Care Frictions: A Critical Reframing of Patient Noncompliance in Health Technology Design

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Patient work encompasses a challenging set of activities necessary for learning about and managing chronic conditions over time. Many patient-centered health technology interventions focus on supporting types of patient work, such as symptom tracking, medication adherence, and information sharing between patients and providers. However, people may not always follow, or may actively resist, the activities prescribed by their formal patient role. In this paper, we present three case studies about patients with different chronic conditions to critically reflect on the types of patient behavior commonly taken up in health technology design as acts of "noncompliance." Detailing conflicts that emerge when patients are caught between meeting their personal needs and following clinical best practices, we show how everyday life and health system goals are often misaligned in ways that can't be easily reconciled through current design approaches. As a way forward, we argue for alternative ways of understanding the tensions routinely shaping people's healthcare experiences. We introduce the term *care frictions* as a sensitizing concept useful for helping designers reframe "noncompliant" behaviors as legitimate forms of patient work. Our paper also offers design considerations—both on challenges and generative possibilities—for future CSCW research seeking to support a wider breadth of patient behavior. In this, we call attention to the value of designer and researcher reflexivity in making visible the problematic assumptions in health technology design that can lead to social and emotional patient harms.

CCS Concepts: • Human-Centered Computing → Empirical studies in HCI

Additional Key Words and Phrases: Patient work; care work; chronic illness; care friction; breast cancer; chronic kidney disease; behavioral health; mental health; patient-provider communication; patient behavior; noncompliance; reflexivity

1 INTRODUCTION

Millions of patients worldwide manage chronic illness(es). Across long-term conditions, including diabetes, cancer, chronic kidney disease, and behavioral health conditions, researchers, clinicians,

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and policymakers have created best practice recommendations for treatment and care. These best-practice recommendations present an expected path for a patient, their clinicians, and caregivers. For example, shared decision-making is broadly considered a best practice for patient-provider communication and aims to involve patients in their care through co-determining health goals and treatments with their healthcare providers [44,83].

Over the last twenty years, information technology has been widely used as an important healthcare intervention tool for promoting clinical best practices. A common approach to health research in CSCW and HCI has been to create technologies which aim to shift or nudge people towards adopting clinical best practices (e.g., [30,35,71]). While useful for some patient groups, this design approach can easily miss the social or emotional significance of patient activities that do not conform to current best-practice approaches.

This paper highlights the need for health technology researchers and designers to better understand and attend to the types of patient behaviors that do not easily fit within (or potentially conflict with) clinical guidelines or expectations. Such types of patient activities—referred to in this paper as "nonidealized health behaviors"—include everyday practices such as not disclosing health information to one's clinical team or seeking alternative forms of treatment. We use the term "nonidealized" behaviors to distinguish our analysis from the standard view of "noncompliance" as found in medical literature (e.g.,[32,40,43]), a framing which obfuscates the social considerations that impact people's care activities and decisions.

Drawing together findings from three qualitative research projects on chronic illness that were independently conducted by each of the three authors, this paper offers the CSCW/HCI community a more situated understanding of patient behavior. Looking across chronic illness contexts, we saw nonidealized patient activities—behavior typically understood as noncompliant from a medical viewpoint—as quite commonplace and routine, even among so-called "good patients." Through a thematic analysis of qualitative patient data across the sites of chronic kidney disease, breast cancer, and behavioral health, we detail: (1) types of nonidealized health information behaviors common in the management of chronic illness, (2) meaning(s) and goal(s) of engaging in nonidealized behavior from the patient perspective, and (3) typical responses from the formal healthcare system.

Having witnessed the emotionally stressful and even stigmatized clinical encounters experienced by people living with chronic illness, we aim to better understand the values and norms guiding the design of patient-centered technology, and who this might leave out (and why). Specifically, our goal in this paper is to critically re-examine the types of patient activities we have found to cause conflicts and tensions in clinical encounters in order to craft design approaches that better identify and respect the diversity of patient health information needs. Our study findings collectively show that clinicians generally viewed certain types of behavior negatively, including patients doing insufficient or excessive amounts of information work, withholding healthcare experiences from clinicians, and adapting (or even rejecting) clinical protocols, such as instructions on taking medication. Despite inspiring numerous health design interventions aimed at "nudging" patients to be more compliant, such activities stubbornly remain an important part of people's everyday care.

Importantly, we maintain that design which is solely focused on getting people to stop nonidealized health behaviors can place unrealistic expectations and emotional burdens on patients by failing to address the social context of living with chronic illness. People who can't meet the standards of a "good patient," for instance, often fear damaging their relationship with healthcare providers or risk receiving poorer quality care [65,73]. These potential harms can be

reinforced by well-meaning technology design aimed at promoting patient compliance and adherence. Digital health interventions, often guided by clinical best practices, can further marginalize people who are unwilling or unable to take on common patient tasks and behaviors due to the complex social and emotional dimensions of this work.

Recognizing that an important part of what it means to be an empowered and engaged patient (for some) might include the rejection of medical best practices, we theoretically unpack patient information work as a site of ongoing tension and negotiation in care relations between clinicians and people living with chronic illness. Drawing inspiration from anthropologist and science and technology studies (STS) scholar Anna Lowenhaupt Tsing's writing on friction [114], we introduce the term ***care frictions*** as a sensitizing concept that grapples with (to use Tsing's phrase) "sticky engagements" in health contexts. Here we are specifically referring to healthcare settings where differences in stakeholder goals and social worlds do not neatly align, but actively conflict with one another. While health technology designers typically look to ease user "pain points," fix breakdowns, and bridge gaps in care, there are nevertheless remain many sticky spaces that design can't smooth away. Instead, care frictions points us to the new design possibilities that arise in valuing difference and engaging the types of patient work that have been traditionally dismissed or misunderstood. In this, care frictions offers an alternative design lens for patient-centered health technology that better accounts for diverse social needs and the complicated emotional dynamics around chronic illness.

In the following sections, then, we situate our paper within related CSCW/HCI research on patient work and design approaches for supporting patient care. Next, we present our study findings on nonidealized health information activities commonly taken up by patients across our field sites. Finally, we offer several considerations for future CSCW health research that seeks to support a wider range of patient behaviors, and share one approach towards engaging care frictions in design through a reflexive analysis of our own assumptions around good care and designing patient-centered technology. We argue that reframing nonidealized patient behavior through the lens of care frictions allows CSCW researchers and designers to see routine and everyday tensions as generative sites of diverse patient work that call for careful attention before intervention.

2 RELATED WORK

Understanding the richness of people's experience living with chronic illness is a fixture of CSCW health research. Regarding patient work, researchers have underscored the herculean effort people undertake to learn about their conditions [28,56,69,76], maintain daily self-management [9,13,24], coordinate with others [18,79], and persevere through these activities over the course of their illness trajectory [110]. In this section, we overview the role of patients and clinicians to highlight how expectations of patient work have changed over time, and highlight key approaches used by CSCW researchers to support patient work.

2.1 The Role of Patients and Clinicians

Many researchers across fields as varied as medical sociology (e.g., [31,105,110]), healthcare informatics (e.g., [25,81,91]), and health and wellness-focused human-computer interaction (e.g., [19,20,41,80]), have sought to characterize the work of individuals involved in healthcare experiences. For example, studies describe who conducts this work (e.g., clinicians, patients, caregivers [12,33,53,66,83]) and where it physically happens (e.g., in the hospital, at home

[21,31,81]). Other researchers describe specific health management activities (e.g., [36]) and related challenges (e.g., [69,73,101]). We focus on two topics within this literature. First, we describe the role of patients and clinicians, highlighting popular views about how they should (ideally) collaborate. Second, we describe different conceptualizations of patient work.

2.1.1. Patient and Clinician Collaboration. Throughout time, there have been different predominant views of the roles and responsibilities of patients and clinicians. One view highlights the clinician as the primary source of information and knowledge, and the patient as a relatively passive recipient of that knowledge which they then integrate into their life [68]. However, while information dissemination remains a key role of clinicians, not all patients follow clinician recommendations or appear motivated to do so. To understand patients' willingness to engage in clinician-recommended self-management activities, researchers created and used tools such as the Patient Activation Measure (PAM) [54]. However, metrics such as patient activation can position the patient as the source of resistance or opposition to carrying out self-management in ways preferred by clinicians [45].

