for participating in the focus groups. Semi-structured focus group discussions centered around how patients assess their own health status, communicate with their care team, and self-manage their condition outside of the clinical context. Focus groups lasting ninety minutes were carried out until information saturation, resulting in five groups and 21 participants (3-6 participants per group, allocated based on convenience of availability). Patients were all women and their age ranged 21-41 years old (31.5 years mean). Time since diagnosis ranged from less than one year to 21 years (4.6 years mean). Patient characteristics are detailed in Table 1.

3.3 Analysis

Interviews and focus groups were recorded and transcribed for analysis. Transcripts were checked against the audio recordings. Thematic analysis was guided by our goals to elucidate the types of work entailed in endometriosis care and to identify opportunities for the design of technology to support this work. We followed the methodology as detailed in [14]. Coding was carried out iteratively, with initial codes generated broadly as margin notes, then organized to search for and generate themes. The codebook was revised until consensus was reached among coders that data were represented in proposed grouped codes. Themes related to our overall research questions of work of different actors were selected from the broad list generated. Transcripts were coded for themes by two independent coders and discrepancies were discussed. The final Kappa coefficient for two coders was 0.89 [27], calculated using two transcripts. After the coding was complete, a third coder addressed the extent to which coders applied the coding framework to the transcripts. Findings from patients and providers were synthesized, then compared and contrasted against each other. Finally, once the themes were identified, we shared them with our participants for feedback and to assess their fidelity. This type of member checking provided further confidence in our findings.

4 RESULTS

In this section, we describe the results of the thematic analysis of interview and focus group transcripts, focusing on the work of patients and providers that is due to dealing with an enigmatic condition like endometriosis and the technology used or envisioned to support this work. The themes highlight the illness complexity and how this complicates care, the partnership dynamic where patients and providers negotiate and navigate roles, expertise, and expectations within this challenging care context, and the role of and opportunities for technology to facilitate care (Table 2).

Patients and providers both dedicate substantial effort in thinking about, reflecting on, and making sense of the endometriosis illness experience, planning for clinical encounters and care, and caring for endometriosis both with treatments and self-management regimens. Participants described much of this work being supported or facilitated by self-tracking technology and clinical data. Providers keep clinical documentation, but many patients also keep detailed records of their

Theme 1	Enigmatic condition means uncertainty and frustration in care
Theme 2	Multi-factorial and systemic condition overwhelms patients and providers in working together for comprehensive care
Theme 3	Chronic condition with different temporal resolutions adds confusion for both patients and providers
Theme 4	Patients and providers negotiate knowledge and expertise, attempting to align perspectives

Table 2. Overview of themes across provider interviews and patient focus groups.

illness experience and clinical encounters. Individuals use this information for their own self-management and illness work, and can also use it when planning for visits and within the clinical encounter. Despite finding some evidence that some care needs are being met with existing tools, limitations, open challenges, and emerging opportunities were also evident in our analysis.

4.1 Theme 1: Enigmatic condition means uncertainty and frustration in care

Patients and providers both lamented the substantial gaps in medical knowledge about endometriosis, the lack of established symptomatology or biomarkers to monitor its progress, the absence of a cure, and the lack of standard treatment pathways. These complexities came through most obviously in discussions around patients reflecting on and trying to make sense of their disease experience on their own and together with their providers to assess health status and evaluate response to treatment. Participants also spoke about this uncertainty complicating care, resulting in a trial-and-error approach to treatment within the patient-provider partnership and a reliance on experimentation with self-management regimens. Self-tracking apps and symptom journals were seen as useful tools for keeping track of endometriosis. But they noted that these tools fell short in providing insights.

On top of the well-documented burden of **illness and everyday life work** required to facilitate day-to-day normalcy and manage a chronic illness (one patient summarized, *"It becomes its own full-time job,"*) patients described considerable efforts to **document, reflect on, and try to make sense of their illness experience**. Patients reported keeping personal records to varying degrees (e.g., details or high-level summaries, medical only or broad experience of illness) and in different ways (e.g., patient portals, hard copy notes and files, digital notes on smartphone or computer, narrative in journal). Patients frequently mentioned their use of menstrual trackers and other symptom tracking apps to log their data, look for trends, and organize their lives. But, they felt existing tools ignored critical aspects of their disease experience and critiqued their limited functionalities in summarizing data into insights, identifying trends, forecasting flare-ups, and supporting them in organizing their lives accordingly. Patients talked about reflecting on their data for self-discovery, but as one patient put it, *"[It's difficult] go back and look at your apps or journaling to see if you can try to find those patterns; it all looks the same."* This is especially true with no established guidelines or key outcomes to track.

