ABSTRACT

Title of Thesis:	MAKING INVISIBLE ENTITIES VISIBLE: NEGOTIATING DISCLOSURE OF INVISIBLE CHRONIC CONDITIONS IN THE WORKPLACE
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Invisible chronic conditions affect the work life of people in ways that are not obvious to others due to the lack of prominent symptoms. This thesis examines the negotiation of disclosure at work for people with invisible chronic conditions. In the first phase of this study, I analyzed posts on two Reddit forums, migraine and fibromyalgia. I found different factors in the workplace that can mitigate or exacerbate chronic pain in people with invisible conditions, and how people negotiate the disclosure of their invisible condition at work. In the second phase, I created five technological design concepts that were then shown to six people with one or both of these conditions in semi-structured interviews. Based on these phases, I contribute understandings of disclosure to take into account in future design efforts, 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. Additionally, I identify design implications and future areas for research.

MAKING INVISIBLE ENTITIES VISIBLE: NEGOTIATING DISCLOSURE OF INVISIBLE CHRONIC CONDITIONS IN THE WORKPLACE

by

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Dedication

This study is dedicated to frontline workers with invisible chronic conditions who are struggling to either convince others or conceal their pain as they work to keep the world running during the COVID-19 pandemic.

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Chapter 1: Introduction

Invisible chronic conditions are defined as health conditions that limit one's activities and functions but without symptoms that are visible from the outside [1]. Joint and muscle pain, fatigue, and severe headaches are some of the symptoms that can present as flare-ups in the daily life of a person with invisible chronic conditions. Due to the lack of prominent symptoms, people tend to find it difficult to communicate their pain and symptoms to others. This thesis focuses on two common invisible chronic conditions, migraine and fibromyalgia, and the workplace experiences of people with one or both of these conditions. I aim to understand the challenges faced by people in concealing and disclosing their invisible condition at work and envision the role of technology in the process of negotiating disclosure in the workplace.

1.1 Motivation

The decision of health disclosure in the workplace is complex, especially for people with invisible chronic conditions. The dilemma of whether one must conceal or disclose their pain and symptoms has been studied among mental health conditions in other fields [18]. However, chronic conditions such as migraine and fibromyalgia are understudied in the context of the workplace. I found that the conversations taking place on Reddit communities (subreddits) of migraine and fibromyalgia contained rich anecdotes of how people with these conditions were navigating through everyday problems. I chose to study the workplace setting because the idea of designing technology for working adults all around the world presents opportunities for future research into more niche user populations within this target audience.

1.2 Research Questions

In order to better understand the problems faced by people and the subsequent strategies used to negotiate disclosure in the workplace, I addressed the following exploratory questions in this thesis.

1. In what ways do people with invisible chronic conditions describe the severity of their work demands on Reddit?
2. How do people with invisible conditions strategize whether to conceal or disclose their condition at work?
3. What role can technology play in supporting people with invisible chronic conditions to negotiate disclosure at work?

1.3 Approach

To answer the above research questions, I conducted a two-phase study. Phase 1 examines the context of negotiating disclosure in the workplace through the analysis of two subreddits, migraine and fibromyalgia. I selected Reddit as a platform to study this topic for several reasons. First, migraine and fibromyalgia are known as invisible chronic conditions due to the nature of symptoms that are not visibly apparent to other people. Thus, both the symptoms and the approaches people take to negotiate disclosure may not be directly observable in everyday life: the struggle to communicate what is not visible and the different ways in which the stigmatic nature of these conditions shapes their involvement in the workplace. Second, Reddit is a useful platform to study stigmatized conditions [10][11][12].

Social media more broadly can help researchers attend to dialogue among people affected by a health condition, which allows different topics to come to light, potentially those more important to the participant than when the topics for discussion are initiated by a researcher [34]. And lastly, among invisible chronic conditions being discussed on Reddit, migraine and fibromyalgia were two of the most popular communities.

In Phase 2 of this study, I followed up on the themes from Phase 1 by creating design concepts that I then presented in semi-structured interviews with working professionals who have migraine or fibromyalgia. This enabled me to refine my understanding of contexts in which the design concepts would assist people in negotiating disclosure of their health condition at work.

1.4 Overview

This thesis is structured in the following chapters. Chapter 2 covers the related work done to understand the perceptions of invisible health conditions in various settings such as patient-physician, social media, and the workplace. In Chapter 3, I present the methods and findings of work done in Phase 1 of this study. The methods and findings of Phase 2 are covered in Chapter 4. Lastly, in Chapter 5 I reflect on the findings from both phases and discuss design implications for the future research of technology for people with invisible chronic conditions.

Chapter 2: Related Work

This chapter provides a background on the prevalence of migraine and fibromyalgia in the world and delves into the past work done by researchers in the area of social media and health condition disclosure. Invisible chronic conditions have not been studied in the context of the workplace in HCI before, so I cover past work done in other fields to understand the dilemmas associated with disclosure at work.

2.1 Why Migraine and Fibromyalgia?

Both migraines and fibromyalgia affect millions of Americans. According to the Migraine Research Foundation, migraine is a neurological condition affecting 39 million people in the U.S. and nearly a billion people worldwide [2]. And according to the National Fibromyalgia Association, fibromyalgia affects nearly 10 million Americans and about 3-6% of the world’s population [33].

In terms of their symptoms, 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 [4]. Fibromyalgia is a chronic condition characterized by widespread body pain [6], fatigue [6], and cognitive difficulties referred to as 'fibro fog' [5].

Like some other invisible conditions, both migraines and fibromyalgia are minimized by others. Past research has focused on how migraines are perceived to be an insignificant issue [3] by those who don't have chronic migraines. Fibromyalgia is also a condition that is minimized by others, and also heavily contested as a medical condition given that the symptoms cannot be clinically measured [6][8][9]. Indeed, in a study to identify which group of people with rheumatic diseases felt that their condition was invalidated the most, fibromyalgia patients ranked the highest [7].

Migraine and fibromyalgia are interesting to study together as they represent two ends of a medical spectrum. Migraine is considered a medical condition, and there are prescription-strength medications made available for people who can get a diagnosis from their physician. But despite being a clinical syndrome since the 1970s, fibromyalgia is viewed as a 'mysterious label' [9]. People with fibromyalgia have described having their symptoms invalidated by medical professionals and needing to take significant efforts to prove the severity of their condition to their doctors [7]: a phenomenon that takes place in this study as well.

Though much work has examined the invalidation of these conditions in the context of patient-clinician settings, there is a gap in terms of our understanding of how this invalidation takes place in other settings. One such setting is the workplace and how employees manage their invisible chronic condition at work, negotiate disclosure of the condition among coworkers, and seek workplace accommodations from the employers. I analyzed the conversations taking place on those communities (or subreddits) of Reddit to form our theory.

2.2 Social Media, Health Conditions, and Disclosure

Social media platforms like Facebook [10], Instagram [10], and Reddit [11][12] are being used to form virtual community support groups to connect people from different parts of the world. Communities formed on social media motivate people to find others beyond the geographical barriers for support, commiseration and to build a shared understanding of chronic health condition management [10].

Another vein of research has examined disclosure on social media platforms. The act of disclosing stigmatized information on identifiable social media was studied with Facebook as an example [14]. This study 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 [14]. Another study about privacy concerns of chronically ill teenagers on Facebook [17] 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.

In a study about online dating and disability, the researchers highlighted the implications of designing platforms that allow people with stigmatized identities to negotiate disclosure [21]. Inviting open discussions to reduce stigma and improve the understanding of people's lived experiences could be an essential design consideration in the CSCW community. The intersection of communications among stigmatized populations on social media and workplace behaviors could spark more design research in the field of Human-Computer Interaction.

A growing body of research in the fields of Interactive Computing and Human-Computer Interaction have explored the unique characteristics of Reddit to understand the disclosure of stigmatized information in studies about #metoo [15], and mental health conditions [11][16], and women undergoing menopause [12]. These studies establish the idea of community building for stigmatized experiences and explore the dialogue among people within stigmatic social groups.

The nature of profiles on Reddit has been described as pseudonymous in past research because people sign up using a screen name that forms the basis of their profile and tracks their activity across the platform [13]. The pseudonymity of Reddit is embraced by communities to practice support-seeking [13] and commiseration [11][12]. Given the invisible chronic nature of migraine and fibromyalgia, I explore the support-seeking behavior exhibited by Redditors (people on Reddit) around the topic of disclosing their health condition at work.

2.3 Invisible Conditions in the Workplace

The fields of psychiatry and psychology are currently studying invisible health conditions in the context of the workplace [18][19][20]. Due to the stigmatic nature of conditions like depression and anxiety, employees find themselves in a vulnerable position concerning disclosure. A study conducted in Australia among male-dominated workplaces identified the gaps between policies at work concerning disclosure and how employees feel about them [18].

Another workplace experience study in the Netherlands was conducted among health care providers with HIV [19]. Self-acceptance in the context of this study is to feel accepted in the work environment, regardless of the health conditions one has. The researchers in this study were able to identify the advantages of disclosing stigmatized conditions at work and how it relates to self-acceptance and supportive workplace accommodations [19]. However, another research indicates that disclosure can be harmful. An Australian National Survey found that disclosure can lead to insensitive remarks and dismissive treatment at work for people with mental health problems [20]. While researchers have studied the advantages and disadvantages of disclosure and concealment of invisible conditions, what is not known is the strategies that people use to do so.

Further, the field of Human-Computer Interaction has not yet studied the intersection of social media, invisible chronic conditions, and workplace disclosure. Given the interest in HCI for universal design [35] and assistive technology for psychosocial disabilities [36], analyzing social media conversations among people with invisible conditions without studying the implications on their workplace experience presents a significant gap. This is particularly notable given the historical focus of Human-Computer Interaction and related fields such as Computer Supported Cooperative Work on the workplace. This study identifies different ways in which technology can be designed to intervene, educate, and empathize with people who anticipate discrimination due to stigma.

2.4 Summary

Since their symptoms are not visibly prominent, people with invisible chronic conditions find it difficult to communicate with others about their chronic conditions. Past work demonstrates the importance of studying the experiences of various populations with invisible conditions on social media. Studies about invisible conditions in the workplace highlight the advantage and disadvantage of disclosure and concealment. However, the strategies and the work done by people to achieve the desired results have not been studied before. This two-phase thesis delves deep into understanding this problem space from the HCI perspective.

Chapter 3: Phase 1 – Qualitative Data Analysis of Reddit

In the first phase of this study, I collected and analyzed data from Reddit to study two particular subreddits, migraine and fibromyalgia. My findings highlight the different factors in the workplace that can mitigate or exacerbate invisible chronic pain in people with invisible conditions. In this phase, I also examined the various ways in which people negotiate the disclosure of their invisible condition at work.

3.1 Methods

3.1.1 Data Collection

After selecting Reddit as a platform to study, I determined the most active subreddits. I 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.

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 [23]. Within these subreddits, I 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.

My search terms were, “work”, “coworker”, “co-worker”, “office”, “job”, “boss”. This dataset included posts, comments, and other metadata (i.e., timestamp, username, unique user ID) from October 2012 to September 2019. I applied constructivist grounded theory to open-code and generated themes for a randomly selected batch of 80 threads from those subreddits. The dataset included rich stories about workplace experiences, but it also had miscellaneous posts about visiting the doctor’s “office” and blood “work” results. I eliminated such threads from the sample set and replaced them with other random threads from the data.

