



Chronically Under-Addressed: Considerations for HCI Accessibility Practice with Chronically Ill People

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ABSTRACT

Accessible design and technology could support the large and growing group of people with chronic illnesses. However, human-computer interactions (HCI) has largely approached people with chronic illnesses through a lens of medical tracking or treatment rather than accessibility. We describe and demonstrate a framework for designing technology in ways that center the chronically ill experience. First, we identify guiding tenets: 1) treating chronically ill people not as patients but as people with access needs and expertise, 2) recognizing the way that variable ability shapes accessibility considerations, and 3) adopting a theoretical understanding of chronic illness that attends to the body. We then illustrate these tenets through autoethnographic case studies of two chronically ill authors using technology. Finally, we discuss implications for technology design, including designing for consequence-based accessibility, considering how to engage care communities, and how HCI research can engage chronically ill participants in research.

KEYWORDS

chronic illness, accessibility, disability studies

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1 INTRODUCTION

Billions of people around the world [18, 53] are diagnosed with chronic illness, broadly defined as a range of conditions and diagnoses that impact functioning and are not expected to go away or be immediately fatal [34, 49, 115, 122, 124, 149]. Many chronically

ill people have symptoms that alter their daily lives, and disability activism [65, 117] and academic theorizing [42, 72, 148] are beginning to integrate chronic illness into their approaches. However, despite an active focus on chronic illness in human-computer interaction (HCI) health research (e.g., [54, 61, 81, 89]), chronic illness remains conspicuously underrepresented in HCI accessibility work [86] (for a few exceptions, see e.g., [19, 57, 69, 85]). We identify an opportunity for HCI accessibility practitioners to understand the access needs of chronically ill people and to create technology-based solutions that are not rooted in medicalized views of chronic illness.

In this paper, we articulate an opportunity for future HCI accessibility research to work with and support chronically ill people. To do so, we present three tenets to guide researchers' approaches to chronic illness: 1) move beyond medical framings to understand people with chronic illness as having access needs and valuable expertise, 2) consider that the variability of ability that many chronically ill people experience presents unique accessibility needs, and 3) adopt a theoretical approach to chronic illness that attends to bodily and sociocultural experiences. We then apply these tenets to three autoethnographic case studies about the authors' own experiences with technology use, demonstrating how our tenets can be used to surface design considerations for chronically ill users.

By placing disability studies, HCI, and our lived experience as chronically ill technology users in conversation, we introduce a new paradigm for designing accessible technology. This shift includes viewing access as produced by both a user's innate abilities and the physiological consequences doing an action causes, which we call a consequence-based approach to accessibility. Further, it encourages researchers to consider technology design for community use and alter traditional HCI methods to better match chronically ill participants' access needs. We also emphasize that approaches to technology design for chronically ill people need to be grounded in community knowledge and can be contextualized within disability studies and activism.

In summary, with respect to designing technology for chronically ill people, we contribute 1) three core tenets to guide research, 2) a in-depth autoethnographic exploration of how these tenets reveal opportunities to understand and design technology for chronically ill people, and 3) considerations for HCI accessibility practice when engaging chronically ill people.

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2 BACKGROUND AND RELATED WORK

To contextualize our work, we situate our definition of chronic illness, explore how HCI has approached work with chronically ill people, and introduce guiding concepts from disability studies.

2.1 What We Mean by Chronic Illness

In this paper, we draw on work from disability studies scholarship to broadly define a chronically ill person as one who has a condition that: impacts functioning, is not expected to go away or be immediately fatal, may be ameliorated through treatment and, particularly when left untreated, can be life-limiting [34, 49, 115, 122, 124, 149]. Conversations around chronic illness and disability often overlap - indeed many people identify as both chronically ill and disabled [119]. While we do not intend to take on questions of chronic illness or disability identity formation, this overlap guides us to engage with disability studies as a source of useful guiding theory and to see chronic illness as relevant to HCI accessibility work. However, we also highlight areas where chronically ill people's experiences diverge from mainstream conceptualizations of disability [119], motivating the need for a chronic illness specific approach to technology design. Billions of people globally are diagnosed with at least one chronic health condition [18, 53] (a growing group in the wake of COVID-19 [142]), leading to a wide range of experiences and varied identification with chronic illness. We, however, are primarily interested in how shared functional aspects of chronic illness could be better considered within accessibility. While our framework may resonate more strongly with people who identify as chronically ill, it may also be relevant to many others.

2.2 Chronic Illness and HCI

Chronic illness has received uneven attention across subfields of HCI - it is a significant topic in HCI health and online communities research but is scarcely engaged in accessibility contexts. Specifically, the primary foci of current HCI health work on chronic illness include: exploring the different information needs and practices of patients and providers [15, 37, 81, 112, 127, 131, 141], how people talk to their support networks [5, 14, 89, 95, 114] how to support pediatric patients, their parents, and providers in effective communication [54, 59–62, 75], and how patients gain the knowledge to manage their conditions [20, 24, 63, 120, 150]. This body of work considers chronically ill people in relation to the medical care they pursue, often primarily referring to them as 'patients', and therefore proposes technology solutions within this medical context. An additional focus of HCI work with chronically ill people is self-tracking, developing tools to track symptoms [76, 101, 116], treatments [7, 21, 158], and medically-necessary lifestyle changes [84, 136]. This work often includes medical professionals and is geared toward helping patients comply with prescribed treatment. Another avenue of HCI research with chronically ill people outside of accessibility frameworks focuses on how chronically ill people connect with and support others via social media communities [41, 43, 66, 82, 90, 92, 129, 144, 159]. This body of research considers and offers solutions for many areas where chronically ill people can be better supported when seeking medical care, but rarely centers access needs that are not immediately connected to the clinic, like accommodations for work or social life.

There is a small, but growing body of work that situates chronic illness in relation to accessibility and the broader disability community. ASSETS has not historically published much work that engages chronic illness - only a small set of papers include participants with chronic illnesses, often focusing on older adults or rehabilitative technologies (e.g., [3, 17, 25, 26, 73, 109, 157, 160]). Some ASSETS publications have considered chronically ill people as having access needs, exploring how people negotiate access at work [85], considering how to make disability activism accessible to chronically ill people [19], and centering chronic illness in theorizing around the role disability studies ought to play in future HCI accessibility research [57, 91]. Outside of ASSETS, HCI work that considers chronic illness within the contexts of disability and accessibility remains sparse. Research on disability-related activist movements has included chronically ill people's perspectives [1, 80], recent conference workshops on accessibility research have explicitly considered chronic illness [4, 140], and researchers have considered the particular access needs of chronically ill people on dating apps [121], in the workplace [47], during research studies [87] and in public places [69]. Considering the prevalence of chronic illness, this body of work is notably underdeveloped relative to other foci of accessibility research [86, 152]. Though this handful of papers examine the access needs of chronically ill people in specific contexts, no work yet theorizes about the broader design considerations needed to make technology for this group. We seek to grow this body of work by articulating a set of tenets to guide future accessibility research with chronically ill people.