Patients reported relying on their lived experiences and personal records, but mostly feeling uncertain when **reflecting and making sense of their own disease experience**, both for themselves and thinking about what to report to their providers. Because of the enigmatic nature of the condition, patients feel lost in **assessing their health status**. *"Things happen to my body and I don't know if it's related to endo." "I have the hardest time figuring out how I'm feeling. Is how I feel normal? I don't know what good is supposed to feel like." "I'm stage one... but the pain does not feel like stage one, you feel self-conscious like, oh gosh have I been really overreacting, is my pain tolerance really low?" "I've had doctors tell me, 'Well this shouldn't be happening'...well it is happening so what now?"* Patients also exhibited doubt about **assessing their treatments**: *"Is this even working? I don't know how to tell,"* said one patient, and another agrees, *"I suck at evaluating,"* and a third said, *"We're all just guessing."* This difficulty in assessing health status and treatment progress was echoed by providers across specialties. Patients and providers pleaded for technological support when assessing health status, evaluating progress or lack of progress with treatments and self-management strategies, and for considering factors they otherwise may not have thought about, giving them a more realistic or balanced picture of the illness experience.

When planning for care, patients and providers described a **trial-and-error approach to treatment** frequently taken in an enigmatic condition, often experimenting with multiple methods of *"hacking endo"* as one provider called it. Many providers spoke optimistically about this approach: *"I have no shortage of options and combinations of options that we can try until we find something,"* while others encouraged caution and close collaboration with the patient: *"We don't know enough about endo to dictate medications or procedures. I have to encourage patients to be involved with the process."* But patients talked about the toll it takes on them to fight a disease without standard care: *"It became this trial and error, [...] 'Let's try this because there is nothing else left to try.' It was exhausting."* They also perceive the providers' frustrations when treatment options are exhausted. One patient says, *"They are almost exasperated when you don't feel better. I do think that it comes from their own frustration with endo,"* and, *"They get frustrated when the textbook answer doesn't work for you."* With the lack of reliable success with treatments, care often falls to patients to **figure out a self-management regimen** that works for them, which often means a lengthy process of experimentation. They have a hard time figuring out what to try (*"I'm literally willing to try anything,"*) and evaluating if these strategies work to mitigate their symptoms, and could not find technology to support their experimentation.

Several providers suggested designing "self-tracking prescriptions" to support the trial-and-error approach to treatment and self-management, where patients and providers collaboratively select key symptoms, triggers, behaviors, treatment, or self-management strategies to track consistently for a specific period of time. One provider noted the potential for collaboration: *"These are the symptoms that are important to you. These are the measurements that are important to me. Let's see if we can narrow down."* Providers highlighted opportunities to garner buy-in from patients, *"I ask the patient 'Hey, I'm noticing a pattern here. Can you over the next three months track these four or five things really, really well for me? And focus less on these other things?' I think that narrows the scope of all the information that's presented and probably increases the quality of the information that's collected if I ask them to focus on less things."* Seeking their approval, *"What do you think about targeting these domains for symptom control or treatment management over the next couple of weeks or months?"* In the absence of population-level medical knowledge, patients are left to identify individualized disease representations and care plans. Participants envisioned technology to support these experiments by structuring the process of identifying domains to track, trying out treatments or self-management strategies, and evaluating to optimize the most appropriate individualized approach to care. New tools have the potential to support patients and providers in figuring out what is going on, with such little certainty understanding and treating this condition.

4.2 Theme 2: Multi-factorial and systemic condition overwhelms patients and providers in working together for comprehensive care

The multi-factorial and systemic aspect of endometriosis further overwhelms patients and providers on top of the uncertainty brought by the enigmatic nature of the condition. Participants discussed that endometriosis can impact different body systems and can bring on non-specific symptoms, which complicate constructing a comprehensive picture of a patient's status and can result in competing demands in care. This element of complexity calls for a holistic approach to each patient, but also places added demands on the patient to coordinate and facilitate care across specialties. Participants reported difficulty in synthesizing their information and constructing a full representation of their illness experience with current tools. But, providers noted that even detailed self-tracked data can benefit the clinical visit by structuring conversation and focusing questions.

Patients emphasized feeling overwhelmed when **reflecting on their health status** because *"there are so many facets of the disease and there are so many different systems of the body that it can impact."* One patient asserted the value of keeping track of these different aspects and using them to gain insight: *"It's easy to get caught in the different kinds of pain in the different organs. But I think assessing the different kinds of pain also helps linking things together."*

Patients reported putting a lot of thought into **prepping for their clinical visits** (*"A lot of leg work and a lot of work up front"*). They described their process to determine what information is critical to convey to their providers. Patients largely relied on their personal comprehensive medical records, some synthesized their medical history into a generic one-page document, and many tailored their assessment to what they assume different specialists want to hear about. One patient described asking herself, *"What's within their specialty? What symptoms do they cover? What's their box?"* while another emphasized the need *"to come prepared with everything in one place."* Underpinning this planning, patients related the time-consuming and non-trivial **articulation work** entailed in navigating the healthcare ecosystem and coordinating care in a complex context. *"A big part of an endo patient's journey is getting doctors to communicate and being the hub of that wheel to make sure that everyone knows what's going on."* Patients frequently described using health portals to inspect, vet, and fill in the clinical data available to providers, but they reported often running into barriers like limited access to provider documentation and lack of interoperability between different institutions. With self-tracking data, patients complained about disconnected data streams from disparate apps with no way to put them in one place or export to share with providers; they rely on manual methods to bring together and organize information before the clinical encounter, highlighting current limitations. Patients envisioned a system where the patient portal *"was combined with the apps that allow you to track your symptoms. Because right now, it's only the medical records as inputted by your care team. If there was a system for us to put in our own–How we were feeling physically, emotionally, mentally, What our goals are?"*

