The Work of Workplace Disclosure: Invisible Chronic Conditions and Opportunities for Design

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Health disclosure at work is complicated for people with invisible chronic conditions. Due to the lack of visible symptoms, invisible conditions affect the work life of people in ways that are not obvious to others. This study examines how people disclose and conceal their conditions in the workplace and opens the design space for this topic. In the first phase, we analyzed posts on two subreddit forums, r/migraine and r/fibromyalgia, and found a range of strategies that individuals use to disclose or conceal their conditions. In the second phase, we created five technological design concepts based on these strategies that were shown to eight people with migraines or fibromyalgia in semi-structured interviews. Based on these phases, we contribute understandings of disclosure and concealment of invisible conditions in the workplace for future research, such as potential areas for intervention ranging from individual to societal level efforts, as well as the potential and limitations of relying on empathy from others.

CCS CONCEPTS • **Human-centered computing** → Human computer interaction (HCI); Collaborative and social computing → Empirical studies in collaborative and social computing.

KEYWORDS: Invisible conditions; Chronic conditions; Migraine; Fibromyalgia; Empathy; Workplace; Accessibility; Disability

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1 INTRODUCTION

Many individuals are affected by invisible chronic conditions. These health conditions limit activities and functions but lack symptoms that are visible to others [1]. The invisibility and immeasurability of symptoms can mean that despite their major impact on one's life, symptoms can be dismissed by others [7,33,59]. In the case of fibromyalgia, for example, individuals experience invalidation by medical professionals and must make significant efforts to prove the severity of their condition to their doctors [51]. While people with visible and invisible chronic

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conditions both face stigma, people with invisible conditions also negotiate the decision of whether to disclose their conditions to others, a complex process that may have negative ramifications regardless of whether they disclose or not [28].

Disclosure of invisible and stigmatized conditions is a topic of interest in CSCW as well as in health and accessibility technology research. Researchers are examining how people with invisible chronic illnesses disclose conditions across different platforms [50], how audiences respond to self-disclosures of stigmatized experiences [3], and how disclosure affects domains and phases of life such as dating [43], parenting [1], and complex life transitions and identity changes [24,57]. Technology also plays a role in disclosure offline. Assistive technology and medical devices can signal the presence of an invisible condition, such as a chest-worn heart monitoring device disclosing an otherwise invisible heart condition [19].

Past work with people with invisible conditions, while rarely considering the workplace explicitly, hints at the ways that information sharing may look different when it comes to bosses [55], colleagues [40], and coworkers [20]. Individuals have distinct motivations and barriers towards disclosing their conditions in the workplace that have been largely unexamined in health and disability CSCW research, and our study selects the workplace as a site in which to study the intersection of disclosure and technology. Research from other fields has established an understanding of considerations in disclosing invisible conditions in the workplace. Individuals calculate benefits and tradeoffs specific to their workplace, including the ability to access key programs and services [61], become a role model for others [8], and create an inclusive environment in the workplace [9], balanced against the risk of significant stigma and discrimination that can arise after disclosure [8,61,63]. While this past research has focused on *why* individuals conceal or disclose their conditions, what is less understood are the strategies that people employ in disclosing and concealing – *how* individuals are able to achieve their workplace goals while also managing others' awareness of their invisible condition.

Our aims with the present study are twofold: 1) to understand how people disclose and conceal their invisible condition in the workplace, and 2) to flesh out a design space involving the disclosure and concealment of invisible conditions in the workplace. To accomplish these goals, the first phase of our study examines the experience of negotiating disclosure in the workplace through an analysis of two of the most popular chronic condition subreddits, r/migraine and r/fibromyalgia. We find a range of strategies individuals use to disclose as well as conceal information about their condition. Informed by Phase 1, Phase 2 involved the creation of design concepts and semi-structured interviews about these concepts with working professionals with invisible conditions. This phase probed the role technology might play in disclosure in the workplace. Based on this work, we contribute implications for designing in this space and articulate an agenda for CSCW and health and disability researchers in the workplace.

2 RELATED WORK

Below, we describe past findings related to social media and individuals with stigmatized conditions, as well as past work on invisible conditions in the workplace.

2.1 Migraine and Fibromyalgia as Two Invisible Conditions

In this paper, we selected migraine and fibromyalgia as the two invisible conditions to study because they are the most popular chronic pain communities (subreddits) on Reddit (see methods for more details). There are estimates that nearly a billion people are affected by migraines [71], and 3-6% of the world's population is affected by fibromyalgia [70]. We briefly describe symptoms of migraines and fibromyalgia to provide context for our analysis. While migraines present themselves in the form of a headache, a migraine headache is different from a common one due to its severity and a combination of other symptoms such as nausea, photophobia, and dizziness [68]. Fibromyalgia is a chronic condition characterized by widespread body pain [7], fatigue [7], and cognitive impairment (e.g., 'fibro fog') [69]. The symptoms of people with migraine and fibromyalgia often present in the form of "flare-ups," where they are felt acutely for a limited time.

Both of these invisible conditions are often minimized or seen as insignificant by others [7,33,49,51,59]. Though individuals with both conditions experience invalidation, migraine and fibromyalgia represent two ends of a spectrum in terms of how they are viewed medically. Migraine is considered a medical condition, and there are prescription-strength medications made available for people who can get a diagnosis from their physician. However, despite being a clinical syndrome since the 1970s, fibromyalgia is viewed as a 'mysterious label' [33].

2.2 Disclosure, Health and Disability

Social media platforms such as Facebook [27], Instagram [27], and Reddit [14,31] are being used to form virtual community support groups on a variety of conditions, including invisible chronic conditions. Communities formed on social media motivate people to find others beyond geographical barriers for support, commiseration, and to build a shared understanding of chronic health condition management [27]. A growing body of research explores the disclosure of stigmatized information for different concerns on Reddit, such as the #metoo movement [22], mental health conditions [14,15], and women undergoing menopause [31]. These studies establish the idea of community building for stigmatized experiences and explore the dialogue among people within stigmatic social groups. Reddit may be particularly appealing for stigmatized topics given its pseudonymous nature, as people sign up using a screen name that forms the basis of their profile and tracks their activity across the platform [36]. This 'pseudonymity' is embraced in the practice of support-seeking [36] and commiseration [14,31]. Given the invisible, stigmatized, and chronic nature of migraine and fibromyalgia, we analyze Reddit threads for the first phase of the study to understand experiences of disclosing health conditions at work.

Disclosure is a topic of interest in CSCW, and researchers have studied how individuals disclose stigmatizing information or stigmatized identities online. For example, one study of stigmatized information revealed on Facebook defined 'Network-Level Reciprocal Disclosure' as disclosures taking place on individual profiles when one is inspired by the disclosure of someone else in the network [2]. Another study about privacy concerns of chronically ill teenagers found that teenagers avoid disclosing their health condition on Facebook because it is an identifiable social media platform where they don't feel like they are "regular" teenagers [65]. Research has also considered how technology affects disclosure in the context of disability. A study about online dating and disability offers implications of designing platforms that allow people to negotiate disclosure [44]. Researchers have also focused on others' perceptions when disability is disclosed, such as how the disclosure of disability status affects willingness to hire in the sharing economy [12].

In addition to attending to digital platforms that mediate disclosure, researchers have studied how technological devices play into disclosure and have framed the use of certain technologies, such as assistive technology, as an act of disclosure of a disability [19,58]. Though individuals can avoid devices that signal to others the presence of a disability due to stigma and discrimination

[58], these devices can also be appreciated for serving important legitimizing functions [19] and playing a part in self-expression [46].