More recently researchers have focused on including the patient's voice in health-related discussions. This shifted the previous view of the physician as the main arbiter of knowledge, toward a more collaborative relationship recognizing the importance of both the medical expertise of the clinician and the lived experience of the patient. How to carry out these collaborations has been codified in what is known as the shared decision-making process (e.g., [44,83]). The focus of this process is to create a partnership between clinicians and the patient and their caregivers. A patient is expected to learn about their condition and their treatment options, and clinicians learn about the patient's needs, goals, lived experience of their treatment, and self-management activities. Through this process they can collaboratively determine a best course of treatment and manage ongoing care. However, to effectively accomplish these shared decision-making goals, Bernabeo and Holboe [15] note that there is an expectation that patients can successfully "articulate health problems, feelings, beliefs, and expectations in an objective and systematic manner" which is not always the case, especially given limited conversation time with clinicians during typical visits.

The views of the role of the patient described above can place challenging self-care expectations on people while they simultaneously are experiencing difficult physical and emotional challenges. More recently, Gronvvall et al. [48] have brought forth the idea of "concordance" – a form of relationship between the patient and provider "that favours an equal and collaborative patient-doctor relationship in the negotiation of care." While aspirational, the authors also note that this ideal has been difficult to achieve given that many solutions, even when designed through a participatory process "are stuck with authoritative de-contextualized models concerning the relationship between doctor, patient, and treatment." In this paper, we contribute to the CSCW/HCI literature on collaborative practices between patients and clinicians, through focusing on why patients may shy away from or actively resist the activities prescribed by their patient role. Better understanding these (often misunderstood) patient experiences is necessary before designers can push back on problematic clinician-patient relationship models that are authoritative and de-contextualized, and instead create systems that respect a greater diversity of patient needs.

2.1.2 Types and Conceptualizations of Patient Work. While much of the medical literature focuses on formal healthcare environments including the hospitals and out-patient care centers (e.g., [22,118,119]), the majority of care activities for chronic illness happen outside of medical settings. In medical settings, these care activities are referred to as "self-management."

Researchers in HCI, CSCW, and STS have developed a rich theoretical language to describe the labor of patients and their caregivers, including sensitizing concepts like: boundary work [1], time work [78], articulation work [113], emotional work [78], body work [37], restoration work [70], and identity work [49], among others. This growing literature shows how "self-management" actually involves many different types of care activities and sociomaterial relations which play out across a patients' illness trajectory. The wide range of types of patient work alerts us to the physical and cognitive efforts needed in chronic illness management and the social and emotional complexity involved in taking care of oneself.

In this paper, we seek to build on and extend earlier discussions in CSCW and related fields of how patient work can conflict with standard clinical processes. Previous CSCW research has investigated why healthcare providers and patients may not align—the medical literature often treats these situations as a form of patient "noncompliance"—and how to bridge or resolve these misalignments in care. For example, prior work by Senteio and Veinot [104] describe the experience of patients in a low-income African American community where following medical recommendations was "effortful, challenging" and required people to address a number of "external contingencies." The authors argue, for instance, that a number of sociocultural and environmental factors such as fear of addiction, lack of trusting relationships with providers, poor housing conditions, and lack of available recreational facilities, among others, led patients to conduct near constant "adherence work" without support from the healthcare system. Similarly, Ancker et al. [4] conclude that personal health information management "should be recognized as an additional burden" for patients who are managing multiple chronic conditions.

These studies (and others) on patient work demonstrated how providers commonly make inaccurate assumptions regarding the resources available to patients which are necessary to follow clinical guidelines; and call for technological and structure-level changes to reduce the burdens of self-management on people living with chronic illness. Our paper adds to these ongoing discussions in CSCW by unpacking some of the problematic assumptions around patient work, investigating how clinical expectations for patients are at times misaligned with people's needs and values, and explicating the significance of the resulting tensions between patients and healthcare providers for system design.

2.2 CSCW and Design Approaches for Supporting Patient Health

Collaborative practices to support health-related activities have long been of interest to CSCW. As Fitzpatrick and Ellingson [41] observe, CSCW researchers have investigated medical practices and technologies for over 20 years, with much of this literature devoted to understanding the situated nature of work in healthcare organizations. Researchers, for instance, have detailed collaborative practices among various clinical roles [42,98], as well as between patients and providers [17–19,73]. Recently, the research space has expanded to include health management contexts beyond the hospital and clinic to the home and community setting [39,47,81], as well as expand research beyond acute injuries and chronic disease to encompass a wide range of self-care and wellness activities [35,74,89,109].

2.2.1. Challenges of System Design for Chronic Illness. As Yin et al. [117] argue, health-related work for many patients is "ever present, invisible, and overwhelming." Given the difficulties and hardships involved in living with chronic illness, patient-centered technology offers promise for better supporting treatment, collaboration, information-sharing, and social support. There is a growing interest in designing and developing information systems to better support patient work, especially for chronic illness contexts. A number of patient systems have been designed to support

clinically meaningful patient behaviors, including information sharing between patients and clinicians (e.g., [10,75]), medication adherence (e.g., [63,72]), and engaging with trusted clinical information (e.g., [60,61,96]). Several of these studies also mention how the behaviors encouraged through these systems are at times misaligned with the patients' lives or values (e.g., [6,38,60]). For example, Jacobs et al. [60] mentioned that a few participants abandoned their MyPath platform because of life priorities that overshadowed their own health and reduced interest in engaging with health information. Epstein et al. [38] looked at why people abandon self-tracking tools and discussed reasons such as discomfort caused by the behavioral information. Similar to our paper's approach, Munson and colleagues [85] reflect across previous research studies in the area of self-tracking to describe disparate goals and communication misalignments in the use of tracking tools that have led to burdensome tracking behaviors, incorrect data analysis, and dissatisfaction in using the tools.

CSCW researchers and designers have also designed systems motivated by the social and emotional aspects of living with a chronic illness. Systems designed for social support often focus on nonclinical settings like online patient forums that provide peer-to-peer mentorship and emotional wellbeing (e.g., [5,90]). Few CSCW systems, however, explicitly tackle the relational dynamics of patient work as a site of conflict or negotiation between patients and clinicians. Notable exceptions include Mamykina et al.'s [75] MAHI system which discusses the use of a novel diabetes support system that allows for co-reflection between patients and trained diabetes educators and nurses in regards to patient self-management activities.

This paper contributes to longstanding CSCW concerns about how to design systems to support patient needs by deepening our understanding of how medical models and patients' lived experiences meet in the patient work of chronic illness management. Specifically, we highlight the significance of patient-clinician conflicts, moments of patient resistance to medical best practices, and alternative care strategies that emerge when the goals of clinical medicine and the concerns and circumstances of people's everyday lives don't neatly align. Our paper contributes a needed critical perspective to the current CSCW health system literature by addressing the limitations (and possible harms) of designing solely for idealized patient behavior. In the remaining sections, we turn to explicating our methods, the reasons why patients may not always follow the activities prescribed by their patient role, and the significance this has for the design of health technologies.

3 METHODOLOGY AND CASE STUDY CONTEXTS

3.1 Research Motivation and Study Design

This paper represents a comparative analysis of three qualitative research projects on patient work and care relations. Motivated by Massimi et al.'s [77] CSCW paper in which the authors offered reflections on several different case studies of online health communities, our project began through group discussions based around our shared interest and research experience investigating chronic illness management and patient behaviors across various healthcare settings. The findings we detail here, however, follow an individualizing comparison process, as originally characterized by Tilly [112]. For individualizing comparisons, specific case studies are profiled in depth. One of the primary contributions of this type of study is that it can "help place some local phenomenon in a broader context" [8]. Similarly, we present a comparison of our qualitative datasets collected on three patient populations managing, respectively, chronic kidney

disease, breast cancer, and behavioral health. We describe the particularities of these case study contexts in section 3.2.

3.2   Data Analysis Process

Drawing on grounded theory, the three authors met regularly to discuss data that had been collected from our individual sites. In these group sessions, we shared fieldwork vignettes and participant quotes to identify thematic similarities and differences. Early in our analytic process, we found striking similarities in the wide range of patient behaviors viewed by clinicians as "noncompliant" or going against recommended clinical protocols and guidelines. While not all the types of patient behaviors described in this paper are formally recognized as clinically noncompliant, we found these types of health activities were consistently viewed negatively by healthcare professionals.