3.1.2 Data Analysis

I open-coded [38] about 8% of the total number of threads from all four subreddits and wrote memos to continue the sense-making process of the data. Example open codes at this stage included “fear of losing the job” (how would disclosure be perceived at work), hiding the pain at work (techniques to manage the condition), receiving advice from Redditors (the impact of ideas found on Reddit). During the discussion of themes that formed at this stage, I realized that condition-specific subreddits (i.e., fibromyalgia and migraine) had rich and experiential data about the job, relationships between boss and employee, coworker-specific posts, and symptoms that caused work difficulty. Therefore, I narrowed down my data analysis to these two subreddits.

With this shifted focus, I selected another randomized sample from these subreddits to create new codes, themes, and memos. I open coded 40% of the total dataset, representing around 200 threads from r/fibromyalgia and r/migraine and continued to memo and theorize with my advisor and our research lab. I stopped coding once data analysis no longer resulted in newer insights about the workplace experiences of people with invisible conditions. Data saturation was reached at this stage [12]. The remaining threads in the dataset were analyzed using a focused coding approach, where the codes formed already were applied to the data.

The analysis of the Reddit dataset derives from qualitative data that focuses on jobs in various types of roles, industries, and geographic locations. All the posts and comments related to the workplace experience of people with migraine or fibromyalgia were tagged to form a comprehensive list of codes. These codes shaped the memos, leading to the creation of focused codes. Through the process of memoing [38], I started developing the themes of hiding and disclosure of invisible conditions at work.

While coding my data, it felt imperative to read past work about impression management at work and current practices of disability disclosure to employers. Analyzing the existing literature helped learn about the actions taken by employers to provide accommodations to people with invisible disabilities. The invisible disabilities explained in past research cover mental health conditions like anxiety and depression [18][20]. These studies aimed to discuss learning opportunities and sensitivity training for organizations.

The analysis in Phase 1 focuses on two aspects: a) understanding how disclosure or concealing of one's invisible condition at work is perceived on Reddit and b) the different ways in which people with migraine and fibromyalgia are negotiating disclosure at work. The pseudonymous nature of Reddit [13] promoted uninhibited discussions on both subreddits. Therefore, the qualitative data generated in this phase was rich, subjective, and insightful. Codes formed around the data saturation 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).

3.2 Findings

Below, I elaborate on my findings. In phase 1, I learned about how different factors in the workplace can mitigate or exacerbate how chronic pain affects people with invisible conditions as well as the ways in which people on Reddit (also known as 'Redditors') negotiate the disclosure of their invisible chronic conditions in the workplace.

3.2.1 Factors Impacting Experiences with Invisible Conditions at Work

Based on my analysis of two subreddits of common invisible conditions, fibromyalgia and migraine, I found three different factors that affect people's experiences with their invisible conditions at work. These factors affected the degree to which symptoms manifested as well as the support and understanding that individuals received from others.

Below, I discuss how the type of role, existence of others with experience with invisible conditions, and workplace support and accommodations played significant roles in Redditors' ability to manage their symptoms.

Type of Role

I learned that the type of role and industry play a major role in the aggravation of symptoms at work. One way in which work demands impact people with invisible conditions was to do with the amount of physical stress that a job requires. For example, <*em65hh1*> explained that their past retail job was a *"nightmare"* because they needed to constantly stand. This individual was impacted to the extent that *"I was constantly struggling to keep a steady job..."*. <*em65hh1*> valued their current desk job because, *"that makes it easier to suffer through during low grade migraine days"*. A desk job did not prevent migraine headaches but made it easier to manage chronic pain and migraine headaches at work. <*deq21qh*> valued 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"*, all factors that led to lesser physical strain at work, and more access to things that could help alleviate a migraine attack at work.

Another aspect of the type of role individuals had that affected their ability to manage the work demands and their health condition was the structure of their role in terms of teamwork. Interdependencies in teams led to issues when individuals were experiencing flare-ups, which are characteristic of these invisible conditions and involve a time period where symptoms increase in intensity or number [26].

For example, one aspect of *<c9xyv4>*'s job involved groups of people working together to process shipments. When *<c9xyv4>* had a migraine attack that left them unable to contribute to the team, it negatively impacted the team and the work environment. They shared, *"we just got in a huge delivery, and physically i can't help break it down. everyone is annoyed with me..." — <c9xyv4>*

On the other hand, when collaboration at work is necessary, being a part of an interdependent team that is understanding of the condition makes it easier to manage flare-ups at work. Being a part of a work team that understands and supports each other can alleviate the stress of managing the work demands and the flare-ups.
"We have a huge project to do and I feel like I'm not pulling my weight with the physical stuff and only doing the "nice" stuff... they all say no, it's fine, we're a team and we can do things to help each other out, and it's not your fault you're ill." — <et48z5y>

In the above example, *<et48z5y>* experienced benefits of having other team members know about their condition. I expand on the benefits as well as detrimental aspects associated with disclosing one's condition later in this study in section 3.2.2. Beyond the differences in physical stress associated with desk jobs versus those requiring physical exertion (such as retail or factory work), the employee benefits often associated with these different jobs, such as good insurance, ample paid time-off, and the ability to work from home can make an immense difference to the ability of individuals to manage their conditions.

<deq21qh> shared that they work in *“library science”* and *“I also get paid sick time and good insurance”.* Receiving such employee benefits led them to say: *“I'm still coming to terms with how lucky I am”.* Further, they highlighted the importance of *“environment and management as well as location and office set up (where applicable)”* to share their point of view on the line of work that is *“understanding of my chronic health condition”*.

Similar Lived Experience in the Workplace

A second aspect of the workplace that helped manage the severity of the work demands was the way that the workplace dynamic shifted when individuals worked with people with similar lived experiences. Individuals discussed how those with personal experiences of an invisible condition, either self or a close relative, meant that others could offer more understanding in a workplace. For instance, *<em6u14d>* referred to themselves as “*really fortunate*” for having supervisors and managers who had some kind of an experience with migraines. *“All I have to do is mention that I'm fading, or that I feel an attack coming on and they pretty much tell me to go home and rest” — <em6u14d>*. In other instances, people referred to themselves as *“lucky”* or *“blessed”* because of their close working relationship with people who either have a similar health condition or suffered from chronic pain due to a different condition. Later in this paper, I discuss how some people with invisible conditions need to educate others about their conditions to receive needed support. In workplaces where supervisors had more of an understanding of these conditions, the need to educate others about their health was significantly reduced.

In addition to being supported in leaving work to recover from symptoms, individuals described other benefits to having coworkers who are understanding about chronic pain or have some experience with managing it. A small display of understanding from coworkers can seem like a genuinely grand gesture; especially when they were able to share their personal experience with migraines. Being *"seen"* by their coworker made suffering through a migraine attack less lonely for <*ci3peh*>. The coworker in this case, generated an emotional reaction from <*ci3peh*> that resulted in a gratitude post on Reddit, simply because they offered their emergency migraine kit and shared a moment of commiseration about their wife's condition at work.

"His [coworker's] wife also suffers from chronic migraines so he sympathizes with me greatly. he chatted with me for a minute and offered me his emergency kit in his desk if i need it. it's the small and unexpected things that help me pull through sometimes. as invisible as this illness is, it's an emotional experience when someone finally sees us." — <*ci3peh*>

Under circumstances where others at work don't have this experience, the lack of shared understanding can cause a negative environment for people with invisible conditions. In an example in my data, people mocked <*9sdfbk*> when she started experiencing a flare-up at work.

"my job requires a lot of co-op between coworkers… whenever my face turns red or i starts rubbing my temples they know almost instantly that i am going to have a

serious attack. then they will begin to satirize me. it's like "oh, this woman is going to make an excuse again." — <9sdfbk>

Here, the interdependency of the role is intertwined with the (lack of) understanding from others. Having people at work with similar lived experiences may lead to fewer such instances, meaning that in some cases, people's ability to get the help they needed was up to the fate of having others in their workplace with shared experiences.

Workplace Support and Reasonable Accommodations

U.S. Government websites such as the Job Accommodation Network (askjan.org) and the U.S. Equal Employment Opportunity Commission (eeoc.gov) provide employers and employees with details on how to remove barriers for employees that restrict their full participation at work. There are several advantages to working for organizations that provide employee benefits listed on these sources, such as, additional time off requests [27], options to work remotely [30], and modifications to office facilities [28][29]. These kinds of benefits can allow people with invisible conditions to manage the severity of work demands and interdependencies in the office. People apply for labor laws such as the Family and Medical Leave Act of 1993 (FMLA) and Americans with Disabilities Act of 1990 (ADA) to protect themselves from discrimination and getting terminated for their medical condition using "reasonable accommodations" at work. "Reasonable accommodations" are mandated in certain situations by law and used to describe modifications or adjustments that are provided specifically for qualified people with disabilities as necessary for their ability to do their job. I found that Redditors with reasonable accommodations were willing to share their experiences and helpful resources with others who found it difficult to manage work and invisible chronic pain.

“I work in an office and sit at a desk for 8 hours a day and I have fibromyalgia. My company has made the following [reasonable] accommodations for me. I have a new chair I got to pick out myself from office depot…a private cubicle…computer stand that raises if I need to stand up …I have free time to get up and walk around when I need to” — < e11egml>

“I am on FMLA in the US so I can work from home on some days when I have attacks. It's been a life saver, and kind of the only reason I've been able to keep my job.” — <eq773qn>

Another advantage of reasonable accommodations, especially seen in the data about the United States was the ability to protect people’s jobs. FMLA (Family and Medical Leave Act) is job-protected leave [32] and one cannot be fired for requiring these accommodations because it could count as employer discrimination against a disability [31].

“once you have the form and the letter...use the FMLA Act. This will 1) keep them from firing you and 2) get you paid leave that cannot count against you each time you are out for a migraine.” — < eip5mfx>

“You can take what's called intermittant FMLA... It protects your job - you're guaranteed a job with the same salary - you might be moved departments but your salary and benefits must remain the same.” — <eg6xkqe>

Similar policies for job protections and accommodations exist in other countries were also discussed by Redditors. For example, in the United Kingdom *<e32yqz6>* described the benefits as “reasonable adaptations”: *“legislation has changed here in the UK at least (migraine is covered by the Equality Act 2010 as a long term condition if anyone is interested)...This generally means I just get sent for a health check and they ask if there are any 'reasonable adaptations' they can make to support me.” — <e32yqz6>*

And in Australia, *<er0fafj>* was able to highlight how Centrelink[1] can support people in need of accommodations: *"if you are on any form of Centrelink payment, you can contact the disability employment services and they can help you find work with support and accomodations for your disability.” — <er0fafj>*

In this section, I discussed circumstances that can mitigate or exacerbate the ways in which invisible chronic conditions affect work life. The types of work demand, interdependencies with others at work, and access to reasonable accommodations greatly impact how effectively one can manage work and pain on a daily basis.