Like patients, providers across specialties emphasized that they find value in and want to **prepare for encounters**, although restricted time between visits, considerable volume of data, and limited support for reviewing and interpreting data make it difficult to go over clinical and self-tracked data in depth. Providers reported a range of strategies for their preparation work, sometimes looking over patient charts or self-tracked data before the visit starts and other times relying on the first few minutes of a visit to review the patient's history and new information together with the patient. Providers noted how inter-related causes of different symptoms added complexity to their own clinical work and when **reflecting with patients to figure out what is going on with their health**: e.g., *"Is that rectal bleeding because your endo has eroded through your rectum or is it because of constipation due to chronic pelvic pain?"* and, *"Is it chronic pain that was taken over by the central nervous system or is it pain due to a lesion?"* They also noted the systemic impact of endometriosis further challenged understanding a patient's illness experience, sometimes even questioning the patients' reports: *"Sometimes you see patients who come here and everything hurts. You're wondering how much is real, related to the endo, or stuff I cannot help with,"* explained one surgeon, while a physical therapist wondered *"Endo is multi-system, they feel a lot of things in different spots and it's hard to sort through: Did you feel a fleeting pain or was this really disabling?"* To adequately care for this complex disease, some providers underscore the importance of approaching each patient holistically, as a physiatrist explains, *"It's not just their urinary stuff. It's not their GI stuff. It's not their neurologic. I mean, we are standing back and we're putting them all together,"* and a physical therapist says, *"We want to engage not just the pelvis but the brain and the heart in all of it."*

Providers highlighted the complex work that goes into **reviewing and interpreting clinical and self-tracked patient data** from across quite a few domains of health. Deriving insight from raw low-level, day-to-day self-tracking data is cognitively difficult and time-consuming, reconciling these insights with clinical history is complex, and incorporating the information into a patient's medical record adds an administrative burden of manually inputting data due to lack of interoperability. *"I have to make a mental model of what I think is going on based on that data, interpret it, and write it down free-hand into my console note. [...] I have to rely on my ability to quickly process that information and make sure I'm not missing anything."*

Participants imagined technology that could enable interactive exploration of data, balancing between a holistic, aggregated view of a patient and narrowed-down, granular aspects of a patient's status. Providers and patients both expressed desire for synthesized, summary reports to facilitate at-a-glance assessment to get a quick overview of patient data (*"A report rather than raw data because this honestly takes a lot of work to go through all of this,"*) and analytics to support them in summarizing and identifying trends and in discussing these patterns together during the encounter. And while too many details can get in the way of constructing a full picture of the patient, sometimes these details can provide useful clues to disentangle what may be causing symptoms or how to address them: *"Sometimes there is too much information, then you get caught too much in the weeds [...] you just need things that help, you want some granular detail but, you don't want too much that you miss the forest for the trees."* Tools bringing clinical and self-tracked data together could mitigate the multi-factorial aspect of the disease by enabling providers to *"discuss symptoms that patients are feeling, but that we traditionally forget to ask about,"* or *"as a way to target my questions a little more. So, it might not save time but it might get me at more granular information."*

The multi-factorial aspect of endometriosis translates into multiple domains and dimensions to keep track of and treat, but it also complicates **identifying and working towards goals**. Determining goals and prioritizing them required significant efforts from both patients and providers, surfacing several obstacles to this aspect of collaborative work. First, these goals can conflict with each other, as one provider illustrated: *"If you treat pain aggressively, you probably will compromise their fertility. If we support fertility, we often don't completely treat their pain."* Second, goals might be too numerous: *"Nine times out of ten that one goal becomes three or four things,"* Third, patients and providers were not aligned in their goal definitions. Providers dismissed vague goals: *"I ask, 'What's keeping you from 100%?' and all the patient can articulate is 'Oh man', but they don't know what's meaningful for them,"* while patients conceptualized their goals around practical needs: *"I want to be able to take a plane to go see my sister in Florida,"* or, *"My long term goal is to be able to do anything without worrying that I wouldn't be able to do it, and without needing any self-management."* Current tools offer no support operationalizing or translating these goals into treatment plans, especially considering the lack of medical knowledge in determining treatments that could deliver on these outcomes. Patients worried that tracking their goals would be discouraging if they did not make progress, but providers imagined opportunities for technology to help **dealing with setbacks or support during flare-ups by reflecting together**: *"If they go back in time, they could see it was not always so bad and they can hope for better,"* and reviewing past trends so patients *"believe that it's not forever."*