2.3 Core Concepts from Disability Studies

Within the field of disability studies and activist communities, scholarship by disabled and chronically ill people provides a critical lens and crucial background to our thinking on how HCI accessibility practitioners should approach chronic illness. Our work applies disability studies topics to HCI scenarios, building on the tradition set by Mankoff et al.'s 2010 invitation to engage with models of disability [91], Bennett et al.'s integration of interdependence into HCI thinking [12], Ringland et al.'s call to see mental-ill health as a form of psychosocial disability that can be addressed outside of clinical contexts, [126], Williams et al.'s framing of crip HCI [151], and Hofmann et al.'s exploration of crip time [57]. Here we provide a brief overview of core disability studies concepts that we will utilize when considering how to build non-medicalized technology for chronically ill people, namely: social and medical models of disability, interdependence, access intimacy, and crip time.

One of disability studies' central pursuits is to name and analyze the effects of two dominant frameworks for understanding disability: the social and medical models [113]. The medical model of disability characterizes deviation from physical and/or intellectual norms as undesirable defects that medical intervention can eliminate, augment, or cure, motivated by the belief that a better future is one without disability [30, 133]. The classical counterpoint to the medical model is the social model of disability, which names disability as a natural and vibrant part of human diversity and as a basis for historic and current systemic oppression. Rather than focusing on cure, proponents of the social model call for changes to external factors that produce disability (e.g., buildings without

ramps, discriminatory policies) [113, 133]. Notably, early disability studies scholarship, which articulated the social and medical models, did not center chronic illness in its analysis. Initial adherents of the social model drew a distinction between impairments (i.e., differences in functioning) and disability (i.e., context-specific and social dynamics that create barriers for participation by differently functioning individuals) to help combat what Joel Reynolds calls the “*the ablest conflation*” of the concept of disability with “*pain, suffering, hardship, disadvantage, morbidity, and mortality*” [124].

More recent scholarship within critical disability studies and activist theorizing provide key concepts to analyze and understand chronic illness. While the historic push for disability rights often focused on independence [104], disability studies scholars have begun to theorize about the role of dependence in disabled people’s lives [77]. Activist scholars have adopted the framing of interdependence as “*the state of being dependent upon each other*” [65] which emphasizes the networks of connections and care that people provide each other, rather than positioning one person as the sole recipient or provider of care. Disability justice activists have explored how interdependence reveals the ways sick and disabled people form care networks to provide support and access for each other [99, 117, 118]. A related concept, coined by Mia Mingus, is that of access intimacy, or “*that elusive, hard to describe feeling when someone else ‘gets’ your access needs*” [98]. Access intimacy is a meaningful dimension to add to considerations of accessibility as it helps make visible the relationships and shared context that shape how access is felt and received.

Disabled scholars developed another key concept to our work, “crip time,” which theorizes about the different temporalities (or, experiences of the passing of time) in which sick and disabled people operate. Allison Kafer, in first formalizing crip time, imagines its power: “*rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds*” [72]. Ellen Samuels, a chronically ill disability studies scholar, calls attention to the ways that crip time simultaneously provides tools to imagine a more accessible future while highlighting that rigid, normative expectations of life paces can be sites of painful inaccessibility [128]. These concepts provide avenues for thinking critically about the ways that disabled and chronically ill people often arrange their lives differently from nondisabled people and shape our analysis.

2.4 Positionality

This work was deeply influenced by authors’ experience with chronic illness, interactions with medical systems, and (for some) moving through the world with a non-normatively functioning body. Three of the four authors identify as chronically ill and all identify as white, cisgender, women.

3 DESIGN TENETS FOR CREATING TECHNOLOGY FOR PEOPLE WITH CHRONIC ILLNESSES

We present three tenets which outline necessary perspectives to shape technology design for people with chronic illnesses. First, technology designers must view people with chronic illnesses as having access needs and valuable expertise rather than only as

patients. Second, chronic illness causes high variability in ability, which is crucial to consider when designing technology to meet chronically ill people’s access needs. Third, this work must be done using a model of disability that accounts for both physical and mental experiences of impairment while also recognizing disabling socio-political factors.

3.1 Tenet 1: Beyond Patients

We must view people with chronic illnesses as more than medical patients, but rather people with valuable expertise and non-medical access needs.

Much of the existing body of HCI scholarship around chronic illness adopts a health, rather than accessibility, framework (see 2.2). Under a medical lens, chronically ill people are primarily viewed as patients with technology needs defined by medical care and symptom management. However, we call for HCI practitioners to contest the dominance of medicalization and emphasis on patienthood when designing technology for people with chronic illnesses. Longstanding critique by feminist [31, 83], and queer [110] activists calls attention to the ways that labelling people as “patients” takes away their agency and imposes a set of assumptions around what patients ought to want, do, and need. The label “patient” also establishes a clear power hierarchy, implying a subordinate relationship to a more knowledgeable and powerful clinician [39]. Viewing people with chronic illnesses primarily as patients suggests that they can be best understood in a medical context and situates them as recipients and dependents of medical practitioners’ expertise. On the other hand, approaching people with chronic illnesses with an accessibility lens views them as people with access needs and creates room to center individuals’ agency and knowledge, countering epistemic violence [156].

A medical, patient-centric approach often obscures the deeply contentious relationship many people with chronic illnesses have with the medical field. While medical treatments, testing, and guidance can be critical to chronically ill people’s quality of life, the medical field is often simultaneously hostile to chronically ill people [10, 51, 52]. For example, it frequently takes years to get formal diagnoses for many chronic illnesses [39], patients are routinely not believed by medical professionals [78, 94, 102], and complex medical care is often prohibitively expensive [48, 56]. These experiences are exacerbated when people with chronic illnesses are otherwise marginalized because medical racism, sexism, anti-queerness, ableism, classism, fatphobia, and other biases harm people’s ability to access care and be treated with dignity [32, 70, 111, 147]. Future HCI work must understand that while medical care and assessment is crucial for many chronically ill people, it can also be a primary site of trauma, discrimination, and disbelief. Discussion of and engagement with medical systems must be done with caution and recognize this fraught history. This motivates our focus on non-medical access needs that remain under-considered within HCI research.