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[1] A system for the Australian Government Department of Human Services

Yet, many of these circumstances depend on people disclosing the status of their invisible condition. Unless divulged to the employer, the invisible chronic condition remains hidden thereby cutting off access to legal accommodations and protections or understanding (in terms of receiving support from others with similar experiences). The following sections further highlight how differently disclosure at work affects these dimensions. In the text below, I discuss the dilemma of disclosure. First, I discuss motivations for and strategies of disclosure of invisible conditions in the workplace. Then, I present an analysis of reasons why and strategies through which people describe concealing their condition and symptoms at work.

3.2.2 Disclosure of the Invisible Condition

Disclosure of an invisible condition like migraine or fibromyalgia at work can affect how one is perceived by coworkers and upper management. People shared a number of motivations for workplace disclosure, including situations where continuing to conceal becomes untenable. *<e32ksso>* shared their regrets with others:

"I made a big mistake from not having "the migraine talk"[2] *with my boss. I had a string of migraines in a two month period and my boss took it as a lack of motivation and caring about the job…she was talking about letting me go. I ended up having to show a doctors note for her to finally understand that these are more than a headache and that I am being treated…She now understands that I care about my work and am not lazy." — <e32ksso>*

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[2] The concept of a "migraine talk", of proving the severity of a condition, and obtaining evidence from a healthcare professional are further expanded on below.

Disclosing the existence of their condition allowed individuals to access support and resources, such as in the example above. Yet disclosure is not a simple, one-time conversation. Even when all the details are made perfectly clear to others and legal protections are in place, I found that people need to do a lot of work to convince others about the severity and specificity of what they are experiencing – that it is not just a common headache, for example, or that they should not be taken to the hospital no matter how much it looks like they are being affected.

The particular characteristics of invisible conditions such as migraines and fibromyalgia are relevant to this need for persuasive disclosure: these conditions are not visible (hence their being described as “invisible conditions”) and are not even diagnosable by tests or scans. Doctors ascertain the chronic condition based on symptoms described by the patient and understand the progression of their problems over a period of time.

Below, I describe below the work individuals needed to do to convince others of the existence and severity of their invisible condition, as well as appropriate response to flare-ups. My analysis of disclosure is on two levels — informal and formal. The reason that these two analyses are handled separately is due to the ways that formal disclosure is affected by legal accommodations in many countries.

3.2.2.1 Informal Disclosure of the Invisible Conditions

Below I describe different strategies used to do the work of persuading coworkers and supervisors to pay heed to the severity of invisible conditions. The first one is about explaining the conditions to others using a "talk" and how that affects the interdependence. Second, I describe the importance of building a relationship with supervisors to gain their trust. Third, I explore the language or imagery used by people to convey their experience to others. And finally, I share strategies used to help others "see" what is not visible to them.

The "Migraine Talk"

When people have health conditions that are not apparent to or well understood by others, I learned that explaining their condition to coworkers may improve the psychosocial environment at some workplaces. People mentioned having the "migraine talk" at work in several posts on r/migraine. The "migraine talk" involves educating others about how the health condition affects the individual and the symptoms experienced at work. 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 be helpful to them when flare-ups are difficult to manage at work.

The migraine talk can be in the form of an actual conversation, but also in textual form. <*dodwill*> demonstrated the usefulness of migraine disclosure at work using a printed note that explains symptoms and the overall condition.

“*I carry a printed note with my medical information that explains my condition and my symptoms... I explain that have to sit in the darkest, quietest place I can until my symptoms are under control. I explain that I do not have to go to the ER, even if it seems that I am having a stroke and going blind… I include my emergency contact numbers if someone doesn't believe I am safe by myself.” — <dodwill>*

This technique of explaining what a flare-up could look like and who must be contacted in case of an emergency was received well by others on the subreddit. In another instance, *<emh0zn2>* shared their experience with printing their “migraine talk” to display on “*a couple of cards on a lanyard”* in varying degrees of details, “*'I am in too much pain to talk or listen, leave me alone.”, to I have Migraine' and explains about it in really good detail”*.

In the above example, a written document was seen as helpful because migraine can at times impede speech. The ideas of *<emh0zn2>* and *<dodwill>* were supported by others with suggestions to bring in documents, bust myths about migraine medications, and to list possible symptoms to watch out for at work. People added to the discussion of other things to mention:

“*...Maybe even mention how "migraine medications" aren't really a thing. Like, for instance, preventative medications I have tried are all off-label for something else. Atenolol = blood pressure medication. Topamax = anti-convulsant. Nortriptyline = antidepressant. Illustrating it this way may help them go easier on you, as it shows that even doctors don't really know what's going on.”. — <e338uv6>*

In the instance above, one can see how an invisible condition like migraine seems ambiguous due to the fact that people’s symptoms are not completely generalizable. Chronic migraine symptoms can present as a combination of several issues such as dizziness, nausea, and photophobia [4]. Medical professionals rely on patients to describe their symptoms clearly to determine the best course of action. The idea of coworkers “going easier on you” because even medical professionals take time to understand the condition was highlighted by *<e338uv6>*. Some individuals with chronic migraines felt like their migraine journey was supported at work by their supervisor, and in some cases by coworkers too. However, the data about migraines let me see the sharp contrast in terms of the struggles of people with fibromyalgia. Many Redditors shared anecdotes that showed the ways that people continue to believe that fibromyalgia is not a real health condition. Even those with a diagnosis find it hard to convince others – and even themselves – about their chronic pain.

“…With the lack of diagnoses or major signs of fibro i think people believe it is a made up condition more than an actual condition.” — <erjwbt8>

“It really gets me down and its especially eating at me with how my boss feels about my pain. Ive had to have quite a lot of time on and off of work lately due to the pain and fatigue [due to fibromyalgia], I feel like im letting my boss down even though he says hes ok with it....” — <erjwbt8>

Due to the nature of its symptoms being invisible, fibromyalgia is still considered a heavily contested medical condition [6]. This may explain why I did not find a parallel for “fibromyalgia talk” in the data. Another form of disclosure took place through the long-term work of building a relationship with their supervisor or boss. This was a way that people were able to receive resources they needed to manage their condition at work. Below I describe the intricacies of that relationship.

Building Bureaucratic Relationships

Access to employee benefits such as the option to work remotely or a different seating arrangement at work can be very helpful to people with invisible conditions. Such benefits allow people to effectively manage the severity of work demands and the interdependency of the employee and employer plays an important. I found that people spent time building a relationship with their supervisor that involved disclosing their invisible condition and finding ways to manage the workload.
“I work four days a week and declared [disclosed] my disability at work. My manager and I strategically plan my leave so that I can prepare for and recover from high delivery times...” — <emgegqd>

The example below of *<en1xzdp>* highlighted the importance of building trust through disclosure but more importantly, maintaining the bureaucratic relationship by getting the work done. Making up for when they would *“feel bad”* with *“feel good”* time was a strategy that worked in this instance: *“I was very honest with my boss about everything I was feeling...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." — <en1xzdp>*

Disclosure of the condition to supervisors was also seen as a way to seek specific employee benefits, such as the option to work remotely. By highlighting what was causing them migraines and pursuing a specific solution, *<eso08qy>* managed to get approval to work from home: *"Our office allows for flex work, so you can work from home if you're sick or the weather's bad...I realized the lights and placement of my desk were triggering my migraines, so 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 of *<eso08qy>* highlights the time spent building a relationship with their supervisor as well as the use of documentation through a doctor's note about their treatment plan. I found that different forms of documentation (which I refer to in subsection 3.2.2.2) as a type of formal disclosure can be very helpful to seeking employee benefits.

Analogies to Explain Symptoms

In lieu of a "migraine talk", sometimes the language used to convey the experience of a fibromyalgia or migraine flare-up is through analogies. The need for analogies comes in part from situations such as others making assumptions that migraines are similar to headaches that anybody might experience.

Other reasons for needing a different way to explain the symptoms are *"fake concern",* and over the counter medication suggestions. The following instances call attention to the reasons mentioned above.

"One time a coworker of mine said, "Sometimes whenever I THINK I'm getting a headache, I actually do. So maybe try not thinking about it..." — <emgi3h0>

"i'm pretty tired of my coworkers trying to check me whenever I have to take a leave… "oh gosh that's awful (fake concern) maybe try Tylenol"…this happens everywhere I go and i'm sick of explaining my situation over and over again." — <bke6mu>

"Aargh. "Have you tried Excedrin migraine?' Yes, Karen, I freaking have. It's great for a hangover but they really shouldn't be allowed to use the word migraine on the label. It doesn't even kind of work the way real migraine meds do." — <emgrmlc>

People found the use of analogies and phrases helpful to explain their migraine flare-ups to others. For instance, *<ew7wf0s>* expressed the severity of their migraine headache by describing it as: "*when you feel like the any light will melt your eyes out of your head and noise will blow out your ear drums."*. Other than chronic pain, "brain fog" is a cognitive flare-up that is experienced by people with migraine and fibromyalgia. In order to explain "brain fog" to others, people use analogies that can mimic the physical or mental frustration experienced during a flare-up.

On r/migraine, someone shared an analogy after a rough couple of days at work with a coworker who called them out on small mistakes. They highlighted how the use of an analogy was used to explain the effects of daily migraines to their coworker.

“after a few days of daily migraines, my co-worker has been calling me out for making small mistakes at work, of which i always catch, correct and profusely apologize for…i could only think of: “if you’re trying to solve a math problem, and you suddenly stub your toe, how hard are you thinking about that math problem now?” she seemed to get it at the time”.” — <cb8oit>

These following examples of analogies found on the subreddits of migraine and fibromyalgia show me how people are using their imagination to explain their invisible symptoms all around the world. If attempted, the act of slogging, wading, stampeding through the substances mentioned in the examples could result in physical and mental fatigue.

“turtles stampeding through molasses in winter in Vermont” — <etg4slh>

“wading through treacle” — < etgst5j>

“I say slogging through jello” — < etgtiec>

“I say I’m in the wet cement” — <etgwe4v>

“I describe it as trying to read through a stained glass window. Technically possible if you concentrate hard enough but so exhausting for so little result.”. — <eti4m9j>

The visuals chosen for these analogies evoke the feeling of struggle and communicate the fatigue caused by brain fog. In a workplace where team interdependency is vital, creating a language to convey experiences that are not visible to coworkers is seen as a way to disclose invisible symptoms.

"They can’t understand what they can’t see”

Even with techniques like the “migraine talk” and analogies used to describe the symptoms, sharing the experience of pain that is not visible to others was not always enough. The theme of “they can’t understand what they can’t see” became apparent through anecdotes of people wishing for a physical way to represent their chronic pain. < *el5g8s4*> shared this phrase at the end of their lament about the lack of something tangible to display “*sick number of our forehead”*,

“I wish we had a percent sick number on our forehead so others could have something tangible to understand what we are going through... So many of us fake it through day to day life...force ourselves to not only go to work but trudge through the day feeling like our body has turned on itself and we are literally dying... they can't understand what they cant see.” — < el5g8s4>

I learned that people with fibromyalgia flare-ups deal with comments about looking tired, followed by unwarranted comments about looking tired, like *“too young to be tired”, “you don’t look sick”.*

“My favorite is the people that tell you how tired you look (Which thanks for that) then go on to inform you that you’re too young to be tired (you’re the one that brought it up Kevin).” — <el5pzb9>

“I always get told, you look so tired. Yes I’m tired I’m in pain I’m exhausted.. I hear but you don’t look sick ugh just fuck off somewhere else please is what I always think.” — <el5ji1u>

I also learned that people experiencing a migraine attack are sometimes misconstrued as someone who is hungover, or worse, a drunk employee.