4.3 Theme 3: Chronic condition with different temporal resolutions adds confusion for both patients and providers

The different temporal resolutions of endometriosis – its chronic aspect, its cyclical variations, and its rapid fluctuations in symptoms – emerged as an important complicating factor, specifically when **making sense of the disease and planning for the future.** Patients and providers understand these time frames much differently, which confuses patient-provider communication and prevents building a shared understanding of the patient's experience of illness. Patients often referred to their chronic illness as a journey through the years and life events. One patient framed her illness experience *"in stages of life,"* and others related reframing their life goals in the context of their conditions, along with the disappointment that their illness had caused: *"There's a big element of grief to the endo journey."* In dealing with the emotion and uncertainty about the future, one patient said, *"I'm treating this as an adventure."* In this **biographical work**, patients reported reflecting on their journey to understand their illness history, contextualize their current experience, and forecast what their illness trajectory might look like in the immediate and long-term future. When it came to **reporting their experiences of symptoms** to providers, however, patients felt they could realistically make sense of their symptoms short-term only. *"For me, it's such a daily thing. It's hour-by-hour, day-by-day [...] so when a physician asks me, 'How have you been in the past three months,' that's kind of a tricky answer."* Participants imagined that visualizations of self-tracked data could bridge the gap between how patients experience and want to track their illness and how providers need to see this information.

Providers in contrast conceptualized the patients' health status at longer time intervals, like time between appointments. This resolution difference was frustrating to providers: *"It can be really hard to sort through, if they are like 'and on this hour I felt this way and that way.' Most of us think in terms of weeks instead of days,"* while another complained: *"People don't know how long their symptoms lasted. They don't know when they started. They don't know when they first felt them."* To this end, providers imagined that technology could support patients in recalling details of symptoms and reflect on them to extract useful insights for their care with more synthesis and abstraction than what is currently offered in self-tracking technology. *"When I see them every six months or a year, it gets really, really hard I think from a recall perspective of remembering, 'How did I feel seven months ago? I have no idea.'"*

4.4 Theme 4: Patients and providers negotiate knowledge and expertise, attempting to align perspectives

With so many medical unknowns, both patients and providers related the importance of independent research about endometriosis, as one provider explained, *"If you're not educated enough to be your own advocate, you're not gonna make it."* Patients emphasized the considerable **work of becoming an expert patient** about the scientific nature of their disease across their trajectory of illness: *"I really had to do my own research, tons of hours put into. I feel like I'm a bigger endometriosis specialist than my own doctor."* Providers were aware of their patients' expertise: *"Compared to other conditions I take care of, I found most women that are affected with endo are very well versed in the condition,"* and in fact acknowledged that in contrast to most chronic conditions, *"there is not that much difference between what the physicians know and what the patients know."*

While scientific knowledge can act as an equalizer for patients and providers when reflecting and planning for care, this can introduce a new power dynamic into the partnership. Providers stressed their necessary role in **correcting misinformation and filling in knowledge gaps**: *"I do need to educate and I need to dissipate a lot of preset ideas," "As long as what they are reading is accurate, coming to this understanding that we're on the same playing field, and we all understand is critical."* On their side, patients rationalized their expertise as a mechanism to **ensure communication and getting their experience across** (e.g., by using language that is meaningful to providers) and to **counteract potential knowledge gaps** of providers: *"Doctors have these checklists that might not always be right. So we do our own leg work sometimes to have our own checklist."*

Negotiating expertise to assess health status or determine approach to treatment was commonly considered an asset by providers: *"One of my favorite questions to ask is, 'What do you think is going on?'"* or just part of the clinical dynamic: *"Sometimes, they are totally reasonable. Sometimes, they have the absolute right solution. Sometimes, they have one of many right solutions."* But, patients pushing boundaries may threaten the established dynamic: *"It's your reputation, and it's how you deal with those expert patients. They know they are not gonna win against me,"* said a physical therapist, while a surgeon remarked, *"It is better to have a little bit of ignorance. Because sometimes they read too much, and then it's very difficult to then guide them in their therapy."* Patients were frustrated at providers *"not willing to say when they don't know the answer to something,"* while one praised her specialist's transparency: *"He was the only doctor willing to say, 'I don't know what's going on.' That to me was the entire difference between a negative and a positive experience."*

Because of the inherent complexity and medical uncertainties, providers emphasized the need to **manage patients' expectations** at the start of their partnership: *"It's more difficult to manage if you don't set those expectations, they are gonna expect you to cure them."* A surgeon insists, *"It's important to discuss that we are so behind with this condition. We just try to bandage, this may be a battle that we cannot win."* This sentiment carried across specialties, when reflecting on realistic goals with no cure: *"Our goal is to help you take your pain from a 10 down to a 5,"* and, *"It's important to let the patient know that there's limits to what surgical management can do."*

While patients acknowledged the limitations of treatment and the need to remain realistic with their expectations, they felt unheard and dismissed about their own **illness experience**, especially when it came to their experience outside of objective clinical measures. When preparing for the clinical encounter, patients talked about the **sentimental work** involved in reflecting on their own experiences to figure out how to best present their illness experiences to avoid being dismissed by their provider, how to work through the emotional facets of illness on their own, and how to handle negative emotions if they aren't believed about their self-reports. One patient asserted, *"It feels like a trial, I have seven minutes as a lawyer to prove my case, to present enough evidence, to hit the particular buzzwords."* Patients described intense emotional and cognitive prep-work for self-reflection prior to clinical encounters: e.g., *"I have to be mentally strong before I go in there," "Be vocal about how I'm feeling, no down-play,"* and, *"I go through the litany of emotions before my visits, because sharing emotions with these people, sometimes it's triggering."* Patients commonly felt their provider's understanding of their disease did not align with their lived illness experience.

Patients consider their self-tracking data and narratives as a critical component of their disease status and bring these artifacts to the clinical encounter because they want their providers to be aware of the whole picture and to reflect on the information together. Beyond the value of a holistic picture for care, patients felt dismissed when providers minimized the relevance or believability of this information. *"I'm not tracking just for myself. It's going to be used in a way that's gonna help my care. I've been doing 'that' for years now. I know 'that,' but does my provider know 'that'?"* Patients felt that providers ignoring these data could impair their care: *"I did try to share the technology and maybe one person looked at it. [...] I spent all this time journaling and thinking, 'They might see something that I'm not seeing.' [...] Someone could have noticed this problem six months before."* Providers acknowledged that sharing self-tracking data can act as *"a trust builder between [the patient] and I, so she can choose to show me this or not show me this,"* going on to explain, *"It's a way for people that have been so minimized to say 'My pain is very real.'"* Patients agreed, *"When I have something to show them, it's not just me saying things to them, there's actual records of it,"* hinting that self-tracking data can act as an objective metric, considered more acceptable to providers than a verbal narrative. Participants noted they did not know of any technology to help make sure that providers reviewed these data, or to transform data into digestible information for providers. Instead, they envisioned technology to ensure the patient's experience of illness was fully and accurately represented, and used to anchor the clinical visit.

5 DISCUSSION

Using the framework of work (Section 2.2), our research aligns with prior literature documenting the difficult and ongoing work of caring for chronic illness with tools to support patients and providers in partnership (Section 2.1). Our analysis suggests that the complex and enigmatic nature of endometriosis further complicates the independent work of patients and the collaborative work of patients and providers, and results in a care dynamic that demands significant effort to establish and negotiate common ground, both within and outside of the clinical encounter.

The themes we elicited along with the current uses of technology and their limitations bring about three opportunities for design: **(1)** constructing a holistic picture of the patient that links from and synthesizes clinical and raw, daily self-tracking data into a comprehensive timeline useful to both patients and providers; **(2)** building tools to support patients and providers in their work for reflection and sensemaking in the absence of established evidence or medical knowledge about the disease; and **(3)** designing mechanisms to correct potential patient-provider misalignments and facilitate collaborative sensemaking. We note that, especially in the context of endometriosis and probably other enigmatic conditions, these design opportunities are intertwined and with a fluid and dynamic relationship – addressing one of them will help towards addressing the two others. Next, we describe each, situate them in the literature, and discuss their implications for design. We then discuss the limitations of our work.

5.1 Constructing a holistic representation of the patient illness trajectory

Participants in our study described various documentation strategies, keeping multiple records or compiling them into a single artifact to represent their illness experience (e.g., phone notes or calendar, an app, the patient portal, or hard-copy files). These personal records chronicle their lives across the uncertain and long-term illness trajectory and help with processing grief and maintaining a realistic vision for their lives across their "journey" of illness. They also support patients' articulation work to prepare for clinical encounters, for constructing their own narrative and to optimize provider use. Both patients and providers expressed unmet needs for tools that bring together patient data into a cohesive timeline, to reconcile clinical data across a patient's care team and to incorporate self-tracked and contextual data from the patient's perspective. Such timelines would facilitate a quick and accurate way to tell the "patient story," helping to select, synthesize, summarize, and narrate the data.

Design Implications. With no established clinical biomarker to monitor an enigmatic condition, much of the data representing patient status belong to the patient's lived experience, rather than their clinical documentation. Designs to address the unmet need for constructing a holistic patient picture could **link and synthesize clinical and raw, daily self-tracking data into a comprehensive timeline** useful to both patients and providers. Timeline authoring tools that pre-specify representations of time, scale, and layout enable users to form cohesive and expressive messages across different narrative points [15]; a multiresolution view facilitates exploring and comparing temporal patterns across different granularities [34]. Tools that bring together self-tracked data and clinical data have been beneficial in other conditions. Using life-logs of patients with IBS gave providers insight into patients' lives and priorities, strengthening the relationships that underpin patient-centered care [23]. In fact, when clinical and more "soft" data are siloed, the disjointed view of the patient disrupts finding common ground [111]. From a systems standpoint, recent infrastructure solutions that **provide standards for communication and promote interoperability of data** (e.g., FHIR [45, 79]) can enable bringing together patient-generated data and multiple clinical sources. Furthermore, these mechanisms can empower patients as the actor in control of who gets access to which data, while minimizing the administrative burden to securely export and share data.

The multi-factorial and systemic features of endometriosis, and uncertainty around how different disease dimensions relate to each other, leave patients and providers to sift through an overwhelming volume of raw, seemingly unrelated individual data pieces. Further, the temporal dynamics, and absence of guidance on which dynamics to pay attention to, complicates reconciling temporal events at multiple temporal resolutions and determining which events to include in the patient timeline (e.g., daily and moment-level dynamics vs. week-long trends). Parkinson's patients reported similar difficulty reconciling tracking across granularity, from momentary to the progression across years [86]. Although patients in our study want to use their personal records to reflect and gain insight, prepare for visits, and then work together with these data in the clinical encounter, there is a major breakdown in **transforming artifacts for independent use into artifacts for collaborative use to support care**, a design opportunity also identified by Chung and colleagues for IBS [24]. Bringing together comprehensive data from across domains of the patient's life will require interactive tools to support patients with **data curation**, i.e., features for transforming patients' comprehensive records into useful representations through content selection, organization, and tailoring to both the specifics of each patient and the information needs of particular specialists.

Through curation, patients can tell their own story in a way that is data-driven, personally meaningful, and at their discretion. Shared data supports patients in their articulation work and can validate their experience of disease (e.g., strengthening accuracy, getting providers to believe them). But disclosure of details may also incur unintended consequences [109, 115], e.g., uncontrolled access to mental health domains or to traces of patients' reflexive work who "go through the emotions" related to their illness before visits (to address their own feelings or avoid an emotional reaction from providers) may provoke providers to minimize or dismiss their symptoms. Given the power dynamics within patient-provider relationships, designs should empower patients to determine how to represent their data, e.g., interactive features to transform data into a shareable representation, by aggregating fine-grained details (e.g., automated high-level summaries by day or part of the body), applying contextual filters (e.g., limiting sharing times, days, or locations), enabling ad-hoc data editing, deleting, or transforming, or simply hiding full days or domains from others to mitigating oversharing [41, 83]. Lessons from outside of healthcare can also guide us, e.g., curating personal details for bullet journaling to maintain boundaries while generating a novel and holistic view of a situation [116]. Giving users mechanisms to deliberately include, exclude, craft, and revise representations of their illness can help them frame their own understandings and create artifacts that can help communicate the lived and experiential dimensions of their illness.

Moreover, without an established understanding of different subtypes of the disease, patient trajectories and responses to treatments seem highly individualized. To enable powerful personalization and individualized representations of the illness experience, **patient narrative could further support data curation** of tailored content and structure of patient timelines. With innovative design features, patients can **use self-tracked and clinical data together with their own annotation to reflect on and craft representations of their personal illness trajectory.** Data-based comics [6] offer a particularly promising design direction, where users can reflect on the illness experience with data extracted from broader data exploration, and translate the experience of the data to construct stories. Patients could create different data comic frames using templates and optional prompts. Provided templates can be guided by design patterns that specify panel layouts and how content relates [7]; design factors further specify how elements can be visually represented, how change can be represented, and how to provide an overview along with details [5]. Adding messaging can convey explanations of the data stories, and can balance author-driven stories that narrowly guide attention and reader-driven stories that enable exploration and discovery [107]. These frames could be available in a sandbox environment arranged by both chronological sequence of events and in narrative order, to allow for non-linear stories and multiple versions with different focus, granularity, or comments [64]. Recently, using life-logging with structured prompts and optional photos helped individuals build a case for disability benefits using storytelling to make sense of and synthesize cohesive evidence supporting their claim [120]. The lack of established guidelines in describing patient status in enigmatic conditions might ultimately empower patients to decide themselves what best represents their narrative, without expectations to follow a script.

To account for the added complexities identified with enigmatic conditions that make it cognitively taxing and stressful for patients to identify what to include within shared representations, complementing interactive data curation tools with **data-driven solutions** will be necessary. Machine learning techniques, in particular unsupervised methods which do not expect human guidance, will prove particularly useful for clustering different aspects of a patient's symptoms (for instance, as a review of systems, as body locations, or rather through time), and to automate identifying useful visual cuts of the data [42]. In the absence of medical guidelines, an interactive exploratory data summarization tool for users to experiment with different clusterings as a curation strategy might support patients in formulating different representations and get away from universalizing representations.

5.2 Enabling reflection and sensemaking in the absence of established evidence

A rich body of work documents unmet needs of providers when reviewing patient data and the design of clinical decision support tools to facilitate decision-making for patient care [90]. In patient-facing technology, multiple frameworks and designs have been proposed to support patients in reflecting on different aspects of their disease (e.g., reflection work described in section 2.3), making sense of their needs and care plans (e.g., [78]), or problem-solve with particular aspects of their condition (e.g., [77]). Sensemaking in other enigmatic conditions has helped patients describe their symptoms, identify triggers, and evaluate treatments [124]. In our study, patients confirmed that sensemaking was a particularly complex activity; providers also reported frustration making sense of patient trajectories.

Design Implications. In an enigmatic condition, patients and providers are left to identify key outcomes to assess health status, decide on care plans, and prioritize among potential outcomes to gauge what to work on. Without reliable treatment guidelines, neither patients nor providers can predict which treatments might be effective for a particular disease presentation. The multi-factorial aspect of the disease makes it especially difficult to identify whether specific treatments or self-management strategies are actually helpful and for which symptoms. Design principles of personal informatics tools to support collecting and reflecting on data can guide development [43, 71], especially since reflection can occur throughout the process of collecting, curating, and communicating about self-tracked data. **Visualizing, exploring, and engaging with the data can help generate insights useful for clinical discussions or directly integrating into care activities.** Through information foraging, patients can bookmark and tag observations for their own record or to discuss with their providers, and then cluster and arrange observations to detect patterns. Different insights or hypotheses can be evaluated, compared, and integrated into patients' own understanding of their illness. Designs for independent patient use will likely present more details for lengthy exploration and reflection, while tools for collaborative use will aim to synthesize and streamline the reflection and sensemaking processes. Design features can support both independent and collaborative use of the tool and promote common ground, by saving the internal state so that providers can see the same visual environment as patients, passing pointers to connect data or insights to specific views, and logging activity traces of the exploration or reflection process [52].

However, like in our previous design opportunity, the enigmatic nature of endometriosis calls for complementary machine-driven support to mitigate the large search space of disease dimensions and potential interactions. Modern **time series analysis combined with visual analytics techniques** could support patients and providers in resolving different temporal resolutions and identifying trends otherwise unidentifiable by human inspection of data (e.g., non-linear combination and sequence of strategies and treatments for a given outcome of interest). In particular, recent advances in **reinforcement learning** (automatically learning which sequence of actions provides which types of outcomes) can provide useful pre-determined strategies for experimentation. Similarly, non-linear time-series analysis can suggest meaningful outcomes that represent patient health status (e.g., a scoring severity system that aggregates and automatically learns the weight of each symptom for a holistic representation of patient status).

But, as increasingly complex computational methods are incorporated into interactive systems to facilitate reflection and sensemaking, new design implications arise. **Trust** in automated processes must be established: methods that elucidate automated solutions to humans show promise (e.g., [63]). Considering algorithmic transparency, designs should visually identify when numbers or suggestions were generated through automated mechanisms along with explanations about how the system uses data [97]. Designs should ensure actors maintain **control over automated processes**, e.g., in an interactive system that learns trends between treatments and symptoms, users might want to control which data to withhold from automated learning (e.g., ignore data tracked while on vacation, or ignore a specific data stream entirely). Similarly, in an interactive system that learns recommendations for self-management strategies, users might want to control which sequences of actions they are willing to experiment with. The **interplay of human-centered computing and artificial intelligence** opens up ample research questions and provides novel avenues for design.

5.3 Designing mechanisms to correct potential patient-provider misalignments and facilitate collaborative sensemaking.

Many endometriosis patients conduct independent research to become their own self-advocate and combat potential stigma and dismissal, commonly developing legitimate medical knowledge beyond their lived experience as patients. On one hand, providers sometimes perceive patient expertise as an asset to promote common ground and shared understanding with patients. But this expertise might also threaten the traditional patient-provider power dynamic with clashing clinical perspectives. This phenomenon has been noted previously in endometriosis [105, 106, 125], other enigmatic diseases like early in the HIV epidemic [44], and rare diseases [59]. With the dearth of knowledge about endometriosis, the medical expertise of both providers and patients is often insufficient on their own. Endometriosis patients and providers emphasize the importance of their collaborative work to figure out what could be going on, guided by lived experience—a point also observed in previous endometriosis literature [122]. Tools to support the patient-provider collaboration in care of chronic illness have been proposed in a variety of diseases and settings (Section 2.2); with enigmatic conditions, designs should enable users to identify and reconcile misalignments that could threaten the patient-provider relationship and disrupt patient care.

Design Implications. Given the necessary collaborative work of patients and providers in an enigmatic disease, **explicit scaffolding and mechanisms for collaborative review** of data, and of overall goals, values, and plans will promote trust and opportunities for aligning their vision for care. Inspired by research with patients managing multiple chronic conditions [12], structured approaches such as questionnaires to help prepare for encounters (i.e., *pre-emptive grounding*) and to guide the study visit (i.e., *just-in-time grounding*) could avoid and correct misalignments. **Templated structuring of independent and collaborative reflection of health status** (e.g., scaffolding to reconstruct illness experience [54]) can facilitate a collaborative clinical encounter. **Scaffolding mechanisms for patients to figure out their goals, convey these goals and values to**

providers, and discuss treatment plans guided by these goals helps operationalize and communicate about the patient's priorities [72]. Explicit features to anchor and guide care can support patients with varying levels of numeracy and literacy.