2.3 Invisible Conditions in the Workplace

In studying invisible conditions in the workplace, we draw attention to an understudied but important area for CSCW. Much research on invisible conditions in CSCW and HCI has focused on how people find information and support about conditions whose symptoms are minimized or contested by others [34] and how individuals can track intermittent symptoms to create documentation for themselves, clinicians, and their wider social circles [13,40,55,56]. Some of this past research, while not focused specifically on disclosure or the workplace, point to the specific and differing needs people have at work. A study of self-tracking by people with migraines found that people share information to obtain better acknowledgment from social partners, including colleagues [55]. The paper includes participant quotes about individuals being motivated to share certain types of data with their bosses [55]. Other past work hints to how the workplace acts as a very different setting to personal life, wherein people are reluctant to obtain needed help in response to a migraine from colleagues [40] or share details of chronic pain with coworkers [20]. Our analysis of disclosure dilemmas in the workplace provides a framework to make sense of findings like those in past studies.

Our understanding of the disclosure experiences of people with invisible conditions in the workplace comes largely from research outside of CSCW. Legislation exists in many countries to prohibit discriminatory treatment and to make workplace adjustments for people with disabilities and health conditions, including invisible conditions. Yet, even with legislation and workplace policies in place, the disclosure that is necessary to obtain protections and accommodations can be complex and fraught. Motivations for disclosure include stigma reduction [63], access to assistive services [61], improved psychosocial work environment [39], better relationships at work [9], the ability to become a role model for others [8], and the motivation to create an inclusive environment in the workplace [9]. In terms of deciding not to disclose, researchers have found stigma and discrimination serve as major barriers to disclosing conditions [8,61,63]. Negative experiences after disclosure include insensitive remarks and dismissive treatment at work [47]. People fear that disclosing their invisible condition will undermine their professional role [39]. One study found concerns of people with less apparent disabilities about losing health care benefits, a lack of understanding from supervisors, being fired or not hired, and limited promotion opportunities [54]. This past work reveals *why* people choose to disclose or not. The focus in the present paper is on the strategies people employ – *how* they disclose or conceal their conditions – and the role that technology might play in these strategies.

3 PHASE 1: QUALITATIVE DATA ANALYSIS OF REDDIT

An analysis of Reddit posts and comments led to our findings of a range of strategies that individuals use to negotiate the disclosure of their invisible condition at work.

3.1 Methods

Analyzing social media posts can help researchers attend to dialogue among people affected by a health condition. This analysis may lead to topics important to those with the condition coming to light, as opposed to interviews where a researcher scopes topics via interview questions or a study topic [30]. We selected Reddit as a platform for several reasons. First, as migraine and fibromyalgia are invisible chronic conditions, both the symptoms and the approaches people take to negotiate disclosure in the workplace may not be directly observable in everyday life. Second, Reddit is a useful platform to study stigmatized conditions [14,27,31], in part due to its pseudonymous nature, which may promote uninhibited discussions [36].

After selecting Reddit, we determined the most active subreddits discussing the topic of chronic pain. We searched for the term "chronic pain" on Reddit, and the top results included the subreddits r/chronicpain, r/migraine, r/fibromyalgia, r/backpain, r/babybumps, and r/sex. Since this study pertained to the workplace experience, r/babybumps and r/sex were excluded from the final corpus. With the four remaining subreddits, we scraped the dataset using PRAW (Python Reddit API Wrapper), a Python package that allows simple access to Reddit's official API for specific search terms.

As of September 2019, r/chronicpain had been active for seven years with 32,685 subscribers; r/fibromyalgia has been active for seven years with 18,824 subscribers; r/migraine has been active for seven years with 35,061 subscribers; and r/backpain has been active for five years with 8096 subscribers [72]. To identify posts related to work, we used the search terms "work", "coworker", "co-worker", "office", "job", and "boss." The search terms were identified through an iterative process. Posts about visiting the doctor's "office" and blood "work" were removed from the sample. The initial dataset included posts, comments, and other metadata (i.e., timestamp, username, unique user ID) from October 2012 to September 2019.

We took a constructivist grounded theory approach to analyze the scraped data [11]. We began our analysis with a broad interest in understanding the experience of having an invisible condition in the workplace. The first author open-coded approximately 8% of the total number of threads from all four subreddits and wrote memos to facilitate the sense-making process. Example open codes at this stage included "fear of losing the job, "hiding the pain at work", and "receiving advice from Redditors". During data analysis and discussions among the research team at this stage, we identified that condition-specific subreddits (i.e., fibromyalgia and migraine) had richer experiential data about jobs, relationships between boss and employee, coworker-specific posts, and symptoms. Therefore, we narrowed down our data analysis to these two subreddits.

With this narrowed focus, we selected another randomized sample from the two subreddits to create new codes, themes, and memos. Overall, we open-coded 40% of the total dataset, representing 252 threads and 3736 comments from r/fibromyalgia and r/migraine (each thread had an average of M: 14.82, SD: 20.01 comments). The dataset had 231 uniquely identified authors. As we started to open code, memo, and theorize the data from these two subreddits, we began to develop the themes of concealing and disclosing of invisible conditions at work (which became the focus of this paper) [11]. Codes that we formed at this stage included "analogies to explain symptoms" (ideas used to describe the condition to coworkers); "keeping it together at work" (techniques used to seem efficient at work); "you don't 'look' sick" (acts of dismissal by employers). As we analyzed and theorized, we familiarized ourselves with the past literature on disclosure in the workplace for people with conditions like anxiety and depression [47,61], which led us to recognize that while motivations for workplace disclosure are well studied, we are missing research on the strategies that people employ when disclosing or concealing their invisible condition in the workplace. With this understanding, we proceeded to analysis with the codes that related to the strategies people discussed.

Once our codes were formalized, the remaining threads in the dataset were analyzed using a focused coding approach. Data saturation was reached at this point, as data analysis no longer resulted in new insights [31]. In total, we coded 479 threads and 7174 comments (each thread has an average M = 14.98, SD = 18.55 comments) about the workplace experiences of people on r/fibromyalgia and r/migraine. Given the sensitive nature of the topic, to prevent reverse searches, we took a "moderate disguise" strategy to obscure quotes in this paper for almost all posts and comments [10]. The only texts which are not obscured are the analogies describing experiences with the condition (section 3.2.1.2). These rich descriptions are important to keep as written and are less sensitive as they focus on the experience of the condition rather than conflict with it. Participant notation includes the forum that the quotes came from (M for r/migraine and F for r/fibromyalgia) followed by a number. The number is linked to the order in which the quotes are introduced in this study.

A constructivist grounded theory approach necessitates our reflecting on our positionality in relation to our research aims [11]. The first author is a woman in tech with an invisible chronic condition who has encountered dilemmas comparable with many of the themes found in our data. She has been subjected to invalidation of her symptoms from her medical team, coworkers, and supervisors. In her work experience in the industry and academia, expressing pain in the absence of visible symptoms was met with doubts, advice to "stretch more often", and suggestions to try alternative medicine (e.g., homeopathy). The need to prove to others the existence of symptoms that affected her ability to work affected the ways in which she could disclose her health condition. The first author's experiences and both authors' shared stance of working towards a more equitable and accepting workplace for people with invisible chronic conditions surely influence our analysis.

3.2 Findings

Individuals on r/migraine and r/fibromyalgia described working in a wide variety of industries, roles, and workplaces, from elementary school teachers to IT professionals. The roles included ones where people described more physical stress on their bodies (e.g., from standing), such as in retail, warehouse/factory work, and the food industry, as well as a variety of office jobs. Individuals also worked in different kinds of team structures, including ones where teams were highly interdependent, and described varying benefits. Across these roles and job types, individuals discussed motivations and strategies to disclose and conceal their invisible condition in the workplace. Below, we overview motivation for disclosure briefly before turning to strategies for disclosure. Then, we provide a parallel analysis of concealing conditions and symptoms.

3.2.1 Disclosure of Invisible Conditions

Disclosure of an invisible condition at work can affect how one is perceived by coworkers and upper management. People shared several motivations for workplace disclosure, including job security. *<M-101>* stated their regrets related to not disclosing their condition: *"I made a big error by not having "the migraine talk" with my boss. I had a string of migraines in a 2-month period and she took it as a lack of motivation and caring about my job...my boss was talking about letting me go. I ended up needing to show a doctor's note for her to finally understand that these are not just a headache..."*

Disclosing one's condition can allow individuals to access needed support and resources, as in the example above. Yet, disclosure is not a simple one-time conversation. Even when all the details are made clear to others and legal protections are in place, individuals work to convince others about the severity and specificity of what they are experiencing – that a migraine is not just an ordinary headache, or that they should not be taken to the hospital no matter how debilitated they appear to others. Below, we describe the strategies individuals use to disclose their condition in a way that convinces others of the existence and severity of their invisible condition and allows them to access the resources and care that they need.