*“... i give them the heads up that i will sometimes call in late with a migraine... other times, nothing will work, the migraine will lead to nausea & vomiting, and i'll be out of commission for the whole day. but, i am **not hungover**...” — <91ycmq>*

“a coworker came up to me to “ask if i was okay”. she was very close to me when talking, closer than a workplace setting would call for, 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.” — <75cozp>

These kinds of misconceived remarks are indicative of how invisible conditions can be misunderstood in the workplace setting. In order to instantiate the invisible aspects of migraine and fibromyalgia, people like *<emheqyo>* and *<exhrqak>* 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) so [do] easy work”*, <*exhrqak*> managed to be left alone in quiet by their coworkers.

In the case of <*emheqyo*>, coming into work with *“buggy eyes”* and letting people hear them *“throw up violently in the bathroom”* made sure they were left alone during a migraine attack. They said: *“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 and 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 to them to generate understanding in the workplace. Other than coworkers, people with invisible conditions must also do the work of explaining their flare-ups to their supervisors.

While building trust, as described in the above subsection about “Building Bureaucratic Relationships” was considered a good strategy, formal disclosure was found to provide more options. Below I describe ways in which involving the upper management in negotiating formal disclosure in the workplace can affect people with invisible conditions.

3.2.2.2 Formal Disclosure of Invisible Conditions

Formally disclosing a health condition to the upper management has a different effect compared to informal disclosure because unlike informal conversations that are reliant on building a social relationship, formal disclosure establishes legal requirements for the employer to provide work support.

Formal disclosure can help receive employee benefits in the form of workplace support and in some countries like the UK and the US, there are laws to provide adequate support for those who need them. They are referred to as, “reasonable adaptations” or “reasonable accommodations”, respectively. In the following sections, I will use the term “reasonable accommodation” to refer to the laws that help employees with invisible conditions.

I found evidence of positive work environments with supervisors who trust people to manage the work demands and interdependencies in the office. Such supervisors offered them the benefits needed to manage the severity of the symptoms. However, I also found situations where invisible health conditions got discredited at work. *<e31x6c2>* shared, *“…once I made a small mistake while on a migraine and my boss was saying that i was just using that as an excuse and that everyone can work with a headache…”*

In the case of people with fibromyalgia, dealing with supervisors who dismiss the condition can lead to feeling insecure about the status of the job. For example, *<ejdeo2e>* who disclosed their condition to the supervisor, *"I had a bad flare and told him I needed to take it easy for a bit"* realized that upon learning this, their supervisor felt that: *"suddenly I was lazy and useless. I got my promotion taken from me and forced to train my replacement as punishment. He purposely scheduled me on days I had my school ambulance rotations. Would make me stay hours later for literally no reason…"*

Instances like those described above, where the impact of disclosed conditions were minimized, or people faced threats to their job security led them to seek protection and employee benefits described in the subsection 3.2.2.2. Reasonable accommodations can help make work environment more conducive to their health needs. In order to get approved for them, people did the work of documenting proof of health condition and work environment. They also sought the laws that could help protect their job and provide support. I describe the ways in which people engage in formal disclosure in the sections below.

"Document everything"

Official documentation submitted to employers can help provide "reasonable accommodations" that can protect people's jobs and provide additional time off work for recovery. The kinds of documentation that help individuals access these resources and protections can take the form of doctors' notes, work performance records, leave records, and any other kind of record that could help create a strong case for accommodations. These forms of documents have been given a lot of importance on both subreddits for helping people feel more empowered to share information at work. People are advised to provide medical documents to their managers so that they understand migraines, how symptom management works for the individual, and why reasonable accommodations were necessary for them. This is a bureaucratic version of the "migraine talk" through documentation.

"*...provide medical documentation if they ask for it, so you can feel less guilt when you need to call out. It will happen again, because migraine is stupid like that, but you can plan for it by letting your managers know it will happen…" — <ecak8ck>*

A migraine journal, as described by *<eron0zy>* could help keep track of symptoms and offers medical professionals an insight into the day-to-day of people with invisible conditions. This information can ensure that doctors include specific details in the documentation submitted to the organization providing reasonable accommodations.

"I'd suggest recording everything and keeping a migraine journal if you haven't already, Include other major symptoms... Don't be afraid to ask your doctor to record details, they often don't. When you get a good size to the journal (I'm chronic daily so 30 days was well enough), take it to the Dr. and have them put it in your records. Documentation is key to getting assistance.". — <eron0zy>

Strong emphasis was placed on documentation on both subreddits because it is vital to receive the appropriate level of work support, job protection and legal recourse (if terminated). Documenting everything, including how one is treated at work in a journal was said to be helpful until the accommodations were officially made at work. A journal could also be used to highlight how reasonable accommodations could reduce mistreatment at work and allow people to work better according to this example: "*My advice would be to document as much as possible, keep a journal of maltreatment [mistreatment] if necessary, maybe ask sympathetic coworkers to sign off on notes or statements if they witness a particularly big argument, use email where possible instead of phone calls for easy documentation. Know your local recording/consent laws if you decide to record phone calls...etc."— < e7365dw>*

As mentioned above, people also record interactions such as meetings, email threads, and online chats, to keep in case of being terminated for reasons pertaining to their condition. The examples below demonstrate that documentation was essential to build a case of wrongful termination if a company took such actions against people. "*As somebody who was let go under a bogus excuse of restructuring (it was really my illness), the one thing I would do over and stress that you do is to document every interaction like that with as many details as you… You may never need it but if you do and don't have it you will kick yourself…That is critical. Without a history of mistreatment you will never win a wrongful termination or discrimination suit if it comes to that." — <ejrqs3i>*

“I think there are laws against firing people, without proper cause. The company might be at fault legally, especially if you get fired soon after you reveal your condition. Document events, so that you have proper proof (when you told them, when they fired you, what they said etc.)” — <eplvrky>

Documentation is vital to receive adequate support and protection by law and it becomes the responsibility of the people with invisible conditions to do the work of documenting everything.

The Employees’ Need to Protect Themselves

People with invisible conditions like migraine and fibromyalgia should be able to participate to the best of their abilities in a workplace. Laws such as FMLA and ADA protect people from discrimination and ensure that people with medical conditions and disabilities have the same employment opportunities as everyone else in the country. To afford the same employment opportunities as others, employees with invisible conditions can request reasonable accommodations.

Reasonable accommodations are modifications or adjustments to the tasks, environment or to the way things are usually done that enable individuals with disabilities to have an equal opportunity to participate in an academic program or a job (U.S. Department of Education, 2007).

At times, people with an invisible condition like fibromyalgia or migraine have to do the work of educating their employers about the need for reasonable accommodations. Drawing parallels between how their decision would impact somebody with a visible disability was considered an effective way to make this point. Refusal to comply with a reasonable accommodation can also be seen as an act of discrimination, but employers may have a harder time understanding accommodations are needed with invisible conditions*: " If you have a disability or illness and request a reasonable accommodation I wouldn't think they can really deny you... If they say it would impact performance imply that means they would essentially be discriminating against wheelchair bound candidates and that's a definite violation of the ADA. If someone in a wheelchair could perform your task and your illness or disability requires accommodation they should not have the ability to say no especially with a Dr note." — <ezsaij2>* .

Reasonable accommodations can be used to seek different kinds of employee benefits to participate effectively at work. These include additional time off requests [27], options to work remotely [30], and modifications to office facilities [28][29]. I found that people were able to apply to receive these reasonable accommodations at work to manage the severity of work demands. To help someone successfully receive additional time off from work, *<ekpqu1s>* explained to someone that they should consider applying for FMLA: *"If you have a chronic condition ie migraines, and you qualify. It might be a good idea to file FMLA paperwork..."*.

Others shared the time frame to receive accommodations. In *<em6h2j0>*’s case, a doctor’s note was the only documentation needed to receive additional time off approved through ADA[3].

“I just started a new job about 2 months ago and found out today the ADA 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”. — <em6h2j0>

I found that requests for modifications at work through reasonable accommodations were not limited to changes to the physical environment of the office. It also included permissions to wear tinted glasses to prevent migraines, or a yoga ball to alleviate pain from fibromyalgia, and more.

“...ask for reasonable adjustments to your workspace. Like having a set work room or such with different lighting. Or asking that light diffusers be placed over the fluorescent lights in your area. Ask that you be allowed to wear tinted lenses or sunglasses if they help.” — <ezd2jxl>

“As far as accommodations that have been made for me, I am allowed to work with my feet up on a chair. I also have a yoga ball that resides in my office that I am allowed to sit on, take breaks on, stretch on, and so on.” — <en1xzdp>

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[3] Americans with Disabilities Act of 1990

Another important aspect of reasonable accommodations is job protection. By demonstrating that one can perform their job as long as accommodations are made at work, these laws protect people from being terminated for their medical condition. I found people who make these suggestions to others on Reddit.

"You should look into FMLA. It 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." — <cwjvcs>

"If you're in the US, you can also make an ADA request. That will also help establish your [job] protection. My boss has been told that she literally cannot discuss my condition unless I bring it up because I've made an ADA request..." — <ajjhfc>

Even though the paperwork required for each law is different and could be time-consuming, people take the effort to protect their jobs and themselves from being discriminated by the employer. Laws like FMLA, ADA, and others in different parts of the world help people with qualifying conditions through employee benefits that can help them manage the severity of their work demands.

Unreasonable Employees Bend Laws

The laws to provide reasonable accommodations are meant to ensure that employers cannot discriminate against employees with medical condition. To illustrate this point, *<evwg378>* brought up the Equalities Act in the UK to convey that companies could land in legal trouble for doing this: *"... fibromyalgia is covered under the*

Equalities Act 2018. If your company implies in anyway you're being treated differently because of your fibromyalgia then you could have grounds to ask ACAS to start tribunal proceedings or get a NWNF solicitor to bring a litigation suit against them"

An extreme consequence seen across the data was when companies tried to manipulate people into quitting their jobs. Given that they were legally not allowed to fire them, companies found ways to make people with invisible conditions feel bullied, thus forcing them to quit. *<pepp8rr9>* talked about their personal experience of how their employer handled reasonable accommodation requests.

"Unfortunately employers are savvy geniuses when it comes to evading the ADA when they've decided they want you gone. It's happened to me 3-4 times; some I quit bc I literally didn't want to wait for them to get my termination approved or was being very clearly discriminated against. Bullied and accused of lying many times."

— *<pepp8rr9>*

The data revealed the different ways in which employers force people to quit because terminating the employment of people for their medical condition is not legal. Bullying people into quitting followed a pattern of discrediting people's work.

