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INVISIBLE PAIN: LOOKING AT WOMEN'S FIBROMYALGIA DISCLOSURE IN THE  
WORKPLACE THROUGH THE LENS OF COMMUNICATION  
PRIVACY MANAGEMENT THEORY

Robert D. Hall

62 Pages

According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (2014), fibromyalgia is identified as an arthritis-related ailment, but it does not damage tissues or cause any form of inflammation. However, individuals with fibromyalgia still experience pain and fatigue. Based on Arnold et al.'s (2008) conclusion that individuals with fibromyalgia experience disrupted relationships, isolation, and loss of or lack of advancement in an occupation, and because women are diagnosed with fibromyalgia more frequently than men, my focus in the study was on the workplace experiences of women with fibromyalgia. Specifically, I was interested in uncovering how these women managed private information about their illness at work, experienced changes in their own and others' behaviors at work, and perceived being stigmatized by others at work due to their illness. I used Communication Privacy Management (CPM) theory as the guiding framework. I conducted nine in-depth interviews with women afflicted with fibromyalgia who also work. Various themes arose from the interviews related to disclosure, behavioral changes, and stigma. I identify various implications for the study and address limitations and areas for future research.

KEYWORDS: fibromyalgia, communication privacy management theory, invisible illness,  
disclosure

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WORKPLACE THROUGH THE LENS OF COMMUNICATION  
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ROBERT D. HALL

A Thesis Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of

MASTER OF ARTS

School of Communication

ILLINOIS STATE UNIVERSITY

2017

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## CHAPTER I: INTRODUCTION

According to the Center for Disease Control (CDC), approximately 117 million people reported having one or more chronic health issues in 2012. The Center for Managing Chronic Disease at the University of Michigan (n.d.) describes a chronic health issue as one that is long-term and controllable, but not curable. The U.S. Department of Labor (2015) states that under the Americans with Disabilities Act (ADA), individuals with chronic illness are protected from discrimination within the workplace. In addition, those needing certain amenities for their workplace environment can receive those accommodations. These include, but are not limited to, a fair schedule, breaks, flexibility, and sick leave. These individuals are to receive these at the cost of the company, not at their own detriment. Despite the legal protection, the U.S. Census Bureau (2014) reports that only 34.4% of individuals with chronic illnesses are employed.

Some chronic diseases can be invisible, that is, not apparently detected by others (Horan et al., 2009). Kundrat and Nussbaum (2003) describe invisible illnesses as “disabilities not readily apparent” and caused by “neuromuscular disease, mental conditions, and cognitive problems” (p. 332). These characteristics are consistent with fibromyalgia, Berne (2001) notes that “fibromyalgia is chronic and has no visible symptoms” (p. 26).

Lawrence et al. (2008) found that five million Americans suffer from fibromyalgia, and most are women. According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (2014), fibromyalgia is an arthritis-related ailment, but “it does not cause inflammation or damage to tissues.” However, fibromyalgia does cause significant pain throughout the body, fatigue, and occasional memory loss. According to the National Health Service of England (2016), medical professionals do not yet know the cause of fibromyalgia. They report that researchers believe that it may be caused by a developmental change in the central nervous

system, chemical imbalances, sleep issues, genetics, or traumatic events. In addition, there is no cure, only management of the symptoms of the disorder.

Martín et al. (2014) report that treatment for the management of fibromyalgia is “particularly difficult” because it has a “complex and unknown etiology [cause], wide range of symptoms and signs, and multiple comorbidities” or the presence of two chronic disease or conditions in a patient (p. 722). The authors mention that the illness affects daily relationships because of its long-term, crippling effects. Arnold et al. (2008) reinforce this in their study citing fibromyalgia as a cause for individuals experiencing disrupted relationships, isolation, and loss of or lack of advancement in an occupation. This shows that fibromyalgia impacts individuals both personally and occupationally. In regards to the pain management literature, most sources discuss doctor-patient relationships, emotional pain, and improving posture (Duggan, Bradshaw, and Altman, 2010; King, 1991; Roman & Samar, 2015; Russell, 1997; Zufferey and Schulz, 2010), but little to no literature on pain management in the workplace.

Fibromyalgia, like other invisible illnesses, differs from a visible illness because others do not know of the illness until the person discloses it (Horan et al., 2009, p. 67). Individuals with fibromyalgia should feel protected from discrimination in the work environment when disclosing their illness due to the protections from the ADA. There are legal protections for these individuals in the workplace, but it is likely that these individuals still experience discriminating behaviors in the work environment, leading to a lack of disclosure.

Therefore, the present study looks at the research on stigmatization and disclosure to explain why people with invisible illnesses like fibromyalgia may not reveal their illnesses to their employers and coworkers. I then discuss communication privacy management theory as the guiding theoretical framework for this study, as it helps explain how and why people with

fibromyalgia manage their private information at work. Then I discuss stigma as it relates to invisible illnesses and fibromyalgia. After this section, I provide an overview of the participants and methodology of the study followed by the reported findings. Finally, I offer discussion, implications, and future research regarding the results of the study.