3.2.1.1 The "Migraine Talk"

The migraine talk involves educating others about how one's health condition affects them. It allows others to learn about the condition, as well as understand the circumstances under which their colleague needs a respite from flare-ups. It also creates avenues for coworkers to help them when flare-ups are difficult to manage at work. Migraine talks were personalized as symptoms are highly individual – chronic migraines can present as a combination of several symptoms, including dizziness, nausea, and photophobia [68]. The migraine talk happens in the form of an actual conversation, but also textual form. *<M-102>* discussed the usefulness of disclosing their migraine at work via a printed note that explains symptoms and the overall condition. *"I carry a printed note with my medical info that explains the condition and symptoms... I explain that I need to sit in the quietest, darkest place I can until my symptoms are under control. I explain I don't have to go to the emergency room, even if it seems like I'm having a stroke or going blind… and I include my emergency contact #s if someone does not believe I'm safe by myself."*

<M-103> shared their experience with printing their "migraine talk" to display on "a couple cards on a lanyard" in varying degrees of details: "I am in too much pain to listen or speak, leave me alone", to "'I have Migraine' and explains about migraines in real good detail." This individual decided which card to show based on context. Physical documents were useful because migraines can at times impede speech, but also to make the invisible experience more visible for others. The data about migraine talks served as a sharp contrast to the experiences of those with fibromyalgia. There was no equivalent for a "fibromyalgia talk", likely since fibromyalgia is still considered a heavily contested medical condition [7].

3.2.1.2 Analogies to Explain Symptoms

Across the subreddits, individuals described analogies that they used to convey the experience of a fibromyalgia or migraine flare-up at work. The need for analogies comes in reaction to others underestimating the impact of invisible conditions. Individuals shared experiences with others who implied that their symptoms could be relieved by over-the-counter headache medications or with positive thinking *("One time a coworker of mine said, 'Sometimes I THINK I am getting a headache, and I actually do. So maybe try not thinking about it'" <M-104>). <M-105>* shared an experience where they effectively used an analogy with a coworker who had been calling them out for many small mistakes during a time when they had been dealing with daily migraines: *"I could only think of [saying]: "if you are trying to solve a math problem, and suddenly stub your toe, how hard are you thinking about that math problem now?' she seemed to understand that."*

Analogies were used to explain the severity of migraine headaches *("when you feel like the any light will melt your eyes out of your head and noise will blow out your ear drums" <M-106>)* as well as brain fog. Brain fog is a term for a cognitive symptom that is experienced during some flare-ups by people with migraine and fibromyalgia.

Phrases that Redditors used to describe brain fog to coworkers included, "turtles stampeding through molasses in winter in Vermont" <F-201>, "wading through treacle" < F-202>, "slogging through jello" <F-203>, "in the wet cement" <F-204>, and "trying to read through a stained-glass window. Technically possible if you concentrate hard enough but so exhausting for so little result" <F-205>. In a workplace where support from others is vital, creating a language to convey experiences that are not visible to coworkers was seen as a way to disclose invisible symptoms effectively.

3.2.1.3 Making the Invisible Visible

Even with the techniques above, verbally sharing invisible experiences was not always enough. *<F-206>* shared their yearning for a more visible representation of how they were feeling: *"I wish we had a percent sick number on our forehead so others could have something tangible to understand what we are going through... they can't understand what they can't see." < F-206>.* Individuals shared experiences of being told, *"but you don't look sick" <F-207>* when they tried to disclose their condition to others. At the same time, as some yearned for visible representations of how they were feeling, others noted that their fatigued appearance was misattributed to being tired or even drunk. *<M-107>* shared an experience where *"a coworker came up to me to 'ask if I was okay'. She was very close to me when talking…and she was speaking to me in a very assertive and dominant manner. Fairly certain she was trying to smell if there was booze on my breath."*

To make the invisible aspects of migraine and fibromyalgia visible, some Redditors shared how they would make sure that their coworkers see and hear them dealing with their symptoms. By *"wearing my sunglasses indoors and moving slowly"* and putting *"a compress on my neck and try to (slowly, gently) [do] easy work", <M-108>* was left in quiet by coworkers. In another instance, *<M-109>* helped people at work see the severity of their invisible condition by letting their supervisor know about an upcoming surgery and showing people at work *"my bags of OTC and non-OTC medications."* Another Redditor, *<M-110>* shared, *"I've had people not believe me, but then I come in looking pale like I saw a ghost. My eyes are buggy and dead, my words come out slurred and confused. Then I proceeded to throw up violently in the bathroom and they heard/saw me. They leave me alone now when I get migraines, no one wants to be near 'Pukey' ..."* By revealing or even amplifying the effects of their flare-ups, people were able to show their coworkers what was not visible and generate understanding in the workplace.

3.2.1.4 Building Bureaucratic Relationships

Another approach to disclosure took place through the long-term work of building a relationship with their supervisor or boss. By disclosing their invisible condition and collaboratively finding ways to manage their workload, individuals were able to receive the resources they needed to manage their condition at work, such as the option to work remotely or a different seating arrangement. For example, *<F-208>* shared that, *"My manager and I strategically plan my leave so that I can prepare for and recover from high delivery times."*

<F-209> shared a different approach that they had worked out with their boss by being "very honest": "My boss also said that if I have a bad day one week, I don't have to make 40 hours, but I should try before deciding. He said that wouldn't be a problem unless I am not getting my work done, so when I feel good, I work a lot to get ahead, and when I feel bad, I don't get as much done but it evens out."

Disclosure of a condition to supervisors was also a part of a larger plan, including obtaining documentation and seeking accommodations, which we discuss in more detail below. *<M-111>* managed to get approval to work from home: *"I had my doctor write a note about my treatment plan and how working from home would minimize my migraines… My boss was super understanding about it, but he's known for over a year about my migraines."* This example highlights how the time spent building a relationship with a supervisor can interact with the pursuit of formal documentation.

3.2.1.5 Obtaining Formal Documentation

Formal disclosure involves authoritative sources such as clinicians or legal documents and can include work performance records, notes from clinicians, and leave records. Some individuals described seeking protections through formal disclosure in response to supervisors not providing accommodations when they had informally disclosed their condition. For example, *<F-210>* had their promotion taken away after asking for a reduction in work duties due to a bad flare. To be legally protected, individuals did the work of documenting proof of their health condition and work environment and sought the protection of labor laws that exist around the world to protect the jobs of people with disabilities and health conditions.

"Reasonable accommodations" are mandated in certain situations by law and used to describe modifications or adjustments that are explicitly provided for qualified people with disabilities as necessary for their ability to do their job. These can include additional time off requests [73], options to work remotely [74], and modifications to office facilities [75,76]. Individuals on Reddit shared the accommodations they had received, including physical configurations (such as an ergonomic chair, private cubicle, and computer-raising desks) and special permissions (including working from home on some days and free time to walk around the office).

Individuals shared the different laws available in their countries (mostly US, but also UK and Australia) and the documentation they had needed to access them: *"I just started a new job about 2 months ago and found out today the ADA (Americans with Disabilities Act of 1990) accommodation I applied for was approved. I get 2 days off a month for migraines (unpaid). This is the first job that did this for me. I just needed a letter from my neurologist" <M-112>*. Other laws exist to protect people's jobs. In the US, FMLA (Family and Medical Leave Act) is job-protected leave [23], and one cannot be fired for requiring these accommodations because it could count as employer discrimination against a disability [77]. Redditors such as *<F-211>* educated others about these protections and what it took to qualify for them: *"[FMLA] is put in place to protect you from being let go due to illness. Your doctor will need to fill out the forms but if you a have a diagnosis it shouldn't be an issue."*

Though some advocated the use of these protections, individuals also shared experiences where companies did not adhere to the law. In such cases, they advised employees to document as many interactions as possible in case they were needed in a lawsuit against the organization.