At the same time, the knowledge shared outside of medical contexts makes clear that, individually and in community, chronically ill people hold vast expertise derived from both their embodied experiences and navigating the world with a chronic illness. Diagnosis-specific and general chronic illness social media communities are

abundant (e.g., [11, 41, 129]), and they provide a place to share in-depth knowledge about living with a chronic illness. While much discussion centers on how to live with and acquire care for illness (e.g., symptom and flare identification and management, possible diagnoses, how to navigate the medical system), people also share information and advice to meet non-medical access needs (e.g., developing horizontal workstations, suggesting how to disclose access needs on a date, preparing meals that don't trigger dietary restrictions) [11]. Indeed, there are myriad individual and group examples that demonstrate the sophistication of this expertise, including a recent reconsideration of graded exercise therapy as a standard of care for myalgic encephalitis/chronic fatigue syndrome (ME/CFS) after ME/CFS advocacy groups demonstrated that it is a harmful practice [8, 143]. HCI researchers should value this individual and community-based knowledge.

To conduct HCI accessibility work on chronic illness, researchers must go beyond patient framings to view chronically ill people as having access needs and valuable expertise to shape accessible technology design work. This view challenges the assumption that medical providers should always be consulted as subject matter experts, while firmly centering chronically ill people as the relevant, necessary experts that can guide the development of accessible technology. This reframing is also necessary to re-render HCI accessibility work as relevant to chronically ill people. If researchers perceive chronically ill people as primarily patients, primarily medical technologies emerge as relevant supports. However, if we view chronically ill people as having a wide range of access needs that are not well-met in their daily lives, HCI practitioners are well-positioned to create non-medical tools to improve accessibility. For example, access-need driven HCI work with chronically ill people may explore how technology could adapt to a user's varied cognitive abilities, develop research practices that better support someone with fluctuating capacities, and examine how existing accessible technologies could be customized to meet chronically ill users' needs.

3.2 Tenet 2: Variability of Ability

The experience of chronic illness is diverse and inconsistent, even for an individual from day to day; consequently, we have to view access not only in terms of capability to complete an action, but also in terms of its repercussions (e.g., consequences such as worsening symptoms).

Chronic illness often causes varying levels of ability, affecting how chronically ill people move about the world, including what technology they use. When people's bodies have vastly different abilities over time, it takes creativity and planning to go about everyday life [9, 38, 106, 117]. For example, someone with fluctuating fatigue may use mobility or other technology aids some days or times in the day, but not others [9, 106]. Like other disabilities, chronically ill people's abilities and access needs vary between people. However, what is especially critical in examining the experience of chronic illness is understanding the variability of abilities within an individual. We break down this phenomenon by, first, categorizing factors that determine (and vary) ability into two main categories: individual baseline fluctuations and action-determined variability. Then, we propose a view of accessibility that is key for

designing technology for people with fluctuating abilities: designing for the consequences of actions rather than solely for static capabilities.

Individual Baseline Variability. Beyond interpersonal variation in experience with chronic illnesses, a single individual can experience internal fluctuations in ability. Many people's chronic illness experiences include "flares", or an overall exacerbation of symptoms for an extended period of time [16, 88, 138, 154]. These flares, as well as shorter periods of fluctuation (e.g., a bad symptom day) can be triggered by unknown or hard-to-control circumstances [13, 51, 97, 154]. For example, environmental factors (e.g., a heat wave, pollen, pollution/smog, season changes) or other physical experiences (catching the flu, menstruation) can trigger an overall higher level of disruptive symptoms and, consequently, a lower level of capability to perform daily tasks [40, 96, 97, 154]. These baseline fluctuations can occur rapidly, and therefore technology that is designed for people with chronic illnesses must be usable at a variety of ability levels to meet the user's current access needs.

Action-determined variability. A chronically ill person's ability levels frequently change after performing actions. While arguably, every person enters a different state after performing an action (e.g., after a run, a person might feel more tired) this difference in abilities/state can be extreme for people with chronic illnesses (e.g., post-exertion malaise [22]). For example, a person without a chronic illness might take a shower and detect no noticeable difference in state. On the other hand, the challenges of showering with a chronic illness are thoroughly discussed (and even meme'd) among chronic illness communities because they often result in extreme fatigue, overall malaise, or other symptoms [2, 50, 155]. Since actions may trigger lasting, negative symptoms, this can result in a cumulative effect that leaves chronically ill people with disruptive symptoms and a low capacity to perform tasks by the end of a day. Therefore, technology design needs to consider not just the abilities a person begins with, but the abilities they might have after performing an action, with or without technological support.

The effects of variability: designing for consequences. Because significant fluctuations of ability pervade many chronically ill people's lives, they often have to map out their days based on the expected consequences of each action they plan to take [100]. A common metaphor used within the chronic illness community for this form of variable consequence management is the "Spoon Theory" [29, 100]. This metaphor for understanding chronic illness, coined by Christine Miserandino, represents capacity or energy with "spoons" and explains that people have to carefully plan what they spend their spoons on in a day, since they are often in short and inconsistent supply; because of *baseline variations*, like a flare, the amount of spoons you can spend in a day may be different on Monday than Tuesday [100]. Due to the variety in abilities and symptoms an individual can experience, the number of spoons an action takes cannot be perfectly estimated. Even for the same person, the impact of the same action can vary drastically from 10 AM to 10 PM, though the consequences they incur for that action may be perpetually higher than they are for non-chronically ill people. In deciding how to allocate spoons, chronically ill people perform a complex cost-benefit analysis, informed by the time they've spent living with a condition, to predict the likely costs (e.g., symptoms)

of performing a task compared to the benefits they will receive. Therefore, we argue that to understand accessibility in the context of chronic illness, we must account for the consequences an action causes. Under this approach, we frame the accessibility of a task as not solely in terms of an individual's capability to perform a task, but rather the ability to perform a task and remain in an "acceptable" state afterwards.

3.3 Tenet 3: Include the Body

Research with people with chronic illnesses must be done using a model of disability that accounts for both the physiological and sociopolitical barriers they face.

Numerous disability studies scholars have explored the ways in which those living in non-normative bodyminds may experience limitations from both physiological impairments and socially constructed dynamics of exclusion [28, 34, 115, 119, 122, 124, 149]. In her foundational essay, Susan Wendell argues that for the "unhealthy disabled"—or people who are chronically ill and experience frequent pain, fatigue or other forms of discomfort—a social model view of disability focused on curing ableism disregards a core part of their disability experience. She highlights the fact that many people *"experience physical or psychological burdens that no amount of social justice can eliminate,"* and calls for an approach to disability that does not seek to avoid the realities of physiological impairment [148]. Motivated by Wendell, we argue that researchers must move beyond the currently discussed social and medical models of disability toward an approach that attends to both embodied and sociopolitical aspects of chronic illness.

Disability scholars have critiqued the social model [52, 132, 133] and developed new ways of thinking about disability that center the interplay between individual experiences of impairment and broader society and disability politics. For example, the political/relational model proposed by Alison Kafer *"neither opposes nor valorizes"* medical care, but makes space for *"the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people"* [72]. This model makes space to see chronically ill people as political subjects while not needing to cast aside the bodily realities of impairment that have historically been ignored under social model politics.