In the following case, their commendation was referred to as a "note" by the HR causing *<emfoybg>* to feel traumatized by the incident and eventually making them quit the job: *"I had a weird moment with HR when they pointed out I already had a "note" in my file from a previous manager. It was a **commendation** for a job well* *done. I didn't have the energy to fight the way they were treating me. It was illegal and very traumatic. HR tried to tell me the FMLA note from my doctor was invalid. Glad I quit that place." — <emfoybg>*

I also observed that not all reasonable accommodation requests are fulfilled. If an accommodation would not be seen as necessary by a supervisor because of the invisible nature of the condition, such requests were denied. *<d20gns>*, a door greeter at Walmart, *"...got approved for an intermittent leave, so i basically get 2 free call ins [intermittent leave] a month"*. However, when they asked for a chair at the door as a reasonable accommodation, it was denied: "*i work at wal-mart as a door greeter so a chair would in no way negatively impact my job or the company...i'm at a point now where i have used all of my call in days, all of my sick days, and i'm still in so much pain i can hardly move" — <d20gns>*

With laws like FMLA[4] and ADA[5] in the United States, the option to take additional leave as needed, modify the office facilities, or work remotely, are considered very helpful by people whose flare-ups can cause severe pain and/or discomfort. Reasonable accommodations allow people to find ways that allow them to participate in work life to the best of their abilities.

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[4] Family and Medical Leave Act of 1993

[5] Americans with Disabilities Act of 1990

This section highlighted how disclosure can provide access to employee benefits, but at the same time, the bureaucratic interdependence could negatively affect the work life of people with invisible conditions. As much as disclosure was stressed as important, the data also revealed case after case in which people chose to conceal their conditions. The following section details the reasons why and strategies through which individuals concealed their condition.

3.2.3 Concealing the Invisible Condition

There were a number of reasons people found it important to hide their conditions at the workplace. Some people expressed their concern about disclosing their health condition because they had personally faced the negative consequences of divulging around their invisible condition at work despite filing paperwork to receive reasonable accommodations.

As seen in the above section, needing reasonable accommodations was seen as a problem by some organizations. Simply requesting for them resulted in getting fired in one case, despite the dubious legality of this occurrence: *"…Filed paperwork, got chosen for a "random" drug test, then 2 days later fired. I should have hired a lawyer"* — < *ekp5urd*>. And in another incident, the idea that one might apply for accommodations led to getting fired from work*: "My husband got fired when he told his work he was sick and they thought he might file FMLA paperwork. Companies can really suck. :("* — < *ekokrso*>

The advice to *"hide your symptoms"* was supported by some Redditors like *<ed9zpwr>*, who commented, *"I know its not possible for many but if you can avoid it, never tell your boss. Never tell HR."* Though avoiding formal accommodations was easy once that decision was made (i.e., by not submitting paperwork), 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 people to find methods to successfully hide flare-ups, symptoms, or the condition itself from others in the workplace.

In this section, I describe three of the strategies that individuals use to conceal their condition. The first strategy was the most common in the data and involved doing what they could to "keep it together at work". In other words, they ignored their symptoms and caring for themselves while at work, with aftereffects of dealing with this in their own time. The second strategy involves the ways that people manage symptoms at work without giving away anything about their health. If the symptoms became impossible to conceal, individuals used a third strategy in obfuscating the real deal. People with invisible chronic conditions who feel the need to hide their ailments use these different strategies to keep "the invisible" well-hidden.

Keeping it Together at Work.

One tactic shared by participants was "keeping it together at work", something that they felt the need to do in order to perform well at work and appear as though they were performing well. One Redditor expressed that nothing mattered aside from work, so they get by without revealing their health issues. Seeming reliable to people at work was the most important goal: "*If you're anything like me, you want to seem put together and like you're constantly kicking butt and anything you struggle with has no effect on you. You want to seem reliable."* <ds4b6fa>

The way that some individuals worked to hide the effects of the conditions they struggled with was described with phrases like *"suck it up and go to work"* — *<e8nwnh3>*, "*block it out*" — *<c6dypv>*, "*go home and die afterwards*" — *<emfo87b>*. They ignore the pain in the moment in order to get through their workday without letting their invisible condition get in the way. The energy spent to do the work while hiding or blocking the pain affects people after work, during weekends, and over holidays. This was pervasive across various job roles, industries, and geographic locations.

"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, but I show up and I do my job so no one else has to do it for me." — <e8nwnh3>

"*Chef here, I work 30ish hours. I honestly go home and die afterwards…" — <emfo87b>*

"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.”. — <c6dypv>

“I work retail and honestly, I don't know how I do it most of the time. It takes everything I have to get through the work week and it's physically and mentally exhausting. *I spend my days off trying to recuperate before starting the process over again*” — <emf5l44>

Trying to keep it together sometimes meant that individuals hiding their condition did not take advantage of employee benefits that could have helped them manage their conditions. This occurred with benefits such as working from home, intermittent leave, and office equipment for mobility assistance. In order to avoid being seen as someone who works from home a lot more than the others, *<emfg7lt>* explained on Reddit that, *“I drag myself through the day, constantly squirming at my desk and checking the clock... I do have the option to work from home if I need to, but I try not to take advantage of this more than my coworkers.”.* This individual would have benefited from this option, and they explained the severity of keeping it together in terms of its impact when they were experiencing flare-ups: “*I drive home, collapse and smoke until my pain is background noise and my work day seems like it was all a dream. Then I wake exhausted the next morning and do it all again. I work 40-50 hours a week, and during flair [flare] ups I typically crash Fridays and will sleep from 9p-noon Saturday” — <emfg7lt>*

Hiding symptom management techniques

Though individuals worked as hard as they could 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 keep it together at work for those who hide their conditions at the workplace. People find different techniques to conceal their symptoms. These techniques vary with the factors I identified as impacting experiences in the first section: severity of work demands, interdependencies with others at work, and access to employee benefits.

For people in jobs that need them on their feet all day, taking bathroom breaks was a way to get a quick respite: "*the pain is so bad. i'm on my feet my entire [café] shift, and if i want a break i have to pretend i'm using the bathroom so i can just sit for a bit." — <cckg56>*

People with their own office spaces, on the other hand, can take breaks in their private space to find chronic pain relief. *<en0ixwt>* 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 office spaces were useful for those who needed to keep resources that would help them deal with symptoms.

Some examples of things that help people at work are small blankets, pillow for back support, pills like Naproxen (over-the-counter headache medication). These things are usually kept hidden in their desk drawer or office bag to avoid questions.

"I have a small blanket and even arm warmers in my drawer. Before I got a better chair I would bring in a regular pillow that would help with back support. Anything to make myself comfy." — <en0l8b6>

"I carry naproxen like active duty military carry weapons (close to me in my bag). They get me home to actual migraine meds." — < emjzefo>

It was particularly helpful for these resources to be inconspicuous (i.e., not immediately associated with an invisible condition) when people were in sight of others. These types of resources allow individuals to manage their pain and continue working even during flare-ups. *<e8n8giq>* said: "*... I keep a few comfort items in my drawer like knitted fingerless gloves, earplugs, a warm sweater, high protein snacks, anything that is inconspicuous and can help me be more comfortable at the office when I'm not at 100%."*

Obfuscating the Real Deal (Symptoms)

In the above examples, individuals share how they hide their symptoms at work. However, this was not always possible due to severity or lack of private spaces. When people were unable to hide the symptoms or existence of their condition at work, they described finding ways to explain away their pain while concealing its true source. If visible symptoms made it difficult to hide the invisible condition, people who preferred to hide it from coworkers found common conditions to attribute to the symptoms. They chose conditions that others would find relatable and possibly 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." — <ephv8y7>*

"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." — <epj5hfc>

Obfuscating the real reason and providing excuses of a bug or flu was considered a good idea because it prevents follow-up questions, meaning that they can *"get the work done",* according to *<epj5hfc>*. When chronic pain causes symptoms that are visible to others, some people also found it easier to navigate the workplace because their condition was visible (while still obfuscated) to others.

"my eyes also are mostly closed and have huge bags underneath thanks to getting no sleep from the pain. I look like I have the plague so maybe that helps them steer clear and keep quiet." — <emheqyo>

In this section, I described the ways that avoiding revealing their real condition at work was considered important by people in a variety of roles and industries. Individuals with invisible conditions utilize a number of strategies, such trying to keep it together at work and waiting to be away from work to take care of their health. Sometimes they found ways to hide their symptom management techniques at work while still keeping it together. If neither strategy could work, individuals obfuscated their symptoms finding a different excuse for their actions or appearance.

3.3 Summary of Phase 1

In phase 1 of this study, I was able to determine the different ways in which people negotiate disclosure at work. Hiding the condition leads to managing the severity of work demands, interdependencies with others at work, and access to work benefits in ways that are different from how one would approach these when the condition is disclosed to others. When they choose to informally disclose, people need to do the work of explaining the condition and despite the efforts taken, tend to get dismissed by others in some instances. Employee benefits and resources like reasonable accommodations can be helpful to people with migraine or fibromyalgia. However, these benefits cannot be obtained without formal disclosure at work. The dilemma of disclosure is a problem space that includes the severity of work demands, interdependencies in the workplace, and access to employee benefits. The overarching themes of how negotiating disclosure is complicated for people with migraine or fibromyalgia was highlighted in phase I. In phase 2, these findings informed the creation and solicitation of feedback on design concepts that address the potential roles of technology in negotiating disclosure.

Chapter 4: Phase 2 – Design Concepts

In the second phase, I created five technological design concepts based on the findings shared in Chapter 3. I recruited six participants with migraine or fibromyalgia to conduct semi-structured interviews in which these design concepts were shared with them. Through the findings of this phase, I contribute understandings of disclosure that should be taken into account in future design efforts, 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.

4.1 Methods

The themes found in Phase 1 told the story of disclosure dilemmas, the uncertainties of disclosing invisible chronic conditions at work. Through Phase 2, I wanted to address some ways in which people successfully managed their professional lives. Based on the themes of informal disclosure (in section 3.2.2) and concealing of the condition at work (in section 3.2.3), I created five design concepts that leverage technology for the purposes of disclosure or concealment. To give interview participants a context for the use for these designs, I created storyboards and shared a narrative with them during the interview.

4.1.1 Participants

Six participants (1 male, 5 female) were recruited for this study through a social media post on Reddit and word-of-mouth. All the participants self-identified as people with migraine or fibromyalgia and are currently employed in some capacity in different parts of the world.

Keeping in mind that people in different roles, industries, and geographic locations would potentially have unique ways to relate to the designs, I wanted to generate a diverse participant pool.

ID	Gender	Invisible Condition	Geographic Location	Industry	Job Role
P1	Female	Fibromyalgia	Canada	Education	Art Teacher
P2	Female	Migraine	India	Banking	Customer Relations
P3	Female	Migraine	America	Marketing	Graphic Designer
P4	Female	Fibromyalgia	Finland	Education	Researcher
P5	Female	Migraine	India	IT	Head Administrator
P6	Male	Migraine	America	IT	Data Scientist

Table 4.1.1: Participant Details

Participants were asked to complete a screening questionnaire and sign a consent form prior to the virtual interview. The participant details collected on the screening questionnaire and shared with me during the interview are shown in Table 4.1.1.