3.2.2 Concealment of Invisible Conditions

As much as disclosure strategies were discussed, the data also revealed case after case in which people chose to conceal their conditions. Some shared the negative consequences of divulging their invisible condition at work, which included experiencing discrimination even when they had legal protection in place. These negative consequences were often attributed to stigma: *"there is a huge stigma around fibro with those who haven't had first-hand experience" <F-221>*. Because of these negative experiences, some expressed regret at disclosing their condition, and even warned others to avoid formally disclosing their condition. *<F-223>* said that they should have been *"much more guarded with my situation" <F-223>*. *<F-212>* commented, *"I know it's not possible for many but if you can avoid it, never tell your boss. Never tell HR."*

Though avoiding formal disclosures was a fairly granular decision that could be made, what was more difficult was concealing pain and symptoms that might lead others to recognize the individual had the condition. Thus, it was imperative for some individuals to find strategies to hide flare-ups and symptoms in the workplace. Below, we share three techniques that people employed across a variety of roles and job types to conceal or obfuscate invisible chronic pain.

3.2.2.1 Keeping it Together at Work

The most common strategy that individuals used to conceal their condition was *"keeping it together at work"*. Individuals wished to maintain the appearance of a well-performing employee, such as *<F-213>* who described their top priority as *"to seem put together and like you're constantly kicking butt and anything you struggle with has no effect on you."* This way that some individuals hid the effects of their conditions was described as *"suck it up and go to work" <M-113>*, *"block it out" <F-214>*, *"go home and die afterwards" <F-215>*. In other words, individuals ignore the pain at the moment to get through their workday without letting their invisible condition get in the way. The efforts required to do work while hiding or blocking pain have negative consequences for people after work, during weekends, and over holidays.

This strategy was pervasive across various job roles, industries, and geographic locations. However, people in jobs that involved physical stress on the body appear to bear more consequences. <F-216> explains their experience keeping it together in a job that required standing: "*I am on my feet for 10 hours a day…I get through my shift just fine… idk (I don't know) if I'm legit not in pain or block it out. but when I get home my feet literally feel like they are broken in half, limping, can't put weight on them, near debilitating pain.*" <F-224> explained that their past retail job was a "*nightmare*" because they needed to stand constantly, and because of this, "*I was constantly struggling to keep a steady job.*"

On the other hand, it appears to be easier for people with private offices and desk jobs to get through the day with this strategy. *<M-116>* described how in their desk job, they did not *"have to do much heavy lifting"*, in an office that is *"relatively dark and quiet"*, and where they have *"constant access to beverages"*. <M-114>'s quote shows how though they still felt the need to keep it together at work, they took advantage of the ability to rest in a still environment at times: "*99% of the time I have a migraine, I suck it up and go to work. Sure, I might have to spend some time in my office with the lights off and an ice pack on my forehead...*"

Trying to keep it together sometimes meant that individuals hiding their condition did not take advantage of resources to help them manage their conditions, such as working from home or intermittent leave.

3.2.2.2 Hiding Symptom Management Techniques

Though individuals described doing their best to keep it together at work, it was not always possible to ignore the pain until a work break or until they got home. Because of this, finding pain management techniques that are easily hidden is essential to conceal one's condition. People find different techniques to conceal their symptoms, which vary with the severity of work demands, interdependencies with others, and access to different benefits. For people in jobs that need them on their feet all day, bathroom breaks are a way to get a quick respite: *"the pain is so bad. I'm on my feet my entire [café] shift, and if we want a break, I have to pretend I'm using the bathroom so I can just sit for a bit" <F-217>*. People with their own office spaces, on the other hand, can take breaks in their private space to find chronic pain relief. *<F-218>* shared that: *"I have my own office so when I'm in pain I am not in the public eye. It is large enough for me to lie down or stretch etc. That's the only way I could manage. I can pop pills when needed without having to explain every time."*

Even when individuals did not have their own office, personal spaces or even office bags were useful for keeping resources such as small blankets, pillows for back support, and medication close-by but *"inconspicuous" <F-219>* to others.

3.2.2.3 Obfuscating Symptoms

In the above examples, individuals shared how they hid their symptoms at work. However, this was not always possible when symptoms were severe or if individuals lacked access to private spaces. When symptoms could not be hidden, individuals found ways to explain away their symptoms while concealing their true source. If visible symptoms made it difficult to hide the invisible condition, they attributed their symptoms to conditions that others would find relatable and therefore less stigmatizing.

"Bad migraines are the only thing that 100 percent affect my appearance…if I'm visibly hurting or moving slow, I just say my "back is hurting" today." <F-220>

"I tell the office that I've come down with a bug and I don't want to spread it on days I need to work from home, not that I'm having a bad flare and my legs hurt too much to walk. The effect is the same - I won't be in the office that day because of a health issue. I'll still get my work done, just remotely." <F-221>

For jobs where physical presence was necessary or roles were highly interdependent, obfuscating symptoms might not be possible or sufficient: for example, one aspect of <M-117>'s job involved processing shipments with others. They shared that they had just experienced a migraine attack, and "*we just got in a huge delivery, and physically I can't help break it down. everyone is annoyed with me...*"

When possible, obfuscating symptoms also helps prevent follow-up questions relating to their invisible condition, meaning that they can *"get the work done"*, according to *<F-221>.*

4 PHASE 2: PERCEPTIONS OF THE ROLE OF TECHNOLOGY IN DISCLOSURE

The themes of Phase 1 summarize strategies people use to disclose or conceal their conditions. In the second phase, our goal was to investigate the perceptions of people with invisible chronic conditions on the role technology might play in these strategies. We created five technological design concepts and recruited eight participants with migraine or fibromyalgia to participate in semi-structured interviews. We shared these design concepts with the participants during the interview.

4.1 Methods

Below, we describe the motivation for the five design concepts, the participants who took part in this phase of the study, and our approach to study design and analysis.

4.1.1 Design Concepts

To probe participants on the role technology might play in workplace disclosure/concealment, we aimed to create a set of design concepts that spanned numerous uses and types based on what we learned in Phase 1. Our creation of the design concepts was iterative, where we went back and forth between two processes. One process involved a focus on the strategies from Phase 1 and envisioning where technology might fit into the practices and goals described by posters. This process started with the creation of memos that detailed a particular strategy with anecdotes and quotes and a proposed technological design concept. Over time, the memos were refined into storyboards or images depicting the design concepts. The storyboards were set in work environments, such as the office cafeteria and personal desk/cubicle area in the office, to immerse the participants in a workplace setting that felt familiar. One design concept ended up utilizing a demo rather than a storyboard or image, as it was the best way to depict the concept (color-changing lights to articulate pain levels).

The second process, which occurred in parallel, involved creating conceptual categories of design dimensions. The goal was for the design concepts to, together, flesh out these design dimensions. We went back and forth between the two processes described above, accompanied by discussions amongst the research group. As one example of the outcome of going back and forth between these two processes with accompanying discussion, we recognized that the majority of our early design concepts focused on disclosure. As a result, we created design concepts that also centered concealment. Table 1 contains the final set of design dimensions, and each design concept is described below.

Table 1: Design Dimensions

Dimension	Rationale
Volume of information shared	What level of detail is necessary/acceptable?
Type of information	Educational-type materials versus indicators of the present status of an individual? Literal or analogical?
Mode of communication	Effective mode of display (e.g., persistent in physical or online space, transient)
Audience to disclose to	Who needs to know (e.g., coworkers, supervisor, everyone)?
Audience to conceal from	Who should not find out (e.g., clients, coworkers, anyone)?