Other scholars have explored ways that living with differences in functioning can generate deep, visceral forms of knowledge available only to others who share the same experience. Tobin Siebers explains that embodied knowledge arises when *"situated knowledge adheres in embodiment. The disposition of the body determines perspectives, but it also spices these perspectives with phenomenological knowledge—lifeworld experience—that affects the interpretation of perspective"* [134]. In essence, knowledge does not solely come from a social location, but from the particular, physical experiences of living in a body. Siebers calls for disability theory that engages embodied expertise, not only as an object of analysis but as a conceptual tool that can strengthen design practices and enrich analytical capacity [135].

We combine these ideas to articulate a theoretical approach to understanding the experience of people with chronic illnesses. To adopt a more nuanced and comprehensive approach to chronic

illness, we believe researchers should center the embodied experiences that often characterize chronic illness. This framing balances the tensions between seeking care for unwanted symptoms and valuing disability as part of human expression. We hope this epistemological shift away from a purely social model approach makes space for HCI accessibility work that can account for people's bodily realities without defaulting to a medicalized approach.

4 CASE STUDY APPLICATIONS OF DESIGNING FOR PEOPLE WITH CHRONIC ILLNESSES

In the following section, we present three autoethnographic case studies from two chronically ill authors to show how different types of technology can be used to negotiate access in different social and work scenarios. We then demonstrate how our tenets can make sense of these experiences and, following that analysis, highlight potential directions and considerations for technology development.

4.1 Background and Methods

4.1.1 Collaborative Autoethnography. Collaborative autoethnography is a methodological approach using autobiographical data as the subject of ethnographic analysis conducted by a group of researchers [23]. Autoethnography is a well-established method among disability studies scholars who have both experienced and studied the social and structural dynamics of chronic illness, disability, or long term pain [45, 148, 161, 162] and continues to be employed by similarly situated researchers today [103, 107, 125]. Conducting autoethnography in collaboration produces rich analyses from multiple 'insiders' perspectives of complex health processes [23, 105, 108, 137, 145]. Inspired by this history of chronically ill people's engagement with autoethnography, we present three case studies derived from our own autoethnographic reflection. We focus on our own experiences and interactions as two chronically ill people to avoid being extractive of broader communities throughout our cases [44].

4.1.2 Background. The first authors, McDonnell and Mack, recognized rich examples in their lives around utilizing technology to navigate their own fluctuating access needs associated with chronic illness symptoms. They therefore chose to employ collaborative autoethnography to critically analyze their everyday experiences and reflect on them as case studies.

McDonnell and Mack started their doctoral studies at the University of Washington in the same year. While they met as colleagues collaborating on accessibility research, the experiences they recount here are primarily shaped by a deep friendship that developed over the course of that collaboration. Mack was diagnosed in 2016 with a chronic illness that results in fluctuating symptoms that include motion sickness in the form of dizziness and nausea that can be triggered by physical movements as well as visual stimuli. She has overall malaise that varies, sometimes feeling perfectly fine, other times feeling ill upon waking up. Although McDonnell has navigated significant dietary restrictions since she was young, her identification with chronic illness shifted in 2019 after what she thought was post-surgical recovery became unexplained symptoms

that took years to diagnose. McDonnell's symptoms include unpredictable malaise, an inconsistent ability to be upright and active, brain fog, heat intolerance, and fatigue.

To develop their cases McDonnell and Mack first independently generated a set of scenarios where technology was either inaccessible and/or allowed them to meet their access needs, identifying individual examples and reflecting on instances where they used technology to support each other. They then met and discussed areas of overlap between their scenarios, ultimately selecting three cases for their variance, rich engagement with technology, and interaction between the two authors. Throughout this process they referenced their shared messaging history to provide more details about interactions. The full set of authors reviewed these reflections, probing for more details and explanations when needed. Collectively the authors engaged in iterative discussions and analyses, producing the results presented here.

4.2 Case 1: TikTok Sharing and Consumption

Our first case examines Mack and McDonnell collaboratively creating access to social media content that is inaccessible to Mack. Their experience demonstrates a community-based solution to a social (nonmedical) access issue and highlights consequence-based accessibility.

4.2.1 The Scenario. McDonnell is both deeply hooked on the social media platform TikTok and fond of sharing videos that she finds amusing. However, Mack cannot watch all TikToks because shaky camera movement makes her sick. Therefore, when McDonnell wants to share a TikTok with Mack, she pauses to assess how much motion is in it, before copying the link over to Facebook Messenger and writing up a motion description of the video [123]. Although they have since discussed how to best craft motion descriptions, McDonnell began providing descriptions without prompting when she began sharing TikToks, paralleling how she shares image descriptions of visual memes with a blind friend. This description explains how much motion is in the video and may also include consumption guidelines (e.g., wait until someone says “get my coffee” to look at the video) to make semi-accessible videos watchable or context on why Mack might watch it (e.g., it is one of her interests, or McDonnell thinks it's hilarious, required viewing). Example motion descriptions McDonnell has shared with Mack are:

“This seems very up your alley though has a lot of motion. The camera is steady when it's still but moves side to side to track the dancers (in fits and starts though, like it moves, stays, they move out of frame and it then follows, not continuous tracking), and they're dancing at a reasonably close zoom so all the spins constitute motion on the screen. I will audio describe and pause for you tomorrow if you want “

“Steady cam tho with a lot of jump cuts- you can look at a still at the start and then away for the rest of the video and get 95% of it”

When Mack gets that message, she reads the motion description and decides if it is something she wants and can afford to watch at that moment. For example, when she receives the first description, Mack decides that since she usually feels best in the morning, she

can risk watching this video after she wakes, particularly because she knows she'll enjoy it. It does make her feel slightly ill. Mack then opens the second video and finds that McDonnell was more cautious than she needed to be, and she was able to watch the TikTok video without triggering symptoms.

4.2.2 Applying the tenets. Whether or not Mack watches a specific video at a given time cannot be determined by either party alone: McDonnell and Mack both provide key information to inform these decisions. This process is deeply interdependent and social in nature.

Because her symptoms fluctuate hourly (Tenet 2), Mack's decision to watch a TikTok at any given time needs to consider several interwoven factors. She essentially performs a risk-assessment where her current symptoms and the described amount of motion determines the risk, the level of novelty of the content determines the potential benefit, and missing events or feeling very ill later in the day determines the potential cost. Mack can make this calculation reasonably accurately, thanks to her expertise derived from years of lived experience around what will and won't trigger her symptoms.