These first-stage analyses were brought together in a shared online document to enable comparative analysis. We also discussed themes in our data in relation to various theoretical writings from sociology and Science and Technology Studies (STS) on both patient work and friction as part of an ongoing iterative analytical process that is typical in qualitative, interpretivist work [29]. These group analysis sessions enabled us to re-examine patient behavior, as well as to identify the overarching sensitive concept of "care frictions" that emerged from the themes in our data. A continued engagement with social theory during our analysis sessions also provided us with a critical lens to interrogate the multiple meanings in patient work and to explore the ambiguities in people's health activities. For example, with regards to our language, in this paper we use the term "nonidealized" patient behavior instead of "noncompliant." Our phrasing reflects an intent to recognize and push back on the stigma and negative associations associated with many of the everyday patient activities we observed, while acknowledging the limits in fully extricating our study participants (or ourselves) from the power dynamics inherent in the social role of 'the patient.' Grounded in the complexities of our data, "nonidealized behaviors" embodies the inevitable tensions that come with trying to question who has authority and power in patient care and technology design.

With this conceptual anchor in place, our research goal was to understand the reasons for nonidealized patient activities across the chronic conditions investigated in our previous studies and to re-evaluate how medical ideas like 'noncompliance' have been treated and taken up within system design. To further elucidate and conceptualize the different types of non-idealized patient behavior we discovered in our field sites, we conducted multiple rounds of thematic coding [23], which involved interactive group analysis sessions and collaborative memo-writing in which we shared specific quotes and examples of the observed themes from our individual studies. We met bi-weekly over the course of 9 months to conduct our analysis and memo-writing.

3.3   Case Study Contexts for Patient Behavior

Below, we present brief overviews of our three case studies and subsequent field sites. We note that each co-author independently studied a different chronic illness context using diverse data collection approaches, including interviews (conducted both in the clinic and in patient homes), focus groups, field observations, surveys, and technology field trials. All three studies, however, shared a focus on patient work and how to design technology to better support patient-centered care.

3.2.1 Chronic Kidney Disease. The first case study draws from an investigation in the chronic kidney disease (CKD) context of digital technology use, information-seeking practices, and use of online social support technologies [36]. Data regarding patient work were collected across two hospital sites in the United Kingdom, one in a large metropolitan area and one in a more rural location. The study consisted of semi-structured interviews with 13 patients, one caregiver, and 6 healthcare practitioners (specialist renal nurses and social workers), as well as 9 field observations including at dialysis units, patient organization conferences, a patient group education session, and others.

3.2.2 Breast Cancer. The second case study draws from investigations into personal health management following a breast cancer diagnosis [59–61]. The research involved a multi-year project studying patient work, information needs, and the influence of digital tools on health management behaviors throughout the course of treatment and post-treatment. The study consisted of interviews and focus groups with 56 breast cancer survivors, 14 interviews with cancer navigators and oncologists, and 2 field trials of novel digital tools. This research was in partnership with a rural cancer clinic in the Southeastern United States.

3.2.3 Behavioral Health. The final case study draws insights from a multi-year ethnographic research project that explored the lived experience of behavioral health in a small city in the Midwestern United States [64,67]. The data discussed here are from 22 semi-structured interviews conducted with people living with a wide range of behavioral health conditions such as depression, anxiety, bipolar disorder, and schizophrenia. A total of 16 women and 6 men from a wide variety of socioeconomic backgrounds participated in the interviews which explored people's everyday care practices, local resources, and challenges in managing their health conditions, and how "care" was understood in their social worlds. Observations involved visits to health clinics, offices of care managers and coaches, churches, and meetings of a civic group that was composed of city staff, community health workers, and concerned residents that was dedicated to addressing local behavioral health issues. 12 community stakeholder interviews were also conducted with local clinicians, social workers, therapists, pastors, and government health workers, among others.

3.3 Researcher Position and Perspective

Through the data analysis sessions for this paper, we returned to data that we had previously published, viewing it anew from an analytic distance and with a comparative perspective. Looking at chronic illness and patient work in our collective research sites presented a unique opportunity to analyze a focused set of behaviors across contexts, which we contend strengthens the validity of our empirical findings. We realized, for instance, that none of the co-authors alone could have written this paper about nonidealized behaviors using only our individual study data because it was often more of a peripheral finding. However, when we combined data from all our case studies, strong themes emerged regarding the significance of these forms of patient work.

Furthermore, as a reframing of a popular health technology design motivation, and a reflexive engagement with our own past research work, this paper draws upon critical theoretical approaches that are currently being taken up more broadly in fields like CSCW/HCI and critical data studies [11]. Importantly, for us as health technology researchers, theoretical writing on friction helps conceptualize patient work in new ways and make visible the types of patient behavior that are supported through design. We discuss the implications of this critical theory and reflexive nature of our analysis further in section 5.

4 "PROBLEM PATIENTS" AND INFORMATION WORK: SITUATING NON-IDEALIZED BEHAVIORS IN CHRONIC ILLNESS MANGAGEMENT

In this section, we detail three case studies of patient behavior in chronic illness management. Looking at nonidealized forms of patient work in chronic kidney disease, breast cancer, and behavioral health, we specifically highlight extreme interactions with clinical information, (non) collaboration with clinicians, and alternative strategies for medication management. While each case study describes findings derived from each author's independent investigations into chronic illness, the patient experiences we share here resonated across our research sites. Presenting types of nonidealized patient behavior through individual case studies, however, allows us to better contextualize the messy, everyday practices of patient engagement and the resulting tensions between information, people, and healthcare systems. The examples we discuss here are not meant to be exhaustive but were selected for the purpose of analyzing how the concept of the "problem patient" is tied to practices around adherence and compliance in various clinical settings, and to show why this perspective needs to be challenged in system design.

4.1 Case Study 1: Engaging Extreme Information Needs in Chronic Kidney Disease

People's ability to access, understand, and make informed decisions regarding health information can have significant implications for their health and quality of life. In chronic illness management, patients are often provided with a standardized set of health guidelines and clinical protocols to help inform them about the best way to care for their condition. Information resources for educating and disseminating information like paper pamphlets and personal interactions (e.g., such as discussions with clinicians and peers) aim to involve patients in their own treatment decisions and provide people with a consistent and trusted source of health information. While this can be a helpful approach for many health conditions, patients encountering information that requires them to make difficult treatment decisions that are both physically painful and emotionally fraught can create drastically different expectations and needs around what being an engaged patient looks like. In this first case study, we present experiences from patients living with Chronic Kidney Disease (CKD), a complex condition whose diagnosis indicates serious declines in patient health and often necessitates major lifestyle changes.

While research has long shown the diversity of individuals' information work behaviors, (e.g., Schneider et al. [100] described controllers, collaborators, cooperators and avoiders) that stem from personal preferences as well as variations in health and technology literacy, information for CKD is still provided from the perspective that there is an "ideal" patient who will read, understand, and know what to do with all the presented information and resources. This ideal of patient engagement, however, often breaks down in everyday care situations. We highlight in the CKD context patient examples of what is viewed by clinicians as the undesirable "extremes" of patient information work—both patterns of very low engagement and very high engagement—where the standard health information provided can simultaneously be too much for some people, and too little for others, leading to ongoing tensions in CKD care.

4.1.1. "Insufficient" information work. Given the serious nature of CKD, specialist nurses who encountered people with low-information monitoring behaviors often saw them as "problem patients." In health informatics research, low-information monitoring is a term used to describe aversion to information-heavy activities, such as reading the CKD information leaflets provided by the clinic or participating in decision-making conversations with clinicians about how to treat one's CKD. People who did not read or have questions about the provided health information could appear to nurses as being "in denial" and unwilling (or unable) to accept that their health

was declining and needed careful management. Furthermore, by not following best-practice decision-making timelines and processes such as deciding between hemodialysis and peritoneal dialysis within a given timeframe, these information-avoidant patients were perceived as also disrupting the flow of clinicians' work practices. For instance, delaying getting on the schedule for an operation for a buttonhole fistula to prepare for future dialysis was a situation which could result in adverse health outcomes.

Unlike other chronic conditions, chronic kidney disease often has a relatively straightforward condition progression, measured by the kidney's glomerular filtration rate GFR) and its decline over time. In the early stages of decline, clinicians use this biometric as a guide to know when they should introduce the topic of dialysis to a patient (usually about a year before dialysis is projected to be needed [34]). However, some individuals experience what is known as a "crash"— a sudden drop in kidney function—and these individuals are usually rushed to the hospital and immediately put on dialysis treatment, meaning that there is not necessarily time to think through and prepare for dialysis needs in advance.