We shared the storyboards, images, and demo with participants during the interviews. The first design concept, **"Make-Your-Own"** (Figure 1), was based on the "migraine talk" strategy, where individuals educate others about their condition through ongoing conversations. Redditors described a range of the kinds of information that was included in the migraine talk, including medical terms used by their physicians, typical flare-ups, emergency contact, and how coworkers could help. We incorporated this flexibility into the concept. "Make-Your-Own" is an application for individuals to gather and then display the information they wish in the format that best suits them at the time, such as email signatures, office communications platforms (for example, Microsoft Teams or Slack), a printed display in their office, or on a lanyard.

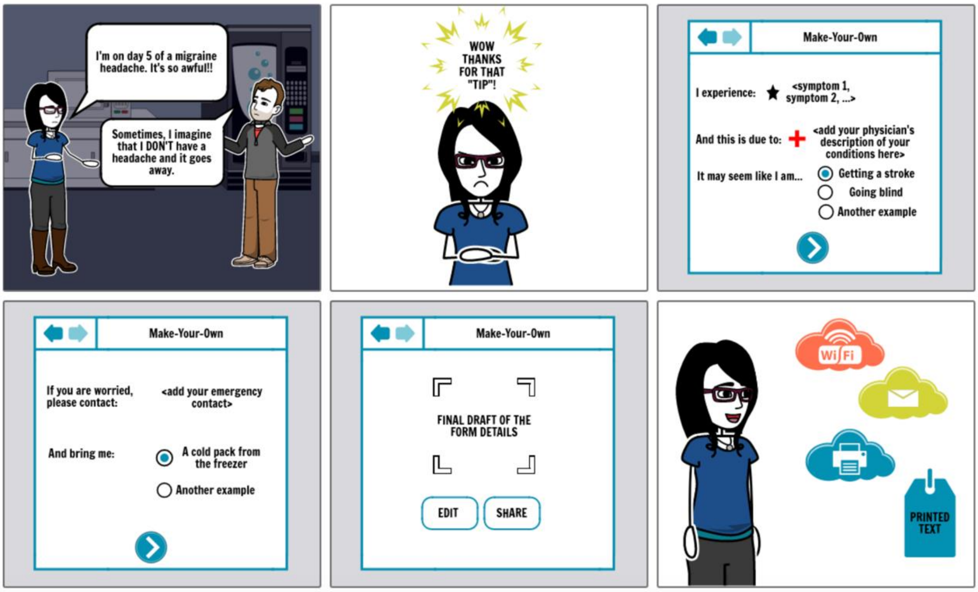

Figure 1: Storyboard of Make-Your-Own

The second design concept, the **Pain Level Indicating System** (Figure 2), is geared towards providing a nonverbal mechanism to let coworkers and supervisors know in real-time how someone with an invisible condition is feeling. The system involves a color-changing LED system to signify the severity of a flare-up, with red lights signaling unbearable pain and green lights as doing okay. This light metaphor was inspired by how individuals used the act of switching the lights in their office off or putting on sunglasses indoors to indicate to others that they were experiencing flare-ups. To be effective in different work settings, the system can flexibly be mounted in workspaces or as a wearable [48].

Figure 2: Pain Level Indicating System

The third and fourth design concepts, **FilterFace and Reverse FilterFace** examine the potential of technology in online spaces to support the strategies of amplifying or concealing symptom visibility. Both concepts use augmented reality filters that integrate into video conferencing systems that often connect teams.

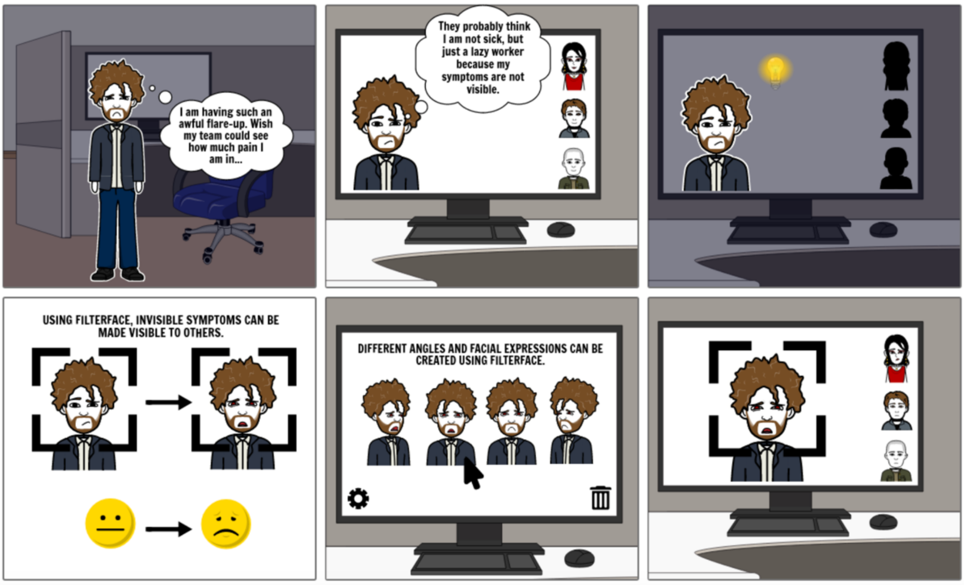

Figure 3: Storyboard of FilterFace

FilterFace was built from similar motivation to the Pain Level Indicating System but allowing someone to visually depict themselves as not feeling well, rather than relying on ambient signals. FilterFace makes the symptoms of migraine and fibromyalgia visible with "*bags underneath the eyes*" or "*buggy eyes and pale skin*" <M-110> through augmented reality. The storyboard (see Figure 3) shown to participants depicts the motivation for FilterFace, with an employee with a bad flare-up who is concerned that his team thinks they are "lazy" due to a lack of visible symptoms. The employee selects a filter that augments their flare-ups to make the bags under their eyes and the redness of their eyes more prominent. This filter allows the employee to share their pain visibly with coworkers during video conference calls.

In contrast, **Reverse FilterFace** leverages augmented reality technology to better support an employee in concealing their invisible condition at work. In this concept (one frame shown in Figure 4), filters created using augmented reality can conceal visible flare-ups like *"buggy eyes and pale skin"* <M-110> on people's face. To demonstrate the idea, we created a storyboard narrative in which the protagonist chooses to hide their condition from people in the workplace during a team meeting using Reverse FilterFace. Their red eyes and pained expression are transformed into an enthusiastic and alert-looking employee.

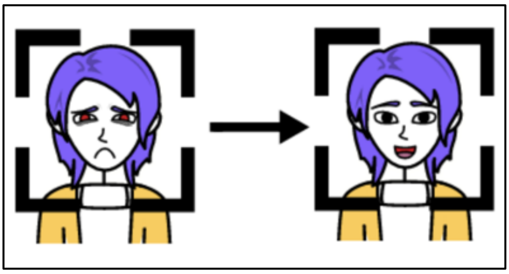

Figure 4: Image from the Reverse FilterFace Storyboard

The final design concept, **VR Analogies,** was based on the different ways in which individuals used analogies to help others understand their experiences. Since we found several instances of trudging and wading through mud/treacle in Phase 1, we created a scenario where others could be immersed in a virtual reality experience of *"trudging through mud"* <F-222>. The design concept is similar to recent work that involves co-created tangible materials to communicate pain experiences with others [21] in that it utilizes the senses to convey an experience. However, this concept is distinct because it was presented to participants as something that might be used as educational material (e.g., in company-wide training sessions) rather than by an individual to communicate their symptoms with others [21].

4.1.2 Participants

Eight participants responded to recruitment through social media posts on the subreddits of migraine and fibromyalgia and word-of-mouth. One participant expressed their interest and chose to participate in the study after seeing a blog post reporting a narrow set of preliminary findings. P6 was male, and all other participants were female. All participants self-identified as having migraine or fibromyalgia and as currently employed.