What videos to send and what to describe in these videos is highly situated in understanding how elements of the social environment impact Mack's physical abilities and symptoms (Tenet 3). To make motion descriptions effective, Mack and McDonnell rely on building a shared understanding of Mack's symptoms and how to categorize motion. They work together to define a shared vocabulary to consistently describe elements of the social environment (e.g., what is “unsteady camerawork”) so that Mack can best predict her physical response to the stimuli. This process involved demonstrative examples and considerable trial and error; to this day, there are still elements of guessing at what kinds of visual stimuli would be accessible and how to convey risk.

Mack's deep, embodied knowledge and McDonnell's efforts to learn her access needs are crucial to this process (Tenet 1). Mack gained an understanding of how her symptoms change in response to different stimuli over years of self-reflection and trial and error, sometimes accidentally triggering negative symptoms. This self-knowledge is crucial to craft social accommodations. As McDonnell is her only friend who regularly sends motion-described TikToks, it is the only way Mack has to safely access this content – there is no existing external mechanism to learn about the motion stimuli in a TikTok in advance. However, McDonnell is not acting as a visual/motion interpreter for Mack – rather, it is an act of friendship that deeply considers access. In practice, McDonnell develops the knowledge of what to include in motion descriptions from being a curious friend who watches a lot of content with Mack, and also from Mack being very open with sharing her physiological reactions. They rely on access intimacy and interdependence to translate Mack's expertise into a social workflow that meets her access needs.

4.2.3 Potential for Technology Support: Contextual Awareness and Customization. This example highlights opportunities and considerations around how technology could better support people with fluctuating symptoms that can be triggered by external stimuli like motion. First, we found that context (i.e., Mack's current state and her future plans) was critical in determining what content she

would consume and when. Therefore, gathering users' contextual information through smart device sensors (e.g., microphones, pulse sensors) or other information logged in personal devices (e.g., calendar events)¹ could be a promising application for future work [27, 74, 130]. However, Mack's example demonstrates the sophistication of expertise needed to identify a user's current state and predict the impact of content consumption, suggesting that solutions may need to include a human-in-the-loop to ensure that sensed contextual information is adequately interpreted. Finally, Mack's experience of chronic illness is also unique from others, and the heuristics she has for what videos may be accessible are particular to her life and body, indicating that personalization would be key if designing accessible technology for this scenario.

Further, this case raises questions of how one might develop machine learning models to increase access when target users can't label training data and face significant consequences when using inaccurate models. While recent developments in customizable machine learning models (e.g., few-shot learning [146]), may seem well-suited to the questions of describing motion stimuli or identifying accessible videos, this example challenges several core machine learning practices. Even few-shot learning requires that users provide a training set and then give feedback to iteratively improve models. For Mack to independently curate a dataset of inaccessible TikToks or types of motion, she would likely have to slowly submit examples of videos that trigger her symptoms throughout daily life or undertake video labeling sessions that are all-but guaranteed to make her sick. An alternative model of data-labeling could explore a communal approach, where others (in this example, McDonnell) could curate a training set for Mack. This is not a panacea, as it takes time, transparency, and trust to train proxy data labelers and adds uncertainty to training data - though McDonnell can often make reasonable calls about what is clearly accessible to Mack, she does not live with Mack's symptoms. Additionally, the process of data labeling may also be a socially-untenable ask to make of others. Further, assessing model performance and providing feedback to improve a model poses significant risk, as the tolerable error rate is very low. Finally, since Mack's decision to watch or not watch a video depends on many interwoven, nuanced factors, this case raises interesting questions for machine learning around how to collect detailed feedback from a user without burdening them.

4.3 Case 2: Hacking Text-to-Speech Technology

We now examine a case around McDonnell and Mack's use of text-to-speech (TTS) technology to improve access during their graduate studies. This common tool had the flexibility required to support two different sets of access needs in performing the same task: allowing McDonnell and Mack to continue reading while symptomatic.

4.3.1 The Scenario. Mack's dizziness varies day to day. She finds that 10 minutes of uninterrupted reading consistently makes her dizzy. Consequently, she started using Text-to-Speech (TTS) technologies to read without triggering dizziness. Sometimes, Mack uses a screen reader as a TTS engine, since it has very fast reading speeds, is easily turned on and off, and doesn't require internet

access. However, Mack is not a "traditional" screen reader user: she uses her eyes to identify the paragraph of interest, highlights the text with the mouse, and then activates the screen reader. Other times she uses an online TTS tool, NaturalReader², designed for sighted users. Some of the visual interactions are useful to her, such as clicking where in a document to start reading, but she has to turn off others due to her motion sensitivity, such as highlighting each word as it is read. While this tool limits listening speed, it works well on PDFs, which are often not fully screen reader accessible.

Context often determines which tool Mack uses. For example, one day, while attending a meeting, her peer sent an abstract for her to read. Since an abstract is short, she chose to read this with her eyes, and it only made her slightly dizzy. However, she was then asked to review an interview protocol draft. This document spanned multiple pages, and given her existing symptoms Mack chose to consume the content with a screen reader. Since it was a group meeting with multiple people, she pulled out earbuds and put one earbud in, leaving the other ear uncovered to ensure she could still hear her colleagues while listening to the protocol. She felt comfortable using the earbuds without judgment or explanation since the meeting attendees knew about her chronic illness.

Meanwhile, McDonnell does not experience any uptick in symptoms directly related to reading. However, her fluctuating fatigue, malaise, and brain fog can make both the physical effort of sitting upright enough to read a PDF on her computer and the cognitive effort of staying focused on a document prohibitively difficult. When McDonnell mentioned that she was struggling to balance work and fatigue, Mack recommended NaturalReader. Initially McDonnell used this tool sporadically, but eventually it became her default reading method. As someone who is not a skilled screen reader user and can consistently navigate interfaces visually, a TTS tool alone serves as a significant access tool.

Through more consistent use, McDonnell has discovered that she uses the tool differently when she needs to get reading done while feeling so physically unwell that she can't be upright than when symptoms are impacting her ability to sustain focus. For example, McDonnell was taking a graduate seminar, which included dense readings, during an academic term where she was experiencing frequent symptom flares. If she was feeling unable to work from her desk, she would pivot to uploading the week's reading to NaturalReader, putting in her headphones, pressing play, and laying down on the floor or couch to listen. This allowed her to continue working and increased the likelihood that she'd be able to complete other work later in the day. If she was instead trying to complete seminar readings while dealing with brain fog, she would load the reading into NaturalReader and then simultaneously listen to audio output while using the tool's sentence-highlighting feature. Multimodal output and consistent pace allowed her to get through a heavy reading load while brain fog made staying focused on reading difficult.