Once the GFR evinces the need for dialysis, clinicians expect that patients will make a series of major life decisions within a particular timeline. This includes choosing between one of two distinct types of dialysis (hemodialysis or peritoneal dialysis) or choosing to instead move into palliative care, an option often considered for individuals close to the end of life. As part of this decision, people also need to consider whether they will remain working or retire, apply for disability benefits, set up their home for in-home dialysis or go to the hospital for treatment, among other decisions. Patients are asked to make many of these difficult and often deeply life-changing decisions in a relatively brief period.

The emotional nature of this health information, along with life changes to be made, however, can easily overwhelm some patients. Being diagnosed with a chronic illness can create fear that can feel dissonant with the initial stages of kidney disease where individuals feel few effects of the condition. Faced with major decisions about their future, it is not uncommon for people to avoid information or even ask their clinicians to make treatment decisions for them. One patient shared her thoughts about why she does not want to read further medical information about CKD:

> *"Because one, I don't think I'd want the responsibility, and two, I just wouldn't be able to deal with—I think it would bring me home too much if I was looking at pictures of kidneys and things. It would make it more real than it actually is."*

Not only was she aware of the potential negative emotional impacts of reading clinical information, but she also spoke about the burden of learning and the responsibility of trying to be an active participant in care decisions, all while feeling unwell. Specialist nurses often viewed these patient behaviors negatively, one nurse referring to people who "*stick their heads in the sand.*" While this language can sound dismissive, in part, clinicians were deeply aware of how information avoidance could lead serious and irreversible health outcomes. For example, CKD patients who did not manage their condition would crash at a certain point, in which case they would find themselves suddenly needing to go on dialysis. Supporting CKD patients who wanted to avoid uncomfortable health information speaks to negotiating both a person's current fears and anxieties, while also helping prepare them for a future with few treatment options.

Other CKD patients felt unable to fully engage with health information in the ways clinical teams hoped for because they did not have the confidence or literacy skills to understand the provided clinical information, especially about biology and chemistry-related topics. These seemingly passive patients often asked the clinicians to decide treatments on their behalf. One story told by a specialist CKD nurse brought home the tensions of patient care in a story of a

young woman whose nephrologist suggested peritoneal dialysis. The doctor, however, did not know that this woman lived on the top floor of an apartment which had a bathroom on the lowest floor. This meant that peritoneal dialysis was physically impossible given the constraints of her living space, yet this was not discovered until she needed to start treatment. While patient engagement interventions typically focus on the informed choice of the individual, in this case, we see an ill woman who in her physical and emotional discomfort sought to be taken care of by those around her. Patient passivity, here, is not a straightforward story of "insufficient" information work, but instead represents a legitimate desire for assistance in a time when a person needs others to take up the work one can no longer do for oneself.

4.1.2. "Excessive" Information Work. On the other end of the information work spectrum, CKD patients with intense interest in reading and discussing medical information also experienced challenges that stem from an expected patient model of engagement. In contrast with passive patients, this group of people did not have difficulty deciding what dialysis type to select; instead, they discussed challenges with getting the types of information they needed from clinicians and the broader healthcare system. One patient described how he felt that the patient portal to view the results of his blood tests did not give him enough information. He said, "*I've cross-checked the ranges that are on [the portal] with other sources...to know whether things are normal.*" These sources included discussing with his friend who is a general/primary care physician and reviewing National Health Service websites. While there are many dedicated information resources provided to patients providing accessible information on CKD (e.g., additional leaflets; the wealth of online resources), nevertheless, some people preferred to dive into the details of expert medical information, especially when comorbidities or other life aspects made general information less useful for a person's specific health contexts.

For example, one patient-caregiver couple carried out an impressive amount of research on CKD. Not only had this caregiver (the wife of the patient) read medical textbooks about topics related to chronic kidney disease, but she also read peer-reviewed articles in scientific journals as soon as they were published. She expressed frustration when some of her husband's doctors said that she did not have to worry about reading this research or asking about specific medical procedures, as they would take care of recommending care.

However, this family's information diligence stemmed from several prior negative experiences in the hospital when clinicians made mistakes with their care. For example, the patient had previously been given medication that he is allergic to (several times) and so he now makes sure to always read the label of a received medication. While this information behavior may have been viewed by some clinicians as a misplaced sense of patient responsibility (bordering on mistrust of their healthcare team), from their perspective this information work reflected a necessary due diligence as people whose needs had previously fallen through the cracks of the healthcare system. Especially at 69 years of age, the patient described how "*what you knew before is not the same now,*" and so it was important for their family to continue learning about how to best care for his condition following the latest medical research.

Overall, unmet expectations regarding care responsibilities and questions around who has expertise to make care decisions create tensions between clinicians, patients, and their families that are not easily reconciled. For example, patients can become worried about the ability of their clinicians to communicate with them and keep their best interests in mind, and clinicians can view patients who follow personal information preferences as disruptive to routine healthcare processes.

Best practices for patient engagement show that involving people like those living with CKD in making more informed decisions about their treatment can help them to adhere to ongoing self-management plans because they were able to consider their options and have an active choice in the direction of their treatment. Yet, as this case study of CKD patients shows, having an active choice in the direction of one's treatment often involves negotiating many conflicting needs, expectations, and preferences with regards to the types of low- and high-information monitoring behavior [36]. Extreme information needs are to be expected when people are dealing with life and death health decisions. The case study of chronic kidney disease challenges the idea of ideal forms of patient engagement with clinical information given the diversity of people's needs.

Next, we discuss patient-provider collaboration in breast cancer management and some of the ensuing tensions that can occur within clinical and lay interactions.

4.2 Case Study 2: (Not) Collaborating with Healthcare Providers in Breast Cancer Management

Patient-provider collaboration has long been seen as a central component of quality healthcare and an important part of creating patient-centered care. The Institute of Medicine (IOM) released their report "Crossing the Quality Chasm: A New Health System for the 21st Century" in 2001 [58], in which they call for improvements in several aspects of healthcare. Since its release, this report has served as both a guide and gold-standard for adopting high quality, patient-centered healthcare practices. In this report, the IOM discusses ten principles for healthcare redesign. One of these principles, "knowledge is shared and information flows freely," specifically identifies the importance of effective communication and information-sharing between patients and providers, stating, "patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information" [44].

Since this report, supporting patient-provider communication and collaboration has been a central theme both within and beyond CSCW research. For example, Hartzler et al. [53] discuss how patients and providers each bring unique expertise to discussions. While clinicians possess critical professional knowledge that can guide care decisions, patients possess important experiential expertise about their health management. Both views are necessary for shared decision-making. Effective collaboration requires patients to communicate their health experiences, questions, concerns, and preferences with their healthcare team. Many CSCW and HCI studies have sought to provide tools that promote collaboration between patients and their providers and reduce burdens to communication (e.g., [16,26,46,93,102]). However, even when communication is supported, patients are not always inclined to share their health experiences with clinicians. In this second case study, we share several breast cancer survivors' experiences to discuss how and why individuals at times decide *not* to share their symptoms, side effects, or other meaningful health experiences with healthcare providers.

Following a breast cancer diagnosis, a patient may undergo surgery (a lumpectomy or mastectomy), treatment (radiation therapy, chemotherapy, or both), and several years of hormone therapy. Each of these phases of care can result in new side effects which patients often must manage at home, though the side effects experienced by patients can vary drastically. Clinicians will often rely on patients to share which side effects they are experiencing, and then offer possible symptom management strategies. Through conversations with breast cancer survivors [62] we learned that they were at times hesitant to share important health experiences with clinicians.

For example, a patient who had been going through chemotherapy treatments found herself struggling with various side-effects. Common issues, like nausea, had been explained to her. As new side effects began, she did not want to bother the clinic staff with just how terrible being a cancer patient made her feel every day, especially because she believed they would be unable to alleviate the treatment's effects. Trying to adopt a stoic perspective, she explained: "*My thing about the pain is there's not a thing they can do about it, so why say anything? That's just how I look at it.*" Another patient desired to get more insight into their situation but found that clinical visits were often too short for deeply discussing their concerns, such as anxiety at returning to work after being on medical leave. They acknowledged, "*We have great doctors. But most doctors don't listen to their patients. And it's so aggravating.*" Without insight into if and how sharing health experience information will be useful to either clinicians or to themselves, patients were often hesitant to share experiences, especially when they believed that their clinicians would be uninterested in the information. Patients were concerned that they would be wasting time or that their doctors would not care about their concerns, particularly mental health concerns that appeared disconnected to their physical health condition. However, clinicians often wanted patients to share aspects of their health conditions that patients expressed hesitation in discussing. While sharing symptoms, side effects, or other health concerns with clinicians can help drive care decisions, this process often remains a black box to patients who experience a great deal of uncertainty about what "counts" as health information and how to share what is often a very personal experience with healthcare staff.