4.2.2 Procedure

The study protocol was approved by the Institutional Review Board (IRB) at the University of Maryland. I invited participants who self-identified as people with migraines or fibromyalgia to participate in 60-minute semi-structured virtual interviews. I started by asking questions to understand their work setting, degree of disclosure of their condition at the workplace, and techniques used by them to manage the condition and their work. After setting the context for the study through this interview, I introduced the design concepts to the participants in the form of storyboards and virtual demonstrations. The storyboards are set in work environments, such as a cafeteria and personal desk/cubicle area in the office to immerse the participants in a workplace setting that feels familiar. When I was examining the design space for potential technologies, I created a set of dimensions that could be relevant to these design concepts. When participants were reacting to the design concepts during the interview, I used in the dimensions in Table 4.2.2 to better understand the concept from their perspective.

Dimension	Rationale
Volume of information shared	How much information would effectively educate others in the workplace?
Type of information	Preventative measures (Educational material) versus constant indicators?
Mode of communication	Effective mode of display — Instant Messaging platform, printed formats, wearable, or email signature?
Audience for disclosure	Who needs to know (coworkers only, supervisor only, everyone)?
Audience to conceal from	Who should not find out (clients, coworkers only, supervisor only, everyone)?

Table 4.2.2: Design Dimensions

4.3.3 Analysis

All the interviews were audio recorded and spot transcribed for analysis. The interview data was open-coded [38] for each concept to understand the circumstances under which the designs would be advantageous, disadvantageous, or unnecessary in people's lives. By probing for specific design dimensions, I found that their job role and geographic location played a significant role in determining the need for concealing or disclosing their invisible condition at work.

4.2 Findings

The goal of phase 2 was to generate design concepts that would allow people to effectively disclose or conceal their invisible conditions at work. Through interviews, I hoped to refine my understanding of the disclosure dilemma. Keeping in mind that there is no one-size-fits-all solution to this dilemma, the design concepts were shared with my interview participants as part of the semi-structured interview. I learned about the different contexts and circumstances under which these designs were seen as being effective and also learned why the concepts would not apply in some people's work environment or job role. Below, I describe those design concept and share findings that refined my understanding of the use of technology to develop solutions that help people negotiate disclosure of their invisible condition at work.

4.2.1 FilterFace

The feeling of having their flare-up misconstrued as something other than a health concern (such as laziness) was evident in the phase 1. It brought sadness to those who felt misunderstood: *"since our disease is basically invisible, there are clearly people there who think i am not sick at all. they think i'm just lazy. they have said so in so many words. being thought of that way brings me sadness." — <c595p3>*

The frustrations of others not being able to “understand what they can’t see” in Phase 1 (subsection 3.2.2.1) led to the strategy that some people with invisible conditions use to share their symptoms – namely, by making them visible to others through the use of sunglasses inside the office during a migraine attack or a cold compress on the neck to indicate a fibromyalgia flare-up.

FilterFace is a design concept that creates a “filter” to help people enhance how their face looks. This concept is viable using today’s augmented reality (AR) technology [37]. FilterFace can amplify the symptoms of migraine and fibromyalgia visibly and create AR filters to that have “*bags underneath the eyes”* or *“buggy eyes and pale skin”*. The storyboard below lets people see how FilterFace would be used in a workplace. Along with sharing the storyboard, I also presented a frame by frame narrative during interviews to help participants imagine themselves in this situation.

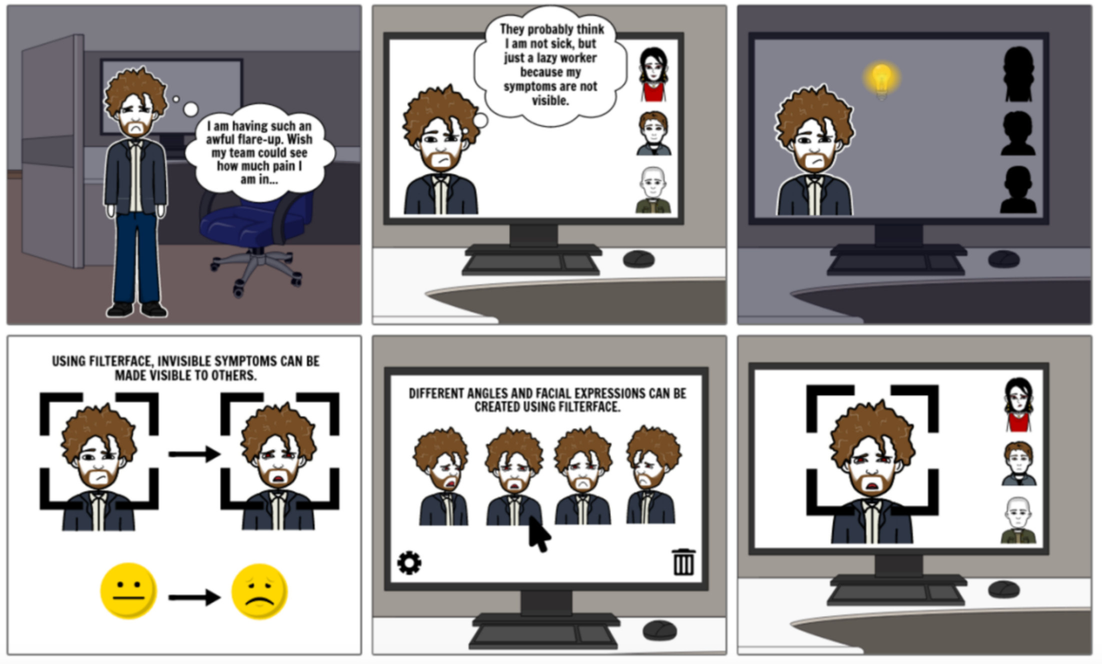

Illustration 4.2.1: FilterFace

Using the above storyboard, participants were able to situate themselves in incidents where they needed the symptoms to be visible to avoid being dismissed or questioned at work. P1 explained that *"...it seems like I have to constantly remind them [coworkers and boss] that I am sick. Because you don't look sick and you try to get things done on time. So, if I say that I need help, they are always like - but why do YOU need help? BECAUSE I AM SICK"*.

Her need to constantly remind people at work that she is not okay even though she may "look healthy" was where a good use for FilterFace was found: *"I definitely see an application for this, like 'you might look healthy, but you are not' sort of like if you are going through chemo and not losing your hair, doesn't mean you are not going through chemo" (P1)*.

P2 highlighted the main audience of this design in her work life and said that she would only use the application among internal stakeholders to shut down rumors at work. *"If I tie my scarf around my head during severe headache and put my head down, I have heard that people have mocked me with the word 'terrorist' due to the head band. This [FilterFace] would make them see how severe my pain is"*

These instances demonstrate how disclosure is not a one-time conversation. On the other hand, P4 and P6 felt that they just had to let people know to be excused from work and using FilterFace to enhance the symptoms was unnecessary.

“If I say that I am sick, my colleagues let me off the hook. I don’t need to exaggerate my symptoms for the sake of it” (P4)

“I like to make sure I get my work done. So if I am not okay, I take my meds, let people know and rest up. My colleagues are good people who understand.” (P6)

As a supervisor herself, P5 felt that people need to speak up when they are not okay instead of resorting to the use of applications like these to make a statement. *“If you are given X, Y and Z to do but you are in a position to only do X, just ask for more time. As colleagues, people don’t care how you look, but only about the work to be done.”*

Through their reactions to this concept, I found that people who experience the emotion of the theme, “they can’t understand what they can’t see” are those who have been on the receiving end of negative remarks from the workplace. When working in a role where team interdependency is high, if people are unable to feel supported by their colleagues, FilterFace can be used to make it easier for them to understand.

4.2.2 Reverse FilterFace

I created a version of FilterFace that would facilitate concealment of invisible condition at work and called it “Reverse FilterFace”. This serves as the antithesis of FilterFace as it helps people conceal their invisible conditions. This concept highlights the overarching theme of “hiding symptom management techniques” at work, as seen in section 3.2.3.

In this concept, filters created using augmented reality can conceal visible flare-ups like *“buggy eyes and pale skin”* on people’s face. To demonstrate the idea, I created a storyboard narrative (Illustration 4.4.2) in which the protagonist chooses to hide their condition from people in the workplace during a team meeting using Reverse FilterFace. This design was shared immediately following FilterFace.

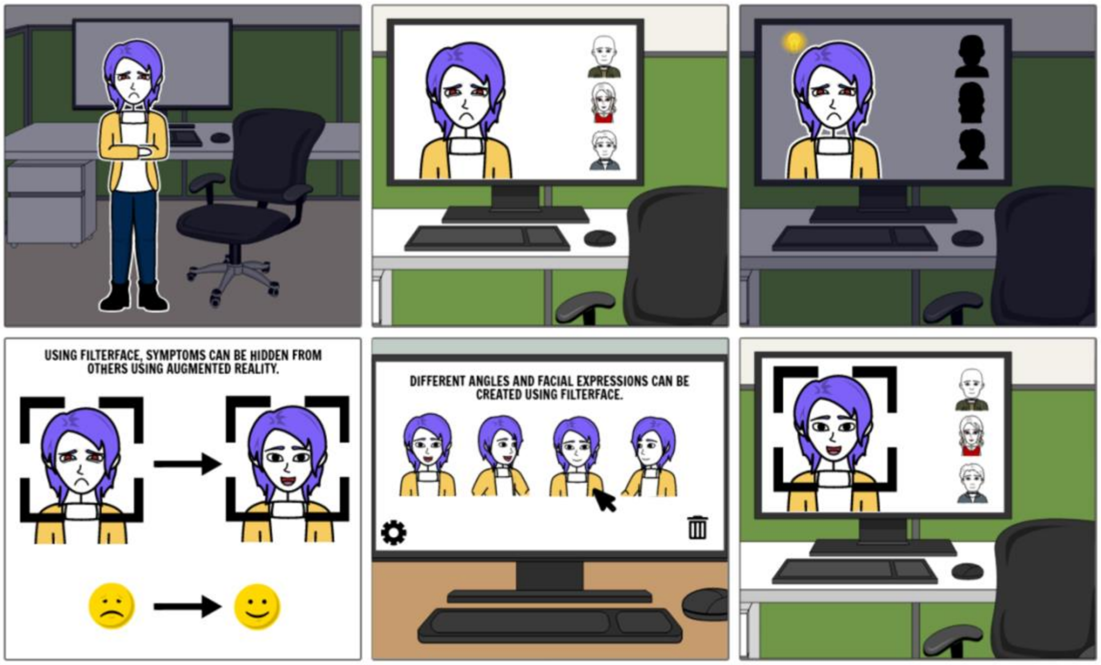

Illustration 4.2.2: Reverse FilterFace

During this concept demonstration, participants shared different instances where concealing the condition would be the best move. P1 was very supportive of full disclosure of the condition at work: *“I wouldn’t hide it. I am one of those people that say that people should learn to accept.”*. But to avoid derailing a conversation about work with health discussions, she found a situational use for this concept: *“when I am having meetings with people outside my organization who don’t know me and are not going to go into my background but this meeting is super important.”*.

She explained that this would also make for a good *“short-term disguise”* in order to *“get through this meeting without questions like “are you okay?” “Are you upset?”. Not what we are talking about right now so if we could stay on task”* when they were *“working from home with a bad flare-up”*. P2 had a similar reaction this concept. Hiding her pain felt like the right decision only 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 FilterFace and get the work done.”*.