4.3.2 Applying the Tenets. This case demonstrates ways that Mack and McDonnell address the access needs that arise from their chronic illnesses in nonmedical contexts (Tenet 1). Seeing McDonnell and Mack as having access needs de-medicalizes their issues and allows widely available, nonmedical tools to be a part of the

¹Note that a heavily sensing-based solution cannot be built without careful consideration for user privacy.

²<https://www.naturalreaders.com/online/>

solution. Further, McDonnell learning about NaturalReader from Mack exemplifies the common practice of communities creating and sharing valuable expertise with each other about navigating through all areas of life with a chronic illness [11, 92, 117]. Additionally, McDonnell's case provides insight into how individual expertise of chronically ill people evolves: she learned about her own access needs and how to manage them through months of feeling sick, trying new workflows (i.e., using NaturalReader when she was sick, lying on the floor), and recognizing where else they could be useful in her life (i.e., using NaturalReader as a focusing mechanism). Both experiences exemplify the creative workflows and rich insights that can be generated by disabled or chronically ill people hacking technology [55, 139].

Mack and McDonnell use TTS in response to the reality of their varied abilities (Tenet 2), despite neither of them being the "typical" target users of TTS systems (e.g., people who are blind, people with dyslexia or other common print-related disabilities). For Mack, TTS works to prevent and manage symptoms. For McDonnell, TTS is a more accessible option than visual reading when she is symptomatic, though she often reads visually without consequence when she is non-symptomatic. In fact, both authors' experiences highlight an interesting perspective on achieving access for chronically ill people: they both can physically read with their eyes, but find reading with TTS to be more accessible. Therefore, for McDonnell and Mack, oftentimes access is about utilizing modalities that lead to less friction during or after the activity more so than working around an inability to perform an activity.

On top of the physical variability that determines technology use, Mack and McDonnell's social and environmental contexts are also key. By default, Mack prefers to read any text longer than a brief email via TTS as it greatly reduces the risk of long-lasting symptoms. However, social context occasionally causes her to be more willing to risk reading with her eyes than to take on the social stigma of using headphones during a meeting. When working with established colleagues who understand her chronic illness, Mack's use of TTS and headphones is unremarkable, but when meeting new collaborators she risks seeming unprofessional or having to disclose full details of her disability to do so. Additionally, McDonnell's use of TTS is highly shaped by her environment - she is far less likely to work from the floor, requiring TTS, when in the office, but will readily do so in her apartment. Both internal and external context are key determiners of what technology support is most useful at a given time.

This case highlights the importance of viewing disability from both a social and physical lens (Tenet 3). For both Mack and McDonnell, TTS meets access needs that are not fundamentally social in nature - they are seeking ways to limit or live with physiological symptoms. This is different from many social model approaches to accessibility which seek to identify and change discriminatory social and environmental factors. However, it is also not a medical model approach - TTS use is by no means a cure or treatment for underlying symptoms, nor does it seek to normalize them to a nondisabled ideal. Further, having access to TTS does, in many ways, meet Mack and McDonnell's access needs in that it allows them to continue their work where chronic illness may have otherwise prevented it. However, they do not reach some ideal state where they are no longer experiencing disability or impairment

when these access needs are met - in fact TTS is often most necessary when they are especially symptomatic. By recognizing the social factors at play while also leaving space for physiological experiences of symptoms, we can better understand the goals of these chronically ill technology users and the role HCI technologies can play in achieving them.

4.3.3 Potential for Technology Support: Broader User Bases and Contexts. The fact that McDonnell and Mack are not the "traditional" users of TTS technology raises interesting design questions around how to describe, and market to, technology users. Often in accessibility research, "people who are blind" and "people who use screen readers" are used synonymously. This case is a demonstrative example: not all screen reader users are blind or have low vision. When narrowly conceiving of who the users of accessible technologies are, this purportedly inclusive design ends up excluding people with chronic illnesses and anyone else who designers failed to imagine might have a use for an accessible technology. Categorizations around who is the "intended user" for a technology can lead to increased resistance from institutions (e.g., insurance companies), social stigma, and even denials of requests (e.g., people with fatigue who can physically walk face resistance requesting wheelchairs [9]). Chronically ill people's access needs often overlap with those that are more comprehensively understood by accessibility practitioners, but a lack of attention to chronic illness within the field means that these unique use cases are not considered in design. Future work in HCI accessibility should consider the multiplicity of ways people could meet the same access need and the multiplicity of access needs that can be met by the same technology, moving towards future tools with a wide range of customizable options.

Looking beyond the individual, the broader social and physical environments affect technology use, and therefore need to be considered in when and how to adapt technology for chronically ill people. Bennett et al. proposed a model of interdependence for viewing a disabled persons' interactions with their environment and assistive technologies where technology use is influenced by factors outside of the disabled person and their technology [12]. In this case, we see examples where social dynamics and the need to disclose and explain her disability affected Mack's choice to use screen readers. In other cases, technology supports may become less critical when a trusted ally can provide the same care.

Finally, this case, mirroring trends in online chronic illness forums [11, 90], demonstrates the crucial role that shared expertise in managing illness has in communities. McDonnell started imagining the ways TTS technologies could benefit her after watching Mack adapt screen reader technologies to her own needs. Since then, McDonnell and Mack have recommended the technology to numerous other people who find benefits in consuming content auditorily. This discovery process could be an area to engage occupational therapists, who frequently focus on creative way to use existing tools to support people in expanding function [58], though we note that occupational therapy is often not offered or available to many chronically ill people. Future access technologies might consider 1) how they market their capabilities and customizability, and 2) how to share settings so that current users could introduce others with similar access needs to their use of a tool. This feature could

reduce the onboarding and learning cost, especially among people with less comfort using new technologies.

4.4 Case 3: Remote work

Finally, we explore the ways that remote access allows McDonnell and Mack to more easily meet access needs that emerge throughout their days. This case highlights the importance of viewing some access barriers and remedies as social and others as based in the body (Tenet 3), and it introduces the idea of *internal access conflicts*.

4.4.1 The Scenario. For both Mack and McDonnell, attending meetings and classes virtually allow them to more easily and effectively manage symptoms and participate in otherwise physically-inaccessible events. Both experience symptoms that can be triggered by activity, such as walking or commuting to campus. Mack finds that she cannot easily attend classes or meetings in the morning (and sometimes all day) without feeling debilitatingly sick. For McDonnell, the COVID-precipitated shift to work-from-home made it so that she no longer has to leave the house at set times. She prioritizes going on walks or completing errands after her daily obligations are met, thus lowering the cost if activity triggers symptoms. On top of remote work enabling Mack and McDonnell to arrange their days to better control symptoms, it also makes it easier for them to manage symptoms as they arise. Both find that the work of managing symptoms requires myriad resources, meaning that leaving the house may require packing beverages, snacks that meet their dietary restrictions, medication, or mobility aids. Additionally, aspects of their environment can impact symptoms, and when working in shared spaces, having control over temperature or a place to lay down is not guaranteed. Mack and McDonnell do sometimes choose to go into campus when feeling well or to see specific people, but by default choose to work from home.