One clear tension that emerged from patients' and providers' differing views on information-sharing was related to discussions of dissatisfaction with care [62]. The power dynamics within healthcare centers, in which healthcare providers remain the primary decision-maker, can make patients feel unable to voice disagreements or problems with the care they receive. One woman described her overall experience as a cancer patient as one of "*limited control,*" explaining that it was hard to articulate one's preferences in care decisions: "*When you go into a hospital you have limited control. You can say no to some shit. But you're in a hospital. You don't want to say no because if bad things happen then they say, well we told you to do this.*" Another patient recounted a disturbing time when she confided to a clinician that she was feeling depressed during her cancer treatment. "*I said things are pretty rough; I feel pretty sad,*" she recalled. "*And he never even looked at me. He goes, 'Have you ever thought about hurting yourself or harming yourself?' Never even looked at me…It kind of made me angry, you just don't treat people like that.*" Such negative experiences impact patient-clinician communication as people legitimately worry that they will not be respected if they fail to follow a doctor's recommendation, or that they will not have their needs met if they do not conform to clinical expectations for being a "good patient"—one that takes personal responsibility, doesn't complain (too much), or take up too much time.

In parallel, clinicians who sought to create positive experiences in patient care found themselves struggling to intervene and develop a timely response when communications were strained or when patients mistrusted their doctor. One very attentive doctor, for instance, expressed frustration with working with patients who would hold back on sharing problems until it was too late to do anything useful: "*What happens is the problem has already occurred and three months later comes to my office. Well, I could have fixed that. Give me real-time data. Let me affect the patient's experience by knowing they're not having a good experience.*"

A key component of group collaboration is the ability to vocalize problems and dissatisfaction. However, in practice, patients shared the everyday ways that they can feel negatively judged for standing up for their preferences if they do not align with clinical guidelines. The lack of structure

to support the communication of dissatisfaction with care inhibits collaboration and ultimately puts patients at risk of poorer health outcomes. Thus, while healthcare systems are continuously evolving to promote patient-provider collaboration, patients currently are expected to learn and comply with a clinically acceptable way of sharing personal and health information. The lack of transparency in the information-sharing process puts the burden on patients to trust that their experiences will be respected and addressed. Further, the power imbalance within health systems has left some patients feeling unable, or even fearful, to openly share their health experiences, care expectations, or discontent with the health system.

Next, in the third and final case study, we show how conflicts between patient goals, healthcare system best practices, local resources and cultural understandings of health create real challenges and harms for people taking medication to manage behavioral health conditions.

4.3 Case Study 3: (Mis)managing Medication in Community Behavioral Health

Several fields, such as public health, family medicine, medical sociology, and nursing, have long explored how people's health behavior is inextricably connected to wider social, environmental, and economic circumstances. Importantly, in under-resourced community healthcare contexts, the ideals of patient engagement—e.g., being informed on how best to manage one's health condition, communicating with one's doctor, and knowing how to navigate the local medical system and find care resources—are all complicated by routine breakdowns in one's healthcare infrastructure [108]. These breakdowns can be understood as sociotechnical misalignments between the organization of medical services and the actual patient work undertaken to manage a health condition, and occur due to a combination of factors, including inadequate and brittle healthcare policy, local economic precarity, and the complexity of cultural understandings of health and wellness.

A growing literature on patient engagement has sought to address some of these infrastructural dynamics by recommending ways to not just empower individual patients, but also engage their families and communities in learning how to better navigate their local healthcare systems [106]. A shared concern with supporting new forms of community health has also been taken up in design research. Recent studies in CSCW and HCI, for instance, have sought to understand the broader context of patient work by attending to the infrastructural or ecological dimensions of how people manage their health and wellness (e.g., [50,51,86]). CSCW research on community healthcare infrastructures [50,57,67,94] has argued that patient work in chronic illness management should be understood as a situated activity within a wider care ecology of technologies like electronic health record systems and online patient forums, national healthcare policies and insurance coverage, as well as social worlds like schools and faith communities.

While supporting patient engagement in a community context is a worthy design goal, little research has grappled with how local strategies and alternative workarounds developed for the management of chronic illness may, in fact, often conflict with clinical best practices. In this third case study of nonidealized patient behavior, we highlight people's experiences of living with behavioral health conditions like depression, anxiety, bipolar disorder, and schizophrenia in a small city in the post-industrial "rustbelt" region of the Midwestern United States [67]. In a community where people struggle to access health services and navigate the unwieldy and dysfunctional local healthcare system, we show how people's everyday health activities can leave them being labeled as "problems" rather than how they see themselves: concerned patients who are actively managing their health as best they can in difficult times. The tensions resulting from

these radically different views of what counts as a legitimate form of patient engagement has a significant impact on people's experience of care in this community.

One ongoing source of tension between clinicians and patients in this community setting was around the issue of compliance with regards to medication management. Nurses and doctors often lamented people's failure to take prescription medication as recommended, even as many of them recognized that this was as a complicated socioeconomic issue. For instance, it was well-known among the staff at clinics and hospitals that many local residents routinely dealt with issues of food scarcity and housing insecurity. Amid such challenging and uncertain life situations, routinely purchasing medication to keep their depression or anxiety in check was often an impossible goal for patients to achieve. Instead, when people could afford to fill their prescription, they often stretched their supply by cutting pills in half or taking a dose every other day. Sometimes, people supplemented a low supply of antidepressants by relying on informal social networks of family and friends to share their pills. A resident who was struggling with depression and also on unemployment shared how her experience with taking prescription medications was mapped to current life challenges, including a lack of income and ongoing stress with family and friends. Nevertheless, she saw herself as a patient who tried, explaining: "*Sometimes I don't take my pills every day. I'll take one, maybe two. I don't take three if I don't need them because my environment is quiet. But if I have to step outside that house, I never know what I'm going to run into. I try to take my medications.*"

While activities like medication stretching was undesirable from a clinical perspective, most clinicians understood people's life circumstances were difficult and responded sympathetically. Many local clinics, in fact, went to great lengths to help patients find needed medication, including providing free samples in difficult time periods. Other alternative practices around medication management were less well understood or accepted. Sharing medications among friends and family, for instance, was not viewed as acceptable, and patients rarely admitted they did this during a clinical visit. Also, a number of patients who did have financial means to take their medications as prescribed (e.g., not skipping or stretching doses), still found themselves struggling with undesirable side-effects from prescription medication. For them, taking medication as prescribed by their doctors impeded their primary social and financial responsibilities such as being a good parent, supportive partner, or a steady and focused employee. The struggle to manage medication side-effects like fatigue, brain fog, or hand tremors was an everyday form of patient work that people engaged in across different social worlds like extended families, bars, schools, and factory floors.

Medication management coping strategies included people tapering themselves off the prescribed dosage until they found a level that allowed them to function well enough to take care of their kids or go to work, even if this lower dosage reduced the much-needed therapeutic benefit. Other people feared becoming dependent and addicted to prescription medications if they took them regularly, a common worry in a community where there was a high number of opioid overdoses. One of the most contentious and controversial strategies (from a clinical perspective) of managing behavioral health conditions like depression and anxiety was the popularity in patients choosing to use alternative substances to manage their behavioral health conditions, such as medical marijuana. While medical marijuana was seen by many residents as a less addictive (and for some more therapeutic) option than antidepressants, many doctors in the community saw a medical marijuana card listed on a patient's file as evidence that the patient was likely to abuse taking their prescription medication as well. For example, one resident who worked a physically demanding and stressful job on the line of an automotive parts company, spoke of his

depression and anger that came from dealing with chronic back pain. He tried antidepressants, but found he ended up experiencing what he called "lost days." He explained that when on the dosage his doctor prescribed, "*I wake up, I don't want to talk to anybody, I don't want to leave my house, I don't bathe…I call them lost days because I was nonproductive for three days.*" Unable to work, he asked his doctor what she thought of using cannabis to help manage his pain as an alternative, but found his doctor assumed he had a drug problem. "*She [my doctor] was very rude. She just instantly assumed that I'm a pot smoker. No, that's not what it's about. I was just going to try CBD oils. They'd rather throw Norcos, Vicodin and stuff like that. I don't want that stuff. I'm not a pill popper. People get addicted to that stuff and, and people die from that. That's not me.*" He stopped taking what he saw as a "temporary medicine" and began to experiment with CBD oil—a potentially more sustainable treatment in his views—without going back to his doctor. "*I've not done any criminal act,*" he emphasized, "*I always had a normal job…I'm passionate about getting better.*" But he also has sympathy for people in the community who feel judged by the formal medical system for struggling to do their best given the often limited options available to live with chronic behavioral health conditions. "*A lot of them [friends at work] that drink or take drugs, it's because the medications that they [the doctors] gave them…have bad side effects. A lot of them do. They have bad side effects and do not address what's really going on with that person.*"