Figure 5: "Trudging through mud" - VR Analogies

Table 2: Participant Demographics

ID	Invisible Condition	Location	Industry	Job Role	Access to Legal Protection	Amount of Work-Related Screen Time (per day)
P1	Fibromyalgia	Canada	Education	Art Teacher	Yes	6-8 hours
P2	Migraine	India	Banking	Customer Relations	No	2-4 hours
P3	Migraine	America	Marketing	Graphic Designer	Yes	6-8 hours
P4	Fibromyalgia	Finland	Education	Researcher	Yes	2-4 hours
P5	Migraine	India	IT	Head Administrator	No	< 2 hours
P6	Migraine	America	IT	Data Scientist	Yes	6-8 hours
P7	Fibromyalgia	America	Non-Profit	Researcher	Yes	4-6 hours
P8	Migraine	India	IT	UX Designer	No	6-8 hours

Participants were asked to complete a screening questionnaire and sign a consent form prior to the virtual interview. Demographic details form the screening questionnaire and interviews are shown in Table 2.

4.1.3 Procedure and Analysis

We invited people to participate in 60-minute semi-structured audio-recorded remote interviews. The study protocol was approved by the Institutional Review Board (IRB). The goal of these interviews was to understand how technology could aid in concealing or disclosing symptoms or conditions at work. We started by asking questions to understand work settings, degree of self-disclosure of conditions at work, and techniques to manage conditions at work. Our findings from Phase 1 informed some questions from this portion of the interview. Examples of questions that relate to Phase 1 included whether employees could take breaks at work (linked to findings on "keeping it together" and concealing and obfuscating symptoms) as well as how many other people know about their condition at the workplace (related to disclosure).

After setting the study context through these opening questions, we introduced the design concepts to the participants. We used the dimensions in Table 1 to probe participants on each design concept. For example, during the interview segment about the Pain Level Indicating System, we probed the dimensions of "audiences for disclosure and concealment" in the context of who should be privy to the meaning of lights by asking questions such as "How would you decide who to share with and who to avoid?".

All interviews were spot transcribed, meaning we transcribed by a set of criteria rather than every statement made by participants. We chose this approach as we spent some time talking to participants about their conditions to build rapport and context. Still, much of this information was less relevant to the analytic goal of this phase, which was to probe the role of technology in the context of workplace disclosure/concealment. We spot-transcribed quotes according to two criteria: 1) where participants spoke to the themes or codes that we had identified in Phase 1, and 2) when they discussed the design concepts, for example, in terms of when they would be advantageous, disadvantageous, or unnecessary. With this approach, the majority of each interview was transcribed. Transcribed quotes were open-coded with a constructivist grounded theory approach [11]. Some examples of initial codes included "educating people about invisible conditions", "building trust at work", and "work is more important than pain to your coworkers". By iteratively open-coding, memoing [11], and theorizing amongst our research team, we generated the themes below.

4.2 Findings

Through the interviews, we learned about the different contexts and circumstances under which designs were seen as playing a useful role in negotiating disclosure at work.

4.2.1 Technology to Relieve Burden of Education

Similar to what we found in Phase 1, some participants described the constant burden of educating others. P1 said that because she was so effective at work and "*don't 'look' sick,"* she had to do the work of *"constantly remind[ing] them [coworkers and boss] that I am sick.* She explained that this impacted her ability to access resources: *"So if I say that I need help, they are always like - but WHY do you need help?" (P1).* Even with statements like *"I am having a flare"*, P1 explained how, *"having to sit down and explain it six times a day to 20 different people adds to that exhaustion and that mental fatigue from constantly trying to educate people."*

Several participants described interest in the concept of Make-Your-Own. For P8, fragrances can cause *"increased nausea during a migraine attack."* She felt that this concept could be used during flare-ups to draft an "Away" or "DND" status message on the office communication platform: *"If you wear perfume, please don't come near me. Some scents are really bad. Sandalwood is a bad trigger for me."* P1 was excited about the Make-Your-Own concept as a way to curate a description of her symptoms on a portal for her coworkers and supervisors. She iterated on this idea further to reduce her burden with QR codes to allow for asynchronous learning: *"I would love to just say, 'You have a barcode scanner? Scan this. Have a read and leave me alone!' so that they can learn in their own time."* This concept appealed to P4 as well, but she wanted to include a way to describe when she needs help as a way of reducing the burden on herself: *"Rather than indicating when I'm okay, I'd just indicate when the situation is dire because I don't want to assume that people are going to be around me noticing my behavior and I do not want them to be constantly checking on* *me."* Having an even more customizable, flexible means to educate others than we had initially envisioned was seen as a way to reduce the burden and fatigue associated with disclosure at work.

4.2.2 Nuance to the Situational Contexts of Concealing

The interviews also validated findings from Phase 1 around how individuals hide symptom management techniques and find a lack of understanding due to the invisibility of their condition. Introducing the concepts of FilterFace and Reverse FilterFace yielded new nuances regarding motivations for disclosure and concealment and a refined understanding of the importance of context for technology in this setting.

Some participants were interested in FilterFace (the augmented reality filter to enhance invisible symptoms) due to their specific experiences at work with invalidation. P1 said, *"it seems like I have to constantly remind them (coworkers and boss) that I am sick."* FilterFace would allow her to signal to others without needing to explain repeatedly. P2, who was mocked at work by others when she tied her scarf around her head and put her face down during severe headaches said, "*[FilterFace] would make them see how severe my pain is.*" P8 shared that FilterFace would help her get a day off from work as her supervisor is usually reluctant under the pretext of, *"Why does she need to take off? She looks fine."*

Past research has identified unpredictability as one of the key characteristics that make it difficult to manage certain chronic conditions, such as migraine and chronic pain [40]. For some individuals, Reverse FilterFace (the augmented reality filter to hide symptoms) was a way to experience greater control in the face of unpredictable symptoms. P3 said that hiding the pain from others *"would actually make the fear of having a migraine attack less paralyzing"* because it could be possible to *"contain it within yourself."* P2 shared a similar response about not wanting anyone to see *"the "sick me" if given a choice."* As a customer relations professional, she felt that displaying her *"bright face"* would help because *"if people are going to see me [look] sick, that will spoil their mood and affect the temperament of the people on the [conference] call. I don't want to be a reason for sure."*

Initially, we envisioned Reverse FilterFace as for individuals who predominantly opted to conceal their condition at work. Yet, some participants who fully disclosed their condition in the workplace were interested in this design concept. P1 explained that even though she was a major proponent of disclosure (*"I am one of those people that say, 'people should learn to accept'"),* she would use the filter in important meetings with people outside of the organization "*who don't know me and are not going to go into my background.*" P2 had a similar reaction to this concept. Hiding her pain felt like the right decision when she had to communicate with clients: *"When a client calls, I can't put that work off and say that I won't be able to join the conversation. So, I would just take a pill, put on this [Reverse] FilterFace and get the work done."* The desire to avoid conversation about one's condition in certain situations was also brought up by P7, a climate change researcher, because she this would get in the way of a productive meeting: "*I would love to avoid small talk about how I 'look sleepy' or my dark circles. I don't want to deal with those questions because if I were to share that I haven't slept in 15 days, you are going to be stumped and not know what to say to me.*" (P7).

In contrast, P3, a graphic designer, explained that she would not obscure her visible symptoms, which are bags under her eyes. She explained how this manifestation of her condition let her clients understand that on migraine days, *"You are clearly not going to get the best out of me today, can't you see that?"* The difference between P3 and those interested in Reverse FilterFace may be that P3 was not able to meet client expectations on migraine days, and therefore benefited from a visible representation of her condition.

Responses to the FilterFace designs led to a more nuanced understanding related to motivation for disclosure. These findings confirm past work that calls attention to the desire for social recognition of people with invisible conditions [40], adding the insight that individuals may have diverse ways of wishing to control the narrative about their condition.