McDonnell found further benefits from the ability to disguise how sick she was feeling or her access hacks during virtual meetings. Because of video conferencing's limited view, she could discreetly make adaptations that reduced symptoms. For example, during one evening class session, McDonnell was feeling particularly unwell - her temperature was dysregulated and she was experiencing malaise from having been upright all day. She attempted to limit her symptoms by grabbing Gatorade from her fridge and opening the window next to her desk to cool down. McDonnell was also able to recline somewhat by putting her feet on her windowsill and leaning back in her chair while still appearing attentive in class with her camera on. However, as time wore on, she continued to feel worse, so she turned off her camera, grabbed her computer, and finished class while lying on the floor.

Remote work, while still Mack's overall preference, is not a perfect solution. Though remote attendance eliminates the need to walk early in the day and trigger symptoms, the shaky video feeds of her peers or professors can trigger her motion sickness. Unlike consuming TikToks, Mack often needs and is expected to pay attention to visual content in work contexts. Over months of remote work, Mack found a variety of hacks to avoid getting nauseous during video calls. For example, one day, when a meeting attendee started walking around with their laptop, causing significant motion, Mack opened a Notepad window on her computer and positioned it so that it blocked only that person's camera feed. However, later in

the meeting when a person was screen sharing graphs she had to examine, they kept scrolling the screen which made Mack acutely nauseous. Since that experience, she often starts meetings by establishing group norms: asking people to share links to documents with her rather than screen sharing and to keep their devices on a stable surface or turn their cameras off if they are moving.

4.4.2 Applying the Tenets. Mack and McDonnell's experiences with remote work demonstrate the need to move beyond traditional models of disability (Tenet 3). While there are some changes to the built environment that could lessen the burden of in-person work for the McDonnell and Mack (e.g., access to a place to lay down as needed), this social model thinking has its limits because it is not solely the built environment that is disabling in their cases. Their access needs arise from their bodies, highlighting that it is critical to include bodily realities of impairment in theoretical approaches to chronic illness. We do not suggest that isolation by way of an inaccessible environment is justifiable for those who are currently prohibited from being able to participate in physical daily life. Instead we consider that sometimes the most accessible or preferable option is to provide the opportunity for multiple environments, rather than one universally accessible space, following Dolmage's invitation to approach the universal design of spaces as "*multiple and in-process*" [36].

The variability of McDonnell and Mack's symptoms and abilities requires considerable, burdensome preparation (Tenet 2). While their homes house a variety of tools to prevent or manage symptoms (e.g., food, medication), these supplies are not usually by-default available in all work environments or in transit. Consequently, they pack their bags with potentially helpful or needed supplies when they leave home to prepare for whatever symptoms might arise. While some days the extra preparation might be fully unnecessary, both find the uncomfortable, sometimes life-threatening, consequences of being unprepared outweighs the cost. This cost is not negligible, however. The process of bringing all the tools to feel prepared takes time, adds stress to their days if they forget an item, and adds physical weight to already fatiguing walks. In McDonnell and Mack's cases, the preparation required for the variability of their abilities is not insurmountable, but the ease provided by a way to remotely engage in work is often preferable.

In this case, we see the benefits and effects on the solutions of viewing people with chronic illnesses as having access, rather than solely medical, needs (Tenet 1). If viewing Mack and McDonnell as patients, the most obvious tools to address the inaccessibility they face while working in person are medical treatments. While both Mack and McDonnell are actively pursuing the medical care that may make the broader world easier to navigate, understanding them as people with access needs makes visible ways they can be better supported holistically. Therefore, the affordances provided by remote work (e.g., the ability to go on and off camera or to block nauseating motion) become legible as accommodations.

4.4.3 Potential for Technology Support: Consider Internal Access Conflicts. While prior work has considered access conflicts between disabled people [35, 57, 85, 87], this case explores how technology can create *internal access conflicts*, a phenomenon sometimes discussed within chronic illness communities [93]. While attending class remotely alleviated early-morning symptoms for Mack, it

created a conflict by causing her motion sickness. Particularly in the case of chronic illness, individuals can have different access needs that overlap, conflict and synergize in ways that lead to unique technology use. For example, a technology whose interface is very visual may lessen cognitive load for users but also lessen the ability to use the tool non-visually. Technology designers should consider that users may have internally conflicting access needs and therefore pay attention to implications of all design decisions and maximize opportunities for customization.

5 DISCUSSION

We have identified three tenets for future accessibility research with chronically ill people (Beyond Patients, Variability of Ability, Include the Body), and demonstrated the ways that they can highlight new opportunities for technology design throughout our autoethnographic cases. We now discuss additional considerations that follow from our reframing; the need to account for consequence-based accessibility, approaching design for community use, and methodological changes for working with chronically ill people.

5.1 Consequence-Based Accessibility

In this paper, we present a paradigm shift in how we define accessibility based on a more dynamic understanding of access. The traditional, binary approach to technology that cleaves access needs into “I can” versus “I cannot” fails to encompass the fluctuating needs of people with chronic illnesses. People with chronic illnesses can often technically perform an action that is practicably inaccessible to them because inaccessibility can arise from the repercussions of doing that action. To demonstrate this difference: handwritten text might be pervasively inaccessible to a blind person without the support of technology or sighted companions. However, for someone with a chronic illness that impacts digestion (e.g., ulcerative colitis) they can technically eat all foods, but face severe and debilitating reactions to certain foods, rendering those foods practicably inaccessible. We, therefore, present a paradigm of designing for consequence-based accessibility, which encompasses the consequences an action causes, rather than solely the innate in/ability to perform a task.

Viewing technology design through the lens of consequence-based accessibility acknowledges that many chronically ill people have the **choice** to incur consequences, even if those consequences cause discomfort or more access needs. Perhaps Thanksgiving dinner is worth a flare in gastrointestinal symptoms, a cute summer outfit without compression socks may be worth later unsteadiness, and running to catch a kid falling off a playground structure might take precedence over the later malaise these actions could trigger. Chronically ill people learn to live in their bodies, and perform a complex calculus to determine which consequences to avoid and which to weather, shaped by variables such as current symptoms, future plans, environments, urgency, social context, availability of accessible options, resources, desire, and many more.