She was quick to add that this would only apply for those conditions: *“Nobody can see my battle with the pain so I won’t try to hide it [symptoms] when it happens in my office because I want them [coworkers] to see how unwell I am despite being present”*. P3 resonated with this idea. She mentioned that her supervisor was understanding so there was no need to pretend to be okay, plus she felt that her clients could set their expectations reasonably only if they knew she was not okay. *“I would meet with people and just let them see me and say, ‘look at me, clearly you are not going to get much out of me, so here is what will get done...”*.

This concept provided me with a more nuanced understanding of how these kinds of designs could be useful to people in various contexts of their work life. Even those who tended heavily towards disclosure in the workplace might conceal their symptoms when the situation demands.

4.2.3 Make-Your-Own

When disclosing their condition at work, the theme of “Migraine Talk” (subsection3.2.2.1) provided the information that people with migraine and fibromyalgia could share with others at work to enable disclosure of their invisible chronic condition. In order to design a way to educate others at work, I created a concept that allows people to add all the important aspects of their condition, medical terms used by their physicians, typical flare-ups, emergency contact, how coworkers could help, etc. in a format best suited to them to display at work. I called this “Make-Your-Own”.

The dimension of volume of information (Table 4.2.2) was important in this design. As highlighted by <*epj5hfc*> on Reddit, the range of disclosure is an important aspect of expressing their pain at work*: “I think there's a range between completely hiding it, and then being completely open about it to the point where people think you are trying to make excuses. Everyone in my office knows about it, but I don't feel the need to keep them apprised of my day to day pain levels unless it's going to directly impact my work in some way.” — <epj5hfc>*

This concept was shared through another storyboard with characters in an office cafeteria setup to give the participant the context of a space where small talk is welcomed and encouraged.

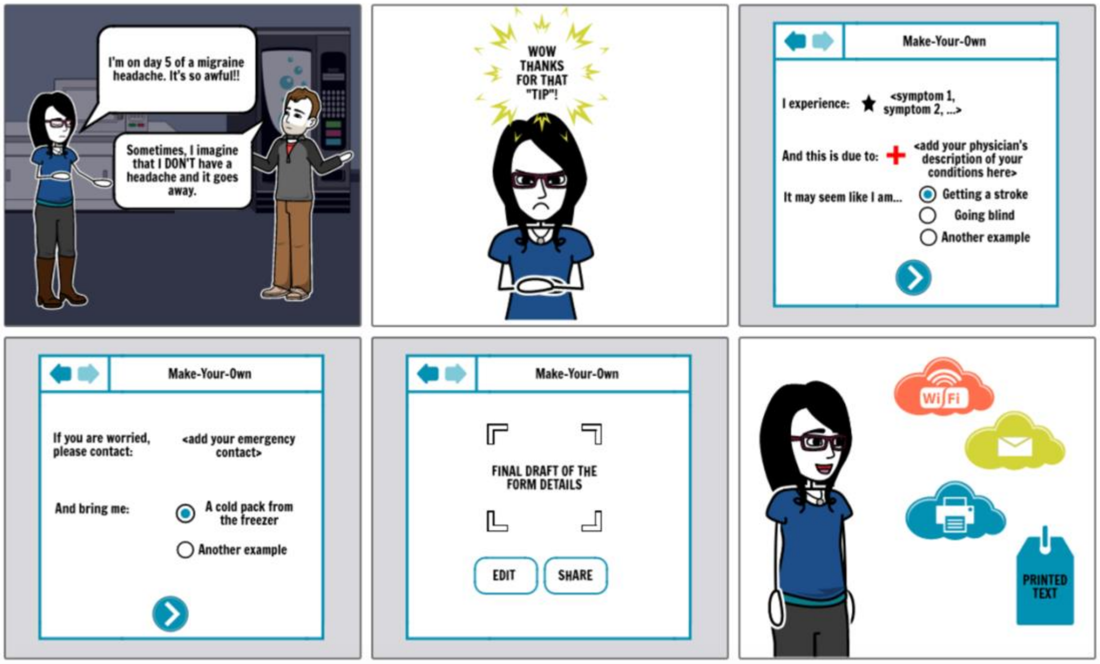

Illustration 4.2.3: Make-Your-Own

The idea of feeling dismissed by their coworker, as seen on the storyboard, felt familiar to my participants and they could immediately think back to a personal experience where something like this happened in the recent past.

It felt imperative to also think about how much information one would want to share to get the attention of people and educating them. Since Make-Your-Own is meant to be a concept that allows people to share their own symptoms and premonitions about what could take place during a flare-up, interview participants were asked to talk about what information they would choose to reveal and why.

P3 shared there is a lot of client-facing work in her role. Therefore, she would use Make-Your-Own to let her clients know exactly what would get done on severe migraine days: *“I would highlight the type of tasks that they can expect me to get done during a migraine attack. It would say something like, ‘I can’t so <fill in the blanks>’ and ‘I can do <fill in the blanks>’.” (P3)*

P4 shared a technique she currently uses to indicate when she needs to be taken to an emergency room and wanted to include that as information in Make-Your-Own instead of the field “It may seem like I am”. Between her close friends and teammates, she developed a hand signal of a cross by putting index fingers together that gestures “medical center”. *“If I am in severe pain due to fibromyalgia and it affects my breathing to a large extent, this hand signal has been helped alert the people around me to take me to the ER” (P4)*

P2 liked the idea of educating others but felt, “*I don’t think people will understand or care. At the end of the day we are colleagues, not friends. They only care about the work getting done and nothing else.”*. This was an interesting feedback that led to discussions about employee benefits in their geographic location.

I learned from P2 that even though she worked in a multinational bank, they did not offer any kind of formal reasonable accommodations and there were no legal actions one could take in her country. The “migraine talk” may only have power when it is backed up by legal recourses.

4.2.4 VR Analogies

I found compelling data from Reddit where people feel the need to have others learn about the invisible condition by feeling it. The terms used by Redditors were, *"experience it" — <e8o3wxb>* and *"feel my pain" — <e8nwgdy>.*

"*It really sucks to be in so much pain but get no slack or understanding. I don't think other people realize how debilitating migraines or chronic pain in general is until they experience it." — <e8o3wxb>*
It's shitty but sometimes I wish they could feel my pain, if only for 10 minutes, so they could understand that there's no way ANYONE could work in that sort of condition. — <e8nwgdy>

Though it was not possible to have other people experience their condition, individuals shared a range of analogies to explain symptoms to others at work. Inspiration from the tactic of utilizing evocative comparisons to explain the condition led to the creation of VR Analogies. Since I found several instances of trudging and wading through mud/treacle in Phase 1, I created a scenario for the participants where their office is immersed in the virtual reality experience of *"trudging through mud"* as described by *<cbj20b>* on Reddit.

Illustration 4.2.4: VR Analogies

I shared Illustration 4.2.4 and a video with a first-person view of a person walking through mud. Participants instantly reacted with the analogies that they use in their daily life. Every participant was able to let me know one or many phrases they use to try and explain the severity of their symptoms to others. P1 said that she use the example of Disney princess Ariel to describe their state of being at work: *"I often state the original story of Ariel when she got limbs, every step she took it probably felt like she stepped on blades — 'I am Ariel today. We are going to have heating blankets and no one bother me. I am going to do my duties and if I can't I will get someone to do them for me'" (P1)*

P2 had an emotional response to this concept and exclaimed, *"nobody can see my battle with these headaches. Feels like a 1000 people are sitting in my head and playing drums"* and could immediately think of a simulation that could be created without VR. *"my colleagues should rub pain balm [VapoRub] on their foreheads and when their eyes start watering, they should try doing the work. [I wish] they could also feel the drums in their head but that's not possible..."*

P3 uses the phrase, *"ice pick in the eye socket"* because her migraine causes visual disorientation. In a similar vein, P6 said, *"I say it feels like a baseball is shoved inside my head. There is a tense, hot burning feeling behind my eye that just grows and grows..."*. Suggestions were made to use simulations like the *"beer goggle test" (P3)* and *"simulated pregnancy test" (P6)* to force others to experience the disorientation and physical pain experienced during a flare-up. This leads me to believe that if more participants test this concept, there is a possibility to create a crowdsourced library of analogies for people to choose from during a VR Analogies session in the workplace.

P1 highlighted an important point of creating these simulations in terms of reaching a large number of people: *"I like this and it's just like how to educate people around what they need to know and when they need to know it because if you are like, "I am having a flare", having to sit down and explain it to 20 different people adds to that exhaustion and that mental fatigue from constantly trying to educate people."*

4.2.5 Pain Level Indicating System

Along with analogies to explain symptoms, I found in Phase 1 that people 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. I created a concept with a color-changing LED system and called it the Pain Level Indicating System (PLIS). The color of the LED is meant to signify the severity of a flare-up. For example, if PLIS is switched to red lights using the remote, it would mean that they are in unbearable pain and a green light would signify that they are doing okay (as seen in Illustration 4.2.5). I explored this idea as a fixed system in an office space and as a wearable for people with jobs requiring a lot of movement. The dimensions to probe this design included the type of system that would be preferred by the participants (fixed versus wearable).

Illustration 4.2.5: Pain Level Indicating System

P1 was excited by the idea of having this as an indicator for their office space and as a wearable. She exclaimed, *"This could be a pin that I would proudly wear and walk around"*. P2 on the other hand, wanted to wear the lights and not display them in the office space. She said, *"I would wear it like a crown and make sure that everyone knows exactly how much pain I am in. This will also make sure that people don't ask me questions or wake me up if the lights are red and I am trying to recover."*.

When probed about who they would potentially hide PLIS from and if this would affect how they are perceived at work, P6 had an interesting reaction that supports the insight about formal disclosure. He said, *"Unless this is an organization-wide announcement for everyone to do this, I only want to share this with my immediate team members."*. P1 was also interested in making this a universal setup for everyone at work. She said, *"Everyone in the office needs to have these lights so that we can all be respectful of each other's pain."*.

P6 did not want to conceal his condition from work, so I wanted to know more about this need for sharing only with a small team. He felt that having to explain the meaning of lights to *"everybody who was curious would be exhausting"* if this is not imposed *"directly by the organization with clear guidelines"*. P5, a supervisor in the office also raised this point and the importance of making this a formal disclosure, rather than an informal one because *"explaining to everyone personally will be an ordeal"* (P5). She also dismissed this idea as a wearable because, "*It will look funny. If I am unwell, I will be glued to my chair and resting. If I walk around with a lit-up* *thing on me, people will stop and ask me what is going on"*. PLIS could be concept that follows a VR Analogies initiative at work to sensitize people to the presence of those with invisible conditions. It is important to note that these were product concepts were created from themes found in the informal disclosure strategies. However, interviewing participants and understanding their lived experience helped think about these ideas in a formal disclosure setting as well.

4.3 Summary of Phase 2

In this section, I discussed how the design concepts created from the findings of Phase 1 were used to understand the lived experience of my participants. I probed several dimensions of the design using storyboards and visual concepts that allowed people to share incidents from their own lives. Some of the dimensions included, volume of information being shared with others, audiences for disclosing and concealing, and circumstances under which the design could fail in their work life.