Finally, cultural understandings of health and wellbeing also led to tensions as a number of patients outright rejected the idea of taking prescription medications on religious grounds. For instance, some local faith communities believed behavioral health conditions like depression or bipolar disorder were primarily a spiritual problem that could be healed by faith rather than prescription drugs. While some patients who belonged to these faith-based groups were able to find ways of addressing the tensions between church teachings and clinical expertise, others felt unable to navigate these differences and stopped taking medication altogether. They received limited or no professional clinical help with their illness management. Such patients were often extremely frustrating to clinical staff who saw such spiritual views as dangerous to people's health outcomes. Trying to convince these patients to try medication was considered thankless job, most often taken on by concerned nurses. Many such patients did not follow through with treatment, while other spiritual residents in need of treatment in the community avoided the formal behavioral healthcare system altogether.

Importantly, patients—across all these different life situations—regularly withheld information from (and sometimes intentionally misled) clinicians about how they actually managed their medications. One reason for this silence or misdirection was a deep fear and concern about being mischaracterized or even shamed by clinicians as a "bad patient" and for failing to achieve an idealized standard of patient care, despite living in less-than-ideal circumstances. Furthermore, people experienced real harms if labeled "nonadherent" or "noncompliant" in their medical record. One example included a man living with depression who had been essentially "fired" as a patient by his doctor when he failed to control his substance abuse issues while being treated for depression. Even in less dramatic instances, a general failure to follow recommended clinical guidelines and/or being viewed as "deviant" for activities like using medical marijuana, led patients to fear they would receive less quality attention during visits, as well as reduced general respect from clinicians.

As this third case study demonstrates, the complex ways patient compliance is connected to access to care services and quality of treatment is especially alarming in a community where there were already long wait times of several months for healthcare appointments due to a lack of trained behavioral health specialists in the area. Supporting diverse forms of patient engagement

in communities, therefore, requires looking at patient work from an infrastructural perspective that accounts for different lived experiences across social worlds, access to healthcare resources, and policies that impact everyday forms of care. Doing so helps us as CSCW researchers and designers to see nonidealized patient behaviors around medication management—such as stretching or not taking medication—as creative and resourceful strategies of "self-care" in an (often desperate) community context of chronic illness.

4.4 Case Studies Summary

In these case studies, we presented examples of patient behavior and information work across chronic kidney disease, breast cancer, and behavioral health. Taken together, these case studies offer empirical grounding for the following critical discussion about how popular clinical ideals for patient behavior—such as information engagement, open information sharing, and medication compliance—are woven into the design of health technologies. In the next section, we explore two interrelated questions and provocations: (1) What are some of the limitations and potential costs in adopting formal clinical concepts around patient behavior in systems designed to support patient-centered care? (2) What alternative framings can we use to help researchers and designers to better understand ongoing tensions around patient and clinical encounters? To this end, we propose care frictions as a useful sensitizing concept for exploring how the values of evidence-based medicine meet the lived experience of chronic illness in the design of healthcare systems.

5 ENGAGING CARE FRICTIONS IN HEALTH TECHNOLOGY DESIGN

Over the last thirty years, a rich body of CSCW and HCI health literature has developed around understanding patient behavior, information work, and the lived experience of illness to guide the creation of patient-centered health technologies. CSCW studies of chronic illness, for instance, have highlighted the everyday practices of people living with different health conditions and the importance of situating technology in particular care contexts across hospitals, homes, and communities, as well as online settings [1,87,95]. While CSCW research demonstrates the diversity of patient experiences and needs, the design of many health information systems still widely relies on a narrow set of medical terms like 'compliance' and 'adherence.' Such concepts can help technologists identify pain points and patient needs but can also limit the design space of patient-centered health by privileging particular ways of coping with illness and being well.

In this section, we discuss why it is important for health technology designers and researchers to question the underlying assumptions and power dynamics inherent in popular models of educating or encouraging patients to adopt clinical best practices, as well as to imagine design alternatives. First, we critically examine the relationship between idealized and nonidealized health behaviors as taken up in CSCW research and system design. Next, drawing on Tsing's [114] writing on friction, we articulate the sensitizing concept of *care frictions*, as a way of grappling with health situations where there are ongoing differences and tensions in the way people want to engage with health information and care work (as is often the case with chronic illness). As well, we re-examine nonidealized forms of patient engagement to help make visible (and interrogate) the perspectives and models of patient care that have been privileged in health technology design. Finally, we discuss future research directions and considerations for CSCW in expanding system support for patients with diverse preferences and needs, especially when those health goals might conflict with clinical recommendations.

5.1 Unpacking Nonidealized Behaviors in CSCW/HCI Research

As shown across our case studies, certain patient behaviors are preferred in current healthcare systems. There are many "best practice" guidelines created for chronic illness conditions (e.g., for depression treatment [103]), as well as broader goals for patient-centered care, such as those outlined by the Institute of Medicine [58]. However, little attention is paid to how and why patient behaviors may deviate from these "idealized" ideas of engagement. In fact, people who do not conform to a narrow medical model of compliance and adherence are too often considered as "problem patients," as we found across our case studies. Best practices by their nature are standardized (with some flexibility within the practices themselves). Yet, while standardization is essential to ensure quality of care for all patients, it becomes increasingly obvious that not all recommendations set forth in patient guidelines are equally possible to achieve for people in different communities and living situations. For instance, daily outdoor exercise may be impossible for those who live in neighborhoods which are unsafe [82] or for whom physical mobility [97] is a major challenge.

Recent efforts by other CSCW researchers have called attention to different perspectives of health and health management. For instance, scholars of disability studies have frequently pointed to the significant differences in the medical and the social models of disability in technology design [14,107]. Ringland et al. [99] describe how the medical model focuses on treatment or improvement of symptoms whereas the social model emphasizes realizing self-directed objectives and retaining one's own autonomous sense of self. These models differ in what healthy looks like, who gets to define it, as well as who can contest that definition. In addition, as discussed in section 4.3, many individuals in communities across the United States and globally may not have the resources to carry out medical recommendations, relying instead on alternative care management strategies that can carry negative connotations among medical worlds.

Health information technologies, however, are predominantly designed with the understanding that the people who use these systems all share the same basic goal: achieving better health. Yet, trying to achieve "better health" in practice can be a fraught, frustrating, and often frightening experience, especially if one has a chronic illness or finds themselves treating a condition that can radically alter the possibilities of what "healthy" looks like [4]. And even if better health—at least clinically defined—is within reach, what becomes of other equally or even more important life priorities? People have a wide range of personal preferences, family responsibilities, economic pressures, and cultural understandings of health and well-being. For many people managing chronic illness, medical treatment protocols and clinical best practices sit in constant tension with the pulls of family obligations, friendship, and the "good life."

In CSCW and HCI, where healthcare has long been studied as a sociotechnical system, we are trained to see misalignments between different stakeholder activities and values as opportunities for design intervention—identifying patient and clinician tensions, "pain points," and "breakdowns" as places where technology might help ameliorate the challenges of care delivery and chronic illness management (e.g., [3,111]). For instance, Munson et al. [85] use the language of "misalignments" to highlight challenges in intersections between people's goals and their tools, among the collaborating actors, and within emergent design techniques. Similarly, in the context of diabetes management, Hinder et al. [55] note that "non-engagement with self-management may make sense in the context of low personal resources (e.g. health literacy, resilience) and overwhelming personal, family and social circumstances." We, like many others, have found that design can sometimes successfully bridge the clinical and social differences around chronic illness management, often by reducing the burdens and responsibilities around patient work. For

example, many systems for chronic illness management enable symptom tracking, data sharing, and communication (e.g., [2,60,72,92]).