4.2.3 No Vocabulary for What We Are Experiencing

The lack of vocabulary for invisible conditions was apparent in an anecdote shared by P8, who had a migraine attack that put her on sick leave from a Tuesday to a Friday. Upon returning to work, she learned that people thought she *"went on a week-long vacation."* P8 was not surprised by this rumor because she knew that her coworkers could not understand her migraine experience: *"People who have headaches take a painkiller and feel fine the next day. Migraine headaches are different but that's the level of understanding they (coworkers) have. They don't know how to sympathize with me."*

Participants confirmed the utility of analogies that we found in Phase 1, as they expressed to us the lack of a standard vocabulary to explain what it feels like to have an invisible condition. All participants were excited to share the metaphors that they currently used, and we learned of new dimensions of analogies to describe pain. P1 drew on a popular character's experience: *"I often state the original story of Ariel when she got limbs, every step she took it probably felt like she stepped on blades"* – and then also told people exactly what she needs *"'I am Ariel today. We are going to have heating blankets, and no one bothers me. I am going to do my duties and if I can't, I will ask someone to do them for me'."*

P4 and P6 described using analogies to communicate the effects of migraines on vision: "*ice pick is being driven into the eye socket*" *(P4)* and "*my head is on fire behind my right eye*" *(P6).* These interviews helped further "build the vocabulary" of how to communicate the lived experience of invisible conditions.

Many participants liked the VR Analogies idea and said this concept would be successful in their workplace. P1 said, *"it tells people around me what they need to know and when they need to know"*, implying that an immersive approach to communicating the experience might be a quick and effective approach. Individuals referred to how others without invisible conditions might be open to this approach given the familiarity of simulators like the *"beer goggle test" (P3)* or *"simulated pregnancy test" (P6).* In contrast, P2 and P5 were quick to dismiss the idea of organization-wide initiatives to support others in understanding the experience of invisible conditions. P2 explained that people's priority is to get their work done and go home each day: *"Nobody pays heed to HR initiatives."* P5, on the other hand, spoke from her perspective as the supervisor in the workplace: *"Office is a place to do the job and earn money. Maybe my juniors will be interested to understand if I am in pain, but there is no emotional connection at work. So, there is no point in trying to show others what my pain feels like."* P2 and P5's quotes raise questions about the dangers of relying on empathy, a topic that we expand on in the discussion.

4.2.4 Marshalling Understanding in the Workplace

The Pain Level Indicating System met mixed reactions. P1 and P2 were excited by the idea of using the lights-based pain level indicator as a wearable. They expressed that lights could be an effective way of communicating without having to do the work of informing others.

"This could be a pin that I would proudly wear and walk around" (P1)

"I'd like to wear it like a crown and make sure that everyone knows exactly how much pain I am in" (P2)

However, others felt that the externalized form of this concept might invite unwanted attention or create more work for themselves. P3 said that wearable lights would *"draw a lot of attention to me personally."* She said, *"Maybe if I worked in an office where everyone's office had a strip of lights around them, and that was just the part of the culture, that would be cool."* P6 mentioned that this concept actually might increase their burden of educating others: *"I don't want everyone to keep asking, 'why do you have the light?' If I had to explain to everybody who was curious, that would be kind of exhausting."* Like P3, P6 thought the design would work better if others understood the meaning: *"if it was a company-wide thing then people would already know and understand."* These comments can be understood through the past work that calls attention to the ways that individuals with disabilities experience barriers to employment due to misperceptions of others about their assistive technologies, and the work that they must due to manage these perceptions [58].

Similar to the reaction to VR Analogies, P2 expressed that even if others could see her pain level, *"work is more important than my health to coworkers."* Showing her pain level or the severity of her flare-ups would not necessarily lead to adequate access to needed resource. Some explained that this design might actually threaten their careers: P5 said as the *"administrative head of the [office] building,"* the use of wearable lights would not work because *"if I walk around the building but indicate [using lights] to people that I can't talk, I am not doing my job."*

P7 highlighted that given a lack of "an inherent understanding of fibromyalgia" the design could damage her work life: "using lights without educating people about what it means can be bad for my career. By making myself inaccessible without cause, I will not benefit from this design."

5 DISCUSSION

In this study, we examined the strategies that employees with migraine and fibromyalgia use to disclose or conceal their invisible condition at work and investigated potential ways technology may play into workplace disclosure. It is key to note that decisions to conceal or reveal one's condition are shaped by many factors: personal preference, workplace setting, regulations, the way that work responsibilities interact with flare-ups, and many more factors.

By examining the different strategies that individuals employ on Reddit, we had an empirical basis upon which we created design concepts. These concepts were then discussed by individuals living with invisible chronic conditions. Below, we discuss approaches to designing for disclosure at work and the importance of investigating the workplace for health and disability researchers.

5.1 Designing for Disclosure at Work

Past research has studied the disclosure of invisible conditions in terms of perceived benefits and barriers. Our study highlights that different disclosure and concealment strategies also carry different benefits and barriers – and that these inevitably will carry into technology designed for this context. We present the following table to reflect on findings related to involving technology in disclosure. Each row includes potential technological approaches, potential benefits, and the "shadow side" (the ways that these designs may inadvertently cause harm or reinforce damaging ways of thinking about disability). We then discuss the tradeoffs of focusing on these different goals in dialogue with current debates in CSCW.

5.1.1 Bearing the Burden of Change

Much of the current literature on invisible chronic conditions (as well as health more broadly) focuses on actions individuals can take. In the invisible condition space, this manifests as technologies for tracking symptoms, finding triggers for flare-ups, and managing one's condition. Several of the design goals we identified focus on actions the individual with the condition can take, such as signaling a need for assistance or modulating one's appearance for others. Some individuals in Phase 2 appreciated these designs and spoke about using them in ways we had not considered; from wearing the lights on their head like a crown to using a filter intermittently to avoid being sidetracked by a conversation about their condition during a meeting. Having others interact with what is disclosed through these concepts could, over time, make workplaces more accepting of people with disabilities and health conditions.

Based on our findings that some individuals are interested in disclosing their pain status at work, there are opportunities to draw from research in the clinical setting to enhance our basic concept: such as incorporating automatic pain detection (e.g., validated for facial analysis in orthopedic injury [25]) or low-burden data entry (e.g., tangible standalone devices [45]).

Table 3: Technological Design Reflection

Goal	**Technical Approaches**	**Potential benefits**	**Shadow side**
Helping conceal or reveal physical aspects of the condition (FilterFace)	Obfuscating or manifesting symptoms through image or audio manipulation	Offering greater control over the condition "narrative"	Reinforces problematic norms (e.g., linking looks to competence); Burden on individual
Sharing one's current state for others (Pain Level Indicating System)	Sensing or taking input; output for coworkers via ambient or other means	Making it less burdensome to share the current status of one's symptoms	Relying on people to care; Burden on individual; Potential threat to career
Increasing understanding of one's own condition (Make-Your-Own)	Building the narrative of a chronic condition using templates; output printed or digital (e.g., email signature)	Showing a scientific basis of the condition as well as specific tactics to help (or not harm) someone	Burden on individual; potential threat to career
Targeting attitudinal change at institutional level (VR analogies)	Immersive media or sensory systems	Increasing empathy and understanding	Relying on people to care

In terms of output for these sorts of systems, our findings indicate that the workplace is different from clinical settings. While individuals may wish to share the full picture of their pain with health care professionals, there are many nuances to disclosure at work. These might be dealt with through rule-based systems (e.g., "supervisors only," "only coworkers in my department") or verification (e.g., "Do you want to share that you are having this severe migraine with the office?").

Yet, it is essential to consider the shadow side of approaches relying on individuals tracking, reporting, and educating. Even with interest in these designs, individuals spoke of the fatigue of constant education. One study emphasized how Deaf individuals do much work educating other professionals in mixed-ability groups [67]. The authors argue that accessibility can be best viewed as co-created by all the social actors involved in an interaction, rather than viewing the individual with a disability as responsible for ensuring collaboration goes smoothly [67]. A parallel push in health HCI reconsiders who bears the burden of change, as many health interventions rely on an individual to change their own actions (in our design concepts, spending time educating others) when an oppressive system is what needs to change [41]. The lever of attitudinal change through design concepts such as the VR Analogies is one way of targeting this larger system. Rather than placing a burden on the individual, the employer would bear the responsibility of ensuring individuals understand what it is like to live with invisible conditions as a part of initiatives such as Diversity and Inclusion programming.