## CHAPTER II: REVIEW OF LITERATURE

### **Invisible Illness and Disclosure Concerns**

Individuals with a visible illness often do not choose to reveal their illness to others, as signs of their illness are typically apparent to others. For instance, as Goffman (1963) argued, stammering is a very visible illness because any vocal interaction with the individual results in an unintentional disclosure of the ailment. Diabetes, as he argues, is also an illness unintentionally disclosed when people use insulin pumps or give injections in front of others. This disclosure, although unintentional, makes the illness visible. Goffman argues that visible illnesses “have no initial effect on the individual’s qualifications for face-to-face interaction; they lead us first to discriminate in such matters as job allocation, and affect...social interaction [only if] the stigmatized individual kept [the ailment] secret” (p. 50). Braithwaite (1991) argued that individuals with a visible disability are expected by others to somehow reveal information regarding their disability early in a relationship.

However, individuals with fibromyalgia do not experience visible symptoms (Berne, 2001). Others only know about the illness if and when the individual discloses it to them. There are many reasons why someone with a chronic invisible illness like fibromyalgia would not disclose their illness. Individuals who have a chronic disease face stigma in terms of physicality, psychological capacity, and social interactions (Cardillo, 2010). First, individuals with chronic illness often feel devalued because of the communication they experience regarding their physical state. They feel inferior due to this physical stigma of having a chronic illness. They also feel silenced. These individuals face a psychological stigma in that they must deal with the ways in which members of society view chronic illness. Individuals afflicted with chronic illness “actively confront and challenge negative and discriminatory cultural attitudes toward [their]

treatment” as individuals with the illness (Cardillo, 2010, p. 536). Individuals with chronic illness must continually combat discrimination in their interactions with others about the illness.

Women, in particular, may suffer at work after disclosing their illness. Wrigley (2002) described the glass ceiling as ideas or attitudes that prevent individuals from advancement within an organization. The idea of the glass ceiling applies most frequently to women. Buzzanell (1995) explained that women in the workplace experience many tensions; for example, “women are given more routine tasks, paid less, promoted more slowly and/or into less challenging roles, and are punished for not demonstrating loyalty by working long hours (and punished if they do)” (p. 331). It is important to understand this dynamic of the workplace because most of the individuals with fibromyalgia are women. These individuals may then experience the glass ceiling effect more strongly after they disclose their (invisible) fibromyalgia illness, particularly in light of Arnold et al.’s (2008) findings that individuals with fibromyalgia struggle with job advancement.

Because of the concerns women with fibromyalgia may have disclosing their illness at work, and the possible outcomes of disclosing their affliction, communication privacy management theory provided a useful lens through which to study female employees with fibromyalgia.

### **Communication Privacy Management (CPM) Theory**

CPM is the guiding theoretical perspective for this research. Before I discuss the theory, I will explore the differences among privacy, secrets, and avoidance. Afifi, Caughlin, and Afifi (2011) state that “privacy involves information that others have no right to know” (p. 63). They describe that secrecy is a type of private information, but it adds a level of concealment to those who may have a right to know the private information. Topic avoidance occurs when individuals

refuse to discuss various topics, going as far as actively avoiding a topic if brought up. The topic of fibromyalgia comprises various degrees of privacy, secrets, and avoidance. If the information has no effect on the organization, it would remain private and unshared. If the disorder is affecting the afflicted individual's ability to perform at work, should the organization have a right to know this information? If the organization has a right to know the information, but the individual does not reveal it, the information would be a secret. The issue of topic avoidance becomes an interesting area of research in regards to fibromyalgia. As previously mentioned, fibromyalgia can lead to relational dissolution, isolation, and workplace issues (Arnold et al., 2008). However, it is unclear whether the disorder itself causes these problems, or whether the disclosure of the disorder is where problems begin to occur. CPM may be able to explain further the role that disclosure plays in this issue.

### **Five Suppositions of CPM**

Petronio (2002) describes the five suppositions of the theory which are (1) private information, (2) privacy boundaries, (3) control and ownership, (4) rule-based management system, and (5) privacy management dialectics.

Petronio (2002) discusses private information in supposition one. She argues that “making private information the content of disclosure allows us to explore the way privacy and intimacy are separate but related fundamentally to the act of disclosure” (p. 5). Because self-disclosure is related to intimacy, intimacy is often a goal of disclosing private information. However, in the workplace environment, intimacy may not be a goal for disclosing private information such as a fibromyalgia diagnosis. Petronio acknowledges that private information disclosure may lead to burden relief or self-expression.

In supposition two, privacy boundaries, Petronio (2002) discusses the role of privacy boundaries in private information disclosure. She defines privacy as “the feeling that one has the right to own private information, either personally or collectively; consequently, boundaries mark ownership lines for individuals” (p. 6). Petronio explains personal boundaries as information managed by oneself. Collectively-held boundaries refer to information that more than the individual, such as two individuals, a family, or society, has. Once an individual decides to share private information with another individual, the two individuals are part of a collective boundary. Boundaries are central to the