As designers of accessible technology, we need to reconsider what “accessibility” means to people who have the option to partake in an activity, but with varying costs. While chronically ill people often also deal with more “traditional” access barriers (e.g., low fine motor control in their fingers may make it so they can’t open a

jar), other access needs arise when performing an action. When we consider the impact this framing has on technology, we see areas for innovation. First, technology can collect and provide easy access to the information that chronically ill people need to make well-informed decisions (e.g., a snapshot of what they have planned for the day, recent heart rate trends). Providing the right information at apt times poses interesting technical challenges. Second, systems can consider how to best adapt their interfaces and operations to meet their users’ needs after an action (within or outside of the system) triggers symptoms. For example, symptomatic users may benefit from a lower-cognition interaction mode or shifting from visual to auditory content output. Future research avenues could focus on learning what these levels of accessible modes of operation are and when to enable them.

To operationalize fluctuating access needs, technology designers must recognize that chronically ill people constantly define and redefine what constitutes “unacceptably impaired,” and therefore inaccessibility. Individuals determine what is inaccessible to them at a given time based on deeply personal and contextual factors, performing a situational “consequence calculus” to determine if an activity is worth its consequences. Having the ability to adjust their definition of “accessible” to their current context can afford chronically ill people greater agency, but also introduces internal and external doubt around the validity of people’s access needs. In thinking about the technological consequences of redefining accessibility, we see that supporting user agency and contextual adaptations is key.

Finally, approaching accessibility through a consequence-based lens that centers the underrepresented experience of chronically ill people creates potential to better meet the individualized, contextual needs that many disabled people have when using accessible technology [46, 64]. Future accessibility work done using a consequences-based model could consider that, for example, many blind and low-vision people’s vision changes based on the time of the day, or could account for the optical and mental strain that speechreading for long periods of time has on d/Deaf or hard of hearing people, or better match the needs of people with mental health disabilities that are cyclic in nature (e.g., bipolar disorder). Further, we hope that our interrogation of what designers assume when we think about “accessibility” serves as a useful starting place for future researchers to interrogate the paradigms in which we work.

5.2 Designing for Communities

Our cases provide examples of two chronically ill people sharing access support (Case 1) and knowledge (Case 2); these themes of using care networks or other chronic illness communities to make sense of one’s condition and create access hacks in day-to-day life is documented within HCI (e.g., [43, 66, 82, 90, 92, 129, 144, 159]) and among disability community activists [6, 98, 117, 118, 153]. When working with a group of people who have already built, engaged in, and found joy within [98] a community, we propose that interdependence may be a more appropriate goal for technology design than independence, following Bennett et al.’s framework [12]. Indeed, the act of being cared for, like receiving aid from a care network, might provide emotional benefits that outweigh

the benefits of independence provided by purely technological solutions.

Designing for interdependence involves building for transparency with others and oftentimes giving other users capacity to take action. For example, consider a system where trusted friends could monitor the biological levels (e.g., heart rate, blood sugar) of a person with a chronic illness and be alerted to intervene or provide more support in symptomatic times. The people given these privileges might be trusted members of care networks. However, we must also resist a naively optimistic view of care, and consider how to build systems in a way that could protect and grant agency to a chronically ill person in an abusive or unsafe care arrangement [71]. Further, though interdependence can take the form of a nondisabled person supporting a disabled person, our case studies and examples from communities (e.g., [11, 92, 117]) demonstrate support maintained fully within chronically ill spheres. Thus, any systems designed to support chronically ill people must avoid assuming a distinction between support giver and support recipient - chronically ill people are often already both.

5.3 Doing Research with Chronically Ill People: Effects on Methodology

As we propose an approach to HCI accessibility research with chronically ill people, we also reflect on how research methods may need to change to be accessible to this population. Prior work describes how to plan accessible studies for people with disabilities, including accommodations for varying fatigue or incorporating notions of crip time [33, 79, 87]. Mack et al. describe ways to allow for more flexibility like allowing interviews to take place over multiple sessions, building in breaks, and adjusting the space to be comfortable for participants' bodies [87]. Centering a chronically ill perspective, we add allowing access to food and drink, prioritizing remote facilitation options, explicitly providing the option to participate from nontypical locations (e.g., the floor), and considering potential sensory sensitivity triggers (e.g., motion, light, loud noises).

There are other methods which may be challenging to run with strong internal validity while prioritizing participant beneficence. Consider, for example, within-subjects controlled experiments, which rely on the assumption that an individual's capacities are an experimental constant. How might a testing instrument account for the reality that someone may begin a study reporting a 2/10 on a pain scale but end it at an 8/10 (perhaps directly due to their participation in the study)? Further, what is the procedure if a participant with fluctuating symptoms shows up to a study without the access need for which they were recruited (e.g., someone with fluctuating brain fog has no brain fog on the study date)? This perceived "threat" to internal validity may be appeased if symptoms could be triggered consistently, though we argue that this is unreasonable to ask of participants (e.g., triggering a migraine can have hour or day long impacts). One solution may be to perform data collection *in-situ* when the necessary conditions occur naturally rather than engineering a symptom increase; while this may lessen internal validity, it increases ecological validity and prioritizes participant beneficence. In general, we suggest strategies of planning studies that prioritize the access needs and comfort of participants, even if it means being more creative in the study design. Because

chronically ill people's access needs often manifest differently than HCI anticipates, researchers must pay careful attention to methodological in/accessibility when working with people with chronic illnesses.

6 LIMITATIONS AND ETHICS

Our work has limitations and necessary ethical considerations. First, autoethnographic methods are not designed for broad generalizability, and the examples we provide in this paper come from the experiences of two people with similar demographic backgrounds. We do not intend our work to serve as a survey of chronic illness experiences, but future research could explore how our tenets operate when applied to a wider range of experiences. Additionally, as we outline ways of engaging with a large, broadly defined community, our scope is wide. There are open questions around how chronic illness and other forms of bodymind difference (e.g., mental health disabilities) overlap and diverge, and we encourage future work to explore this nuance. Additionally, we are not able to speak to the wide range of ways that people identify with chronic illness and/or disability, a promising area for future work. Finally, while we believe that HCI accessibility work that includes chronically ill people could serve under-considered populations, we are also cognizant of the harm that technical intervention can cause. We encourage designers and researchers to adopt a critical eye around whether their work is needed and useful, or another disability dangle [67, 68].

7 CONCLUSION

In this work, we present three core tenets for HCI community members to consider when designing technology for people with chronic illnesses. First, we must look beyond patienthood to see chronically ill people as having access needs and expertise. Second, we highlight that variable ability requires us to consider accessibility in terms of the consequences actions cause. Finally, we provide a theoretical approach to chronic illness that highlights both bodily and socioenvironmental factors. We demonstrate the utility of these tenets through the analysis of three autoethnographic reflections on the technology use of two chronically ill authors, noting implications for technology design. Finally, we discuss the implications of consequence-based accessibility and what researchers should consider when designing technology for and conducting research with chronically ill participants. We hope that this work spurs more work in the HCI community that focuses on the access needs of this growing population.

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