Though we have identified levers at the individual and institutional level, reviewing the HCI health informatics literature makes it clear that we are missing an opportunity to examine collaborative approaches. Personal informatics research is expanding past actions the individual can take to recognize the importance of involving others in the social circles, such as family members and loved ones (e.g., [42]). A promising area for future CSCW research might examine how individuals with invisible chronic conditions can benefit from approaches to disclosure and concealment that involve the active involvement of close social partners, coworkers, supervisors, or even clients or HR. Adapting the additional ecological levels identified by Murnane et al. to the workplace and chronic invisible conditions can provide further opportunities [35].

5.1.2 The Promise and Perils of Relying on Empathy

Concepts that target attitudinal change through showing others the experience of living with an invisible condition, based on analogies personally used by people with invisible conditions, were seen as an exciting direction to participants in Phase 2. In attempting to capture and share the experience of living with a particular condition, our findings speak to an ongoing debate regarding the benefits and harms of disability simulators. Disability simulators are intended to allow someone without a particular disability to “try on” some aspect of a disability (e.g., glasses with occluded lenses that simulate glaucoma [53]), often with the stated goal of improving empathy. The effectiveness of these simulators have been contested from a critical disability perspective, as they can provide a false sense of understanding the experience of disability and drive a focus on hardships, as opposed to recognizing the many strategies that people with disabilities use to navigate their environment [38,78].

Based on our findings, we posit that disability simulators may represent a more promising direction for invisible chronic conditions such as migraine and fibromyalgia, where people frequently experience the opposite – others under-registering the existence or severity of their symptoms. Examining the effects of simulations may result in people in the workplace “gaining experience” with invisible conditions and may offer opportunities for mutual sensemaking and shared accountability [6].

Even though VR Analogies may not fall prey to the same criticisms as other disability simulators, it is important to note that the effectiveness of this concept, as well as many of the other concepts we have created, rely on change occurring through increased empathy and understanding of others. Even Make-Your-Own, while not explaining the difficulty of living with a particular condition, still expects that people will respond in appropriate ways, without any institutional or other form of enforcement. While these designs meet the needs pointed out in past work (e.g., for social recognition [40] or as factors that lead to retention [64]), it is important to acknowledge arguments against relying on empathy. One pedagogical researcher argues, “At its worst, resorting to empathy teaches students that the most complex systemic problems can be fixed with behavioral solutions” [16].

Focusing our research and design efforts on "proving" the need for resources and support to others means that whether people with invisible conditions can successfully function in a workplace relies on whether others are willing to show goodwill. And, for some, empathy or understanding from others could actually get in the way of getting work done (such as individuals who wanted to conceal their condition to avoid getting asked questions that would disrupt an important work meeting). While we do believe there is merit to continue pursuing these approaches as part of a broader agenda, it is important to add this critique to the mounting research that questions the centrality of empathy in user-centered design (e.g., empathy exercises that supplant the actual experience of people with disabilities [6]).

If empathy and attitudinal change are not the most effective or reliable ways to support people with invisible conditions, then what are societal-level changes to pursue? We suggest starting with civic agendas and hard-earned progress that has yielded legal protections. One design direction can focus on studying [4] and supporting the activism that has been essential to put many workplace protections in place (and is key to ensuring that they are not dismantled). Another direction might identify non-compliance or enforce compliance with legislation, likely best achieved through collaboration with those with legal expertise [32].

5.2 Work as a Domain for Health & Disability Technology Research

The field of CSCW originated in studies of the workplace, and CSCW's understandings of technology and the workplace have the potential to spur a new area of scholarship for health and disability researchers. The significance and complexity of workplace disclosure in our findings indicate that there is much to learn from CSCW. For example, adopting a lens of affordance-based risks may lead to better-designed systems that play a part in negotiating disclosure [66]. And just as CSCW can yield new understandings for research with people with invisible conditions, there is much for CSCW to learn from people with invisible conditions. For example, the work that people did in highlighting their symptoms may offer new perspectives for applications of impression management that traditionally view people as concealing socially undesirable traits (e.g., [5]).

Considering invisible conditions in the workplace cannot be separated from social justice concerns. Precarity exists in the ability to manage chronic health conditions when even fragmented healthcare is linked to work status and income [29]. Individuals may be most concerned about job security, not because of competence but because of others' perceptions [58]. With these examples, we propose that work as a domain for health and disability research can be fruitfully framed by a social justice-oriented design approach [17]. We highlight three axes relevant to social justice-oriented approaches in the domain of work and disability based on our findings.

First, the political economy shapes life with invisible conditions. Individuals in our data with white-collar jobs often had an easier time concealing their condition and also experienced more benefits such as the ability to work from home or stay seated. CSCW research, however, may tend to focus more on white-collar work. Our own initial set of design concepts largely reflected an office worker's needs, rather than the experiences of other individuals in our Reddit data. Only once we reflected on this bias did we add designs that did not rely on the assumption that individuals spent most of their time in an assigned office or cubicle space. There is an opportunity to expand on the kinds of workplaces and work that we investigate.

A second factor, mentioned in the previous section, is that legislation and regulations are key to consider when examining disability – particularly in a global context. Linked to cultural differences in envisioning invisible conditions, legislation might make it safer for some and affect choices to disclose. In countries like India, invisible conditions are not covered under The Rights of Persons with Disabilities Act [37], which is the only legal recourse one can take to protect themselves from discrimination in the workplace. These differences may explain some of the divergent accounts in Phase 2, where some participants focused on building a bureaucratic relationship to gain the trust of supervisors before choosing to informally disclose their condition. There is much further work to be done to understand the major role that laws, regulations, and culture play in the workplace experiences of people with disabilities such as invisible conditions.

Finally, while not playing a major role in our analysis, gender appears as a relevant axis for future investigation in several ways. Women are disproportionally affected by invisible conditions. Further, women disproportionately experience many of the more stigmatized invisible chronic conditions (e.g., 78% of individuals with certain autoimmune disorders [18]). Further, women experience gender-based discrimination in many workplaces (e.g., less likely than men to be assigned high-visibility projects [60]), which surely intersects with discrimination based on invisible conditions. Gender serves as an important dimension to take into account for future investigations of disability, health, and the workplace.

5.3 Limitations

Our findings in Phase 1 were formed through studying the online community of Reddit, which likely features people who communicate primarily in English. Therefore, our understanding of disclosure and concealment of invisible conditions is limited in scope. Additionally, the number of individuals that we interacted with in Phase 2 was small. Our findings should not be taken as generalizable. Rather, our goal is to identify dimensions that are useful for future researchers.

Further, by studying Reddit data, we were unable to incorporate into our analysis race, ethnicity, job type, gender, or geographical location unless explicitly stated. Though we discuss where job type and role appear as salient to disclosure strategies (e.g., access to quiet, private offices as providing a space to rest and conceal symptoms), it is not within the scope of this paper to analyze fully around this axis. Similarly, though the interviews in Phase 2 include some geographical diversity, we did not collect details on participants' socioeconomic status, race, and ethnicity. The majority of participants in Phase 2 identified as female, and as such we lack gender diversity in our sample. Given that invisible conditions are experienced differently at the intersections of these different dimensions [26,61,62], there is a need to work on this topic in different sociocultural contexts and with different subgroups.

6 CONCLUSIONS

Workplace disability identity is complex and dynamic, shaped by internal, interpersonal, organizational, and societal factors [52]. It follows that individuals use a wide range of strategies to conceal and disclose invisible chronic conditions at work. This paper sketches out a landscape of design directions in the space of disability disclosure in the workplace. Through the findings of Phase 1, we contribute new understandings that should be taken into account, such as how disclosure is not a simple, one-time conversation, nor is concealment an easy route without adequate access to manage chronic pain privately.

The interviews conducted in Phase 2 validated many of the findings in Phase 1 and add new nuances related to differing preferences, contexts in which concealment is helpful, and the precarity of relying on empathy for workplace protections and accommodations. We posit that

CSCW has much to contribute to the study of health and disability in the workplace, including and extending beyond the concept of disclosure.

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