As we describe in this paper, many of the social, emotional, and environmental factors at play in patient care experiences may not be bridgeable by traditional human-centered technology design methods. For example, it is not clear how patient-centered technology can alleviate the economic precarity of an underinsured resident in Michigan so they can afford antidepressants—situations that we have shown can result in patients deliberately withholding health information from their clinicians. In fact, we maintain that the types of nonidealized patient behavior we detailed in our case studies do not present themselves as promising sites for popular types of patient-centered health technology interventions such as increased information sharing or tools for promoting health literacy. We see these care activities, instead, as connected to the fundamental and routine tensions that arise from the rigid ways healthcare providers (and at times designers) understand best practices, and the diversity of how patients experience "good" care. In the following section, we introduce the idea of "care frictions" to discuss the significance of these tensions for health technology design and to push back against (often unquestioned) assumptions of who gets to define "patient-centered" design and a deterministic perspective in using technology to support patient care.

5.2   Reframing Nonidealized Patient Behavior as Care Frictions

Researchers investigating health information systems have previously used the concept of friction [52,115] to explore how the introduction of novel technologies into healthcare systems requires contending with the relationship of technology innovation to the broader social and material processes of medicine (including organizational norms and legacy tools). This prior work notes the misalignments between new technology and established clinical work practices that often lead to conflict in adoption and use. While we share a common understanding of health technology as part of a larger sociotechnical system, in focusing on issues of power and legitimacy in the concept of patient engagement, our project has a separate set of motivating questions than this prior set of literature on friction.

In this paper, we look outside CSCW and health informatics to find inspiration in the writings of anthropologist Anna Lowenhaupt Tsing. In her book, *Friction: An Ethnography of Global Connection* [114], Tsing expounds on the metaphor of "friction" to explore the messy interactions between various human and nonhuman actors involved in industrial forestry management in Indonesia—the reader views the same geography from radically different vantage points, including global supply chains and financial markets, as well as the local communities protesting the processes of deforestation and destruction of their homes [88].

Of interest to our conversation of patient health and design are Tsing's observations of how culture is continually co-produced through interactions she calls frictions or "the awkward, unequal, unstable and creative qualities of interconnection across difference" (Tsing, pg. 4). As a theoretical concept, Tsing highlights the *duality* of friction in both its destructive and also generative possibilities for world-making at the intersection of different communities' values and needs, political and technological systems, and materialities. In detailing the disjointed conservation efforts (and conflicts) amongst various scientists, activists, government officials, and nonhumans, Tsing writes: "Collaboration is not a simple sharing of information. There is no reason to assume that collaborators share common goals" (pg. 13).

Importantly, Tsing sees frictions as a method for anthropologists—and we would argue for CSCW researchers and designers as well—for analyzing cultural difference through the study of

various universals as "sticky engagements," or the sites of misunderstanding, dissent, and resistance. In this way, **friction offers a powerful analytic lens for conceptualizing (and challenging) the universals of health technology design.** In our paper, we have shown how patient behavior in chronic illness management is complicated by multiple intersecting perspectives and the messy realities of multiple social worlds coming together. To reimagine patient behavior beyond compliance, for instance, we can look for "sticky engagements" around care noting the stressed and tired doctors, the waiting rooms full of anxious patients, chemo-bodies-in-pain, and even communities full of spirit-led pill resistance. As with managing Indonesian forests, differences in chronic illness care create friction.

We argue that *care frictions*—a term we introduce here to describe the interactional tensions that emerge when everyday patient lives connect with the formal healthcare system—can be a useful sensitizing concept and critical provocation for health technology researchers and designers. For instance, in Table 1. below, we revisit our case studies to pull out several popular "universal ideals" of patient behavior that typically guide health technology design, as well as corresponding "nonidealized" patient behaviors we observed in our research. In the final column, we then make note of types of care frictions we have observed in chronic illness management, including interactional tensions around patient role, expertise, and communication.

Table 1. Idealized Patient Behaviors, Diversity of Patient Work, and Care Frictions

Idealized Patient Behavior in Design	Nonidealized Patient Behavior	Type of Care Frictions
Patients should read provided information materials and discuss with clinicians to determine treatment.	People choose not to engage with provided information materials because of the overwhelming experience of a chronic disease diagnosis, lack of self-efficacy to understand medical information, and/or negative initial information work experiences.	*Role friction*: Clinicians are frustrated when patients do not decide what treatment best fits into their life. Similarly, patients may view themselves as not able to read the medical information about their condition and prefer the doctor to make decisions on their behalf. *Expertise friction*: Patients may ask clinicians to decide treatment on their behalf, but treatments may not fit well in patients' lives, potentially resulting in noncompliance.
Patients should communicate their health experiences, questions, concerns, and preferences with their healthcare team.	People purposefully withhold information from clinicians, such as mental health concerns or dissatisfaction with care, often due to concerns that clinicians would be indifferent or unable to help.	*Communication Friction*: Clinicians feel frustrated when patients do not share health experiences that they could respond to or are not given an opportunity to improve one's care experience.
Patients take medications as prescribed, following clinical information on dosage amount, time, and communicate side-effects with clinicians.	People adapt and/or create medication strategies in light of the local resources available, social responsibilities, and cultural logics.	*Infrastructural Friction*: Patients feel judged/mistrustful of local healthcare system; Clinicians feel frustrated by forms of "noncompliance."

Applied this way, we see care frictions acting as a prompt for guiding critical reflection on issues like power and control, rather than a static or exhaustive list of all possible conflicts in healthcare. Its usefulness as a sensitizing concept for health technology is in helping to make visible this wider set of relationships and activities in patient care that at first glance can seem problematic or even irrational from a strictly medical viewpoint. Attention to infrastructural care frictions, for instance, highlights the way medication management is not just an issue of patients correctly interpreting instructions on a prescription bottle, but also a situation of access to resources and trust in medical experts. Our findings resonate with Senteio and Veinot's [104] work in high-poverty African American neighborhoods. The authors describe how their participants constantly searched for better care, stretched medications, called on faith, and struggled to change their futures, among many other "adherence work" activities. Adherence work gives weight to the patient's set of perspectives and struggles that are enacted in moments of friction. Thus, care frictions acts as a lens enabling us to unpack the activities and complications of adherence work.

Finally, a sensitizing concept of care frictions encourages increased reflexivity in health system design. Rather than jump in to reconcile tensions, care frictions create space for designers to engage the (perhaps for some uncomfortable) patient experiences of needing assistance, anxiety and anger, secrecy, and creative making-do, among many other experiences. While a traditional human-centered design approach might view conflicts between people and their medical worlds as an opportunity to nudge people into becoming "better" patients, through the lens of care frictions we imagine new generative possibilities as well as challenges. For instance, how might patient-centered technologies change if we took the notion of uncommon goals in healthcare as a starting point? What unique costs and risks does care frictions raise for health technology design? We describe a few specific avenues to address such questions in section 5.3.

5.3 Patient-Centered Design and Power: Lessons Learned for the CSCW Community

The critical reframing of patient behaviors through a lens of care frictions has several implications for the CSCW and wider health informatics communities. A key insight from our investigation is that the technologies we study and design as CSCW researchers rarely support nonidealized patient behaviors. Patients who do not conform to the expectations of the formal healthcare system are viewed as noncompliant, problematic, or troublesome, a situation which influences not only their relationship with clinicians, but also with technology. We are not arguing for design to support all patient behaviors—as noted previously, there are serious questions for designers to consider around patient safety and well-being—however, we maintain that a necessary aspect of advancing toward more personalized, patient-centered medicine is also recognizing the breadth of patient behaviors, even nonidealized behaviors, and using these to grapple with questions including the meaning of health and wellbeing interventions.

Much of the previous CSCW/HCI and health informatics literature has focused on supporting people to act in certain ways such as moving toward patient activation [54], becoming an "expert" patient [28], and tools that enhance self-regulation, reflection, and ownership of one's health condition (e.g., [27,61,75]). While these technologies are certainly useful for some patients, by design they privilege certain behaviors and lifestyles over others. Here, we discuss how we might think more deeply about who is left out from the behaviors we are prioritizing in our designs and consider next steps for the CSCW community.

5.3.1 Use Research Methods to Capture Behavioral Diversity. One way to approach this challenge is by using research methodologies that capture the diversity of current behaviors.