FilterFace and Reverse FilterFace explored the idea of using augmented reality to disclose or conceal invisible conditions from others. The concept of Make-Your-Own explored how people at work could be educated about the severity of flare-ups and the symptoms experienced by people with migraine or fibromyalgia. Using VR Analogies, people at work can be made to experience a sneak peek of how invisible conditions impact people they work with. And finally, the concept of a Pain Level Indicating System would help people share their pain with others without the need for a verbal or written explanation.

Chapter 5: Discussion

This study presents the disclosure dilemmas faced by employees with invisible conditions like migraine and fibromyalgia. Past work has examined health disclosure from the employer's perspective and the legalities that can create a conducive work environment for all the employees. Through this study, I described three factors that impact the workplace experience of people with invisible conditions; type of role, presence of other people with chronic conditions, and workplace support. Then, I examined the work done by employees to manage their condition in light of their work demands in three ways: a) by keeping their invisible condition concealed, b) through informal disclosure among people at work, and c) through formal disclosure that involves laws and official paperwork. By highlighting the different kinds of settings and strategies that individuals employ, the goal of this study is to introduce a design research opportunity in HCI for a population living and working with invisible conditions.

5.1 The Burden of Disclosure

The impact of disclosure of health conditions in the workplace has been studied in past work. In one study, researchers examined the context of health care workers living with HIV [19] and found participants in the study dealt with disclosure by "attributing reactions to ignorance", "seeking social support" or "leaving the job". In another study about mental health disclosure in male-dominated workplaces [18], researchers identified themes of disclosure barriers like, "risk of job or financial loss", and "limited managerial support".

The findings of this study revealed similar findings, such as that people who concealed their invisible condition at work were concerned that disclosure could lead to others questioning their ability to perform the task at hand. However, these past research studies have studied disclosure in the charged contexts – health care for people with HIV, or male dominated workplaces for people with mental health concerns.

In my study, these concerns existed across a range of workplaces. By studying individuals who worked in a variety of settings, I was able to identify some factors that may increase risks associated with disclosure, which I elaborate on in section 3.2.2.1. Concerns about disclosure also stem, in part, from a lack of understanding others have about invisible conditions. Some of the design concepts created in this study are intended to tackle this problem of no understand or misunderstanding.

Through “Migraine Talk” and “Make-Your-Own” people with invisible conditions can guide other employees towards a better understanding of migraine and fibromyalgia. Having such dialogues at work could potentially reduce the need to conceal and obfuscate the real deal from others in the workplace. While the concepts apply to different contexts, one thing remains common among almost all of the ideas, the onus of responsibility of educating others falls on the employee with invisible conditions.

In contrast, “VR Analogies” can do the work of educating individuals while placing the burden of education on the employer. “VR Analogies” have the potential to become a part of Diversity & Inclusion initiatives at work. In this kind of an initiative, where everyone in the organization is expected to get immersed in the experience of invisible conditions, people who feel the need to conceal their condition from others could continue to do so without having to own the responsibility of educating others.

5.2 Who Chooses Informal Disclosure?

While analyzing the data in Phase 1, the theme of workplace support in various countries was noted as a factor that impacts experiences with invisible conditions. My understanding was limited to the countries found in the data and what people had to say about the laws in those geographic locations. The interviews in Phase 2 extended my understanding by including the experience of individuals who did not always have the option to avail reasonable accommodations protected by law. In countries like India, invisible conditions are not covered under The Rights of Persons with Disabilities Act 2016 [42] – which is the only legal recourse one can take to protect their job and themselves from discrimination in the workplace.

Therefore, people with migraine or fibromyalgia work towards building a bureaucratic relationship to gain the trust of supervisors before choosing to informally disclose their condition in the workplace. When asked about this, P2 said, *"There is no possibility of a formal permission. It [migraine headache] can't be proved!"*. This innate need for proof supports the potential utility of focusing on a way to "show" others how an invisible condition can affect a person at work in these settings. It also highlights the major role that laws, and regulations play in the experience of people with disabilities such as invisible conditions at work, thought these rules and regulations have received little focus in HCI.

Informal disclosure was also supported as a supplemental form of recourse when formal disclosure could be obtained. Building a relationship with people at work to manage interdependence is an important dimension of this study. Leveraging these relationships to further educate coworkers and supervisors about the effects of invisible conditions through designs like “Make-Your-Own” can make workplaces more conducive to others in the future.

5.3 Rethinking Design Direction for Invisible Conditions

The design concept “VR Analogies” can be viewed as a disability simulator. Fields like education and rehabilitation psychology have been using disability simulators to improve the understanding of others regarding disability. However, it has been a topic of contention [41]. The idea has received a lot of pushback because it could potentially do the opposite of generating empathy. The ‘slipperiness of empathy’ is explored in a study [40], where authors found that empathy exercises were being used to supplant the experience of people with disabilities.

Subverting the experiences of people who were meant to be understood and uplifted [40] was cited as a strong reason not to model and build a design around empathy. In this study, I found that invisible condition simulators were something that people desired. The need for a tangible way of making the invisible entity visible was observed in Phase 2 when a participant said, *“I would insist that everybody in my organization go through a yearly training through VR to get at least get a mild sense of what I go through during a flare-up” (P1)*. These findings lead me to believe that invisible condition simulators do not supplant the experience of people with migraine or fibromyalgia.

Instead, they allow for a shared understanding of the pain and symptoms, thus leading to a better sense of interdependence at work. This may be because people with invisible conditions are experiencing precisely the opposite issue that many people with visible disabilities experience – where others focus on the physical aspects of the disability and imagine how difficult it is to live with a disability without even using a disability simulator [44]. In contrast, people with invisible conditions experience the opposite – in their workplaces, people do not register the existence or severity of what they are experiencing.

Examining the effects of simulations may result in people in the workplace "gaining experience" with invisible conditions. They could offer opportunities for mutual sensemaking and shared accountability, attributes considered worth working towards in research that argues against the use of disability simulators. [40]

5.4 Towards Social Justice in Designing for Invisible Conditions

Some individuals manage to hide the effects of their invisible chronic conditions and use phrases like *"suck it up and go to work"* when they are able to successfully manage their symptoms in private. When resources like a private office or remote working capabilities are made available to people to manage their invisible conditions, it is important to take note of the geographic location, and type of role and industry that they belong to. Reasonable accommodations are supposed to help people manage their chronic pain and consistently participate at work.

But despite being approved for reasonable accommodations, one Redditor shared their story of being denied a chair to sit because in their role as a door greeter at Walmart, the store manager would not let them remain seated while performing their duties. *<d20gns>* did not feel enabled to perform their job adequately because of the lack of understanding from their supervisor. Being able to sit at work could have meant fewer days off work because the strain of physical pain would not get in the way of their job: *"...i come home from work everyday and cry… i can't help but feel if my store manager would have just let me have a stupid chair i wouldn't be in this situation and my condition wouldn't have worsened over the last month."*.

This lament resulted in emotional reactions on Reddit where one commenter highlighted how refusing seating to a wheelchair user would have been considered discrimination, but due to the invisible nature of their condition, the store manager and the brand could get away with this kind of treatment. This form of discriminatory behavior forces us to think about strategies for social justice research and ways to shift attitudes regarding not only invisible conditions, but also the disparities in accommodations made for people. Conceptually, social justice in HCI research contends with the social impact of technology.

Researchers are starting to reflect on how conceptualizing health technologies that include different socioeconomic perspectives could address the digital divide among members of different cultural and socioeconomic communities [43]. Through the use of technology as an intervention to foster cooperative behaviors at work, I believe that the design concepts created for the purpose of this study can be extended to apply for various user populations.

Appendices

Appendix A: Recruitment Text on Social Media

Title: We want to hear about your experience with migraine or fibromyalgia conditions.

Hi, I am Kausalya Ganesh, a researcher at the University of Maryland, College Park. My team is conducting interviews to understand how migraine or fibromyalgia affects the professional life of people. Your experience can help inform the design of new technologies to support people with these chronic pain conditions. Interviews will be audio-recorded and can last up to an hour. If you are interested in participating in this research, are 18 years or older, and experiencing symptoms of migraine or fibromyalgia, please contact us at kausalya@umd.edu or lazar@umd.edu.

Appendix B: Screening Questionnaire

Thank you for your interest in participating in this study. We have several questions to ensure that you meet recruitment criteria.

	Age 18 and over	**Under age 18**
1. What is your age?	_____	_____ **->** If under 18, individual does not qualify for the study

2. Are you currently experiencing any symptoms of migraine or fibromyalgia? Can you describe some of them?

	Yes	**No**
	_____	_____ -> If no, does not qualify for this study

Appendix C: Interview Protocol

Introduction

Thank you for agreeing to participate in this study. [Intro self if haven't already]. I am interested in learning about your workplace setting and how technology can aid in the concealment or disclosure of your chronic health condition in the workplace.

First, can you tell us about your health history and how you use technology to support it?

- Current age, onset of chronic pain
- Symptoms experienced at work
  - Describe a recent incident that comes to mind
  - What measures did you take to manage the pain?
  - Who do you communicate with about your condition?
- What technology platforms do you use to educate yourself about your condition(s)?

Can you tell us a little bit about your migraine/fibromyalgia symptoms?

- How long have you been experiencing/did you experience symptoms?
- How do your symptoms affect your daily life?
- How do these symptoms affect your work life in particular?

I'd like to hear how you feel your healthcare related to your pain symptoms is going.

- What kinds of support do you feel like are lacking in terms of managing your own health or communicating with your providers about your condition?
- How does your provider support your needs for the work environment in terms of providing adequate documentation?

Can you tell us a little bit about your work environment?

- How long have you been working at this company?
- If compared to your previous employment, how would you describe the work culture here?
- Are you able to take regular breaks to avoid experiencing symptoms at work?
- How many people at work have been made aware of your condition(s)?
- How does your company deal with absenteeism? (e.g. employee missing due to health issues)
  - Is remote work or work from home offered as an option?

    - Are employees able to take paid time-off to recover without negative consequences?

I'd like to hear about if and how technology has been useful for you so far.

- What platforms do you access to get more information about your condition? [e.g. blogs, social media]
    - What do you do with that information? [e.g. bookmark, share]
    - Do you have a support system online?
- What are some examples of suggestions/ideas you got from the platforms that you implemented at your workplace?
    - Did your coworkers support you in this decision?
    - Describe how your employer reacted to this incident.
    - Did you go back to X platform and describe your experience of the suggestion?

I'd like to share some prototypes that were conceptualized based on the research done in the first phase of this study.

- Design 1: Personalized pain-level indicator
    - How do you feel about this prototype?
    - What are some circumstances under which this form of technology could be useful to you?
    - What would you change or add to this prototype?
- Design 2-4: Personalized symptom indicator/concealer
    - How do you feel about this prototype?
    - What are some circumstances under which this form of technology could be useful to you?
    - What would you change or add to this prototype?
- Design 5: VR Analogy to explain symptoms
    - How do you feel about this prototype?
    - What are some circumstances under which this form of technology could be useful to you?
    - What would you change or add to this prototype?

Is there anything else that you think is important for us to know or ask other participants?

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