Structured features could also incorporate **explicit mechanisms to negotiate boundaries** between patients and providers, thus designs have an opportunity to **actively identify and correct misalignments,** e.g., tools could allow users to flag or vote for observations or ideas, incorporate a sandbox for positive/negative evidence, or design for collaborative tags to keep track of and bring forward misalignments for discussion [52]. *Tag-it-yourself* [110] was explored as a way to empower patients as expert contributors of data, which gives patients an **explicit channel to express their concerns**, tinker with their care to gain knowledge and control, and generate bottom-up evidence to assert their perspectives with providers.

Given the complexity of endometriosis and the uncertainty for treatments to help patients, providers emphasized trying to "get on the same page" with patients about expectations. Yet our study identified substantial misalignments and lack of common ground, which left patients feeling discouraged and threatened trust within the patient-provider partnership. Patients did not feel aligned in the priorities guiding the plan for care and were further frustrated by unmet expectations in treatment, a phenomenon also noted in recent work in the context of facial paralysis [127]. **Interactive visualizations are well-suited to support collaborative reflection and sensemaking** [22, 52, 58, 67, 76, 126], especially among actors of varying expertise and roles, and can contend with both gleaning information from massive volumes of data and also the social aspects of this shared work. Recent work suggests visualizing data can act as an objective measure to bridge discussion between a clinical understanding of the disease and the patient's experience [67]. Graham et al [49] assert that intentional shared reflection can bring together different perspectives and expertise to generate new insights, rather than merely exchanging ideas, emphasizing the need for dialogue throughout reflection. Mentis et al [84] look at patients and providers collaboratively "crafting" visualizations of health and goals, to align understanding rather than merely integrating data. Raj et al [98] propose collaborative sensemaking [76], which can consolidate the different viewpoints of patients and providers, and suggest resolving these misalignments by raising awareness of each other's view of patient data. To account for the uncertainty inherent to enigmatic conditions, and to ensure patients and providers both agree on which aspect of care is uncertain, explicitly visualizing the uncertainty of different features might provide grounding for discussion and thus potential alignment of perspectives. In migraine, another poorly understood condition, researchers suggest tools represent uncertainty, especially as they guide users in experiments to figure out treatments that align with their shifting goals [102]. Designing complementary human-curated visualizations with automatic inferences from computational methods, along with their uncertainty, represents an intriguing area of work.

The *self-tracking prescriptions* envisioned by providers could **structure and facilitate experimenting with treatments from the trial-and-error approach of patients and providers together, or self-management strategies for patients on their own.** Given the complex illness work, we propose the design of self-tracking prescriptions to include functionalities to select domains to track (independently or together), pin them at the top of an interactive visualization, and assist patients in experimenting with a range of strategies. Mishra and colleagues suggest a similar *planful problem-solving* approach to guide tracking of Parkinson's symptoms over time (both short-term and long-term) for planning, adjusting care, and to disentangle ambiguous symptoms [86]. Experimentation has been a useful strategy in other conditions, e.g., [36, 102]. With no standard evidence in self-managing endometriosis, a design that lets patients see what worked for others (e.g., [40]) or experiment collectively might be an innovative way to support patients.

5.4 Limitations

There were a number of limitations to our study. Our patient and provider pool was potentially non-representative of the general population. All provider participants were strong patient advocates and made a point to stay up to date about endometriosis research. While the patient participants represented diverse age groups, race, and ethnicity and a wide range of household incomes, they all were actively involved in their care and had already developed a nuanced understanding of the patient-provider partnership and their own role in managing their condition. We limited our unit of analysis to one patient and one provider at a time. Participants discussed the tremendous work entailed in identifying, managing, and coordinating care across a multi-disciplinary care team that was compounded by the enigmatic nature of endometriosis, but nonetheless was outside the scope of this study. Finally, our analysis focused on the work entailed in care after diagnosis of endometriosis. Issues with getting a diagnosis are well-known, the experience is often laden with stigma especially around menstruation and women's pain. Participants indeed noted the many difficulties in the long journey to diagnosis. Building technology to facilitate diagnosis of this enigmatic illness is a critical research question, but out of scope for this particular study.

6 CONCLUSION

Our work elicited patients' and providers' conceptualizations of their work in endometriosis care, on their own and as part of the patient-provider partnership. In comparing, contrasting, and synthesizing their stories, frustrations, and ideas, we confirmed that patients and providers are engaged in multiple arcs of work and their partnerships lay on shifting ground. Because of the enigmatic and chronic nature of endometriosis, these arcs of work are compounded by additional challenges, and the partnership is particularly vulnerable to potential misalignments and misinterpretations among actors. Our analysis uncovers such breaking points, and we propose a set of design implications to support patients and providers in their work in the context of an enigmatic chronic condition. Because of the complexity of this disease, technology should enable patients and providers to construct a holistic and flexible view of the patient's illness experience, facilitate individual and collaborative reflection and sensemaking, and provide functionalities to structure trial-and-error care plans and for explicitly identifying and correcting misalignments.

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