Following Veinot et al.'s [116] concept of "upstream interventions" to improve health equity during the design process, we advocate for researchers and designers to use methodologies that surface the diversity of current patient behaviors and to consider the rationales guiding them. Similarly, Nunes and Fitzpatrick [88] argue that, "understanding the everyday experience of self-care requires one to overcome a medicalised perspective of isolated activities on fixed schedules, and accept the complex negotiations and compromises that are part of the daily life of people living with a chronic condition." We highlight the need to re-consider "problematic" behaviors, even when only a minority of individuals report them, because collectively these individuals are likely to be a substantial part of the overall patient population. For example, this paper arose from the co-authors' collective realization that peripheral, often marginalized patient behaviors in our individual studies gained visibility and import when examined as a phenomenon across our studies. We see care frictions, a concept extended from the STS literature, as not necessarily endorsing a positive or negative view of a particular health behavior, but as a way of exploring the diverse ways people might interact with healthcare systems.

5.3.2 Develop Technologies to Support a Multiplicity of Patient Behaviors. A second approach centering care frictions in design is to develop technologies that support a wider range of health needs, either within the same tool or as multiple standalone resources. Previous public health, nursing, disability studies, and even other CSCW literature has identified patient work activities needed to manage health in different social environments. However, despite the diversity of types of work identified, we do not see this same diversity translated into health support technologies. Given the dominant biomedical view of health in our society, it is the designer's responsibility to be aware of social models and contextual factors that might benefit from technological support.

One promising avenue suggested by Munson et al. [85] in their recent reflection across multiple n-of-1 self-tracking studies, is to focus on eliciting and supporting patient/user goals within conversations with healthcare staff and within self-tracking tools. They break this into two categories: management goals and tracking goals. By understanding health management, questions about how patients want to live their life and self-manage (for instance, not fully eliminating favorite foods from one's diet even if they cause some irritable bowel syndrome symptoms) can be better surfaced. Secondly, to understand and support tracking goals, the authors suggest implementing clear descriptions of possible ways to use a tool to achieve different outcomes, supporting realistic goal setting, and engaging with providers on a regular basis to ensure appropriate analytical understanding of tracked results. Similarly, Ayobi et al. [7] created Trackly, a customizable and pictoral self-tracking tool for Multiple Sclerosis (MS) management. By enabling flexible and iterative creation of tracking visuals, the authors "demonstrate a design perspective that centres on people's creative capacities and experiences of agency rather than persuasion and compliance."

In expanding our thinking to consider supporting non-idealized behaviors, we also recognize that there is a fine line between designing for behaviors that are not perfect, but important to experiences of patient care, and behaviors that can cause harm. As technologists this can be a difficult area to understand as we are not necessarily clinicians nor members of the patient communities for whom we design. Thus, we see the importance of future research with clinicians regarding what could be "good enough" to satisfy a patient's health management, together with conversations with communities regarding what goals they are striving toward in their lives. For example, in both the CKD and breast cancer contexts reported in this paper, even though every patient received a binder and leaflets of information that they would ideally read, designers might probe clinicians by asking: What is the minimum viable information that is crucially necessary

for patients to understand? And, for patients who are emotionally struggling with a diagnosis or treatment, designers may find it valuable to direct people away from online forms of support and find ways of better supporting in-person health information encounters with health experts like nurses or physicians.

As a first step, however, revealing the various disagreements, tensions, and differences bound up in care frictions may provide the foundation for creating appropriate and diverse support tools that reach across patients, communities, and health systems.

5.3.3 Be Reflexive as Designers and Researchers. In our experiences as health technology designers and researchers we have had the privilege of collaborating closely with healthcare staff who have taught us the value of evidence-based medicine in technology design for addressing pressing challenges like health inequities as well as positively shaping everyday care experiences. We have seen patients struggle—sometimes quite desperately—without access to trusted medical information or little support and guidance from clinicians to manage their pain, figure out how to sleep through the night, or find a way to play with their grandchildren. Creating technology that supports patient needs and can lead to better health outcomes is a design goal we share with many in our field of medical and health informatics. However, our work with patients over the years has also shown us the need to contend with why so many patients come into conflict with clinical recommendations, and the significance those sites of resistance have for our design practices.

Research in CSCW/HCI, as well as in adjacent fields like STS and critical data studies, have increasingly called attention to the responsibility designers and developers have for encoding and reifying particular values in the systems they build. When technological interventions also impact people's physical and mental wellbeing—as is the case with health information systems—the stakes of getting system design "right" or "wrong" become exceptionally high. Warranted concerns about patient safety and a desire to improve health outcomes can make questioning the usefulness of clinical best practices as a standard approach for system design an uncomfortable and unsettling experience. While acknowledging the many challenges our provocations brings—including the potential risks for patients, healthcare providers, designers, and researchers alike—there are also real harms in not addressing the power dynamics inherent in patient-centered design. As illustrated by our case studies, many forms of personal distress, as well as wider social injustices arise when patient values, goals, and needs are routinely dismissed or ignored, including experiences of stigma, negative encounters with healthcare providers, and mistrust of the medical community. Such costs, taken on by people amongst the most ill and vulnerable in our society, necessitate exploring a wider spectrum of patient work and information needs in CSCW that both align with and diverge from clinical expectations and best practices of care.

In writing this paper, then, we have found it necessary to reflexively examine our own role as researchers whose work helps shape the design space of patient-centered health. Through investigating chronic illness, we have each confronted the myriad ways differences across gender, race and ethnicity, and class shape health experiences for our patients, but also in the questions we researchers actively investigate and the questions that we do not ask. We also bring our own personal experiences with illness and specific disciplinary training (a mixture of computer engineering, social science, design, and the humanities respectively) together in ways that shape what we consider a health design problem and necessary intervention. Engaging critical theory in this paper—a methodological departure for some of the authors—also helped us create analytic distance to reflect on our field's dominant tools of knowledge production and resulting biases towards technical design interventions. This paper is therefore a direct result of collectively

reflecting on the ways we may unintentionally harm people already facing difficulty in managing complex health conditions through design. For instance, apps and systems that nudge patients to engage with health information or to share personal life experiences with clinicians may at times lead to greater distress, rather than creating desired forms of patient engagement and empowerment.

Through the lens of *care frictions*, we encourage researchers and designers to sit with the tensions arising from "sticky engagements" in health contexts and explore the interrelated care relations which give rise to what can be too easily dismissed as a "problem patient." We have found that comparative analyses that bring together CSCW research and include reflexivity practices [84] will be useful in this future work. Given the combination of disciplinary traditions in Computer Science, Sociology, Anthropology, and Information Science, the CSCW community is well-positioned to take on this type of research, and to collaboratively assess issues of power and bias in health technologies. We recognize that some individuals in our community may already follow this type of reflexive process; however, for those who are newer to healthcare research and design, or desire to think about their work in a different way, we believe this is a generative approach for tackling a greater diversity of healthcare experiences and patient needs.

6 LIMITATIONS AND FUTURE WORK

Our paper's comparative analysis of multiple case studies ameliorated some traditional limitations of single-site and single population studies; however, we note a few limitations that impact the paper's scope. In detailing patient experiences of chronic illness in healthcare systems in the U.S. and U.K., our empirical focus is on patient experiences in the Global North. While types of care frictions are contextually situated, we see our work as offering a helpful (albeit modest) starting point for addressing similar concerns among other locales, populations, and health conditions. Secondly, while we saw patterns of nonidealized patient behaviors across all our studies, our research questions for each individual study did not focus explicitly on identifying and characterizing these behaviors. Therefore, we believe our paper offers a solid foundation for future researchers to continue to investigate patient behaviors and begin to identify new care frictions in health system design. Finally, while not explored in depth in this paper, there is also much more to understand regarding care frictions in the context of multiple chronic condition (MCC) management (e.g., [16]). In the case of MCC, not only may patients and providers be in conflict, but the goals of different specialist providers as well. It is therefore important to make visible the care frictions that exist between different health systems and different healthcare providers, especially to reduce the burden placed on the patient to untangle these differences.

7 CONCLUSION

In chronic illness management, common best practices such as patient engagement, patient empowerment, information sharing, and shared decision-making all include implicit and clinically recommended responsibilities for the patient. In this paper, we share findings from three case studies of chronic illness and patient work to investigate why people may reject patient guidelines. We share examples of several nonidealized patient behaviors, their importance for patients, and argue for CSCW researchers to be critical of singular best practice health promotion activities. We introduce the sensitizing concept of *care frictions* as a critical analytic lens to reframe the idea of "problem patients" and generatively examine tensions arising in patient-

clinician interactions. Care frictions help make visible the power of best practices and the wider social impact of relying on dominant clinical ideals in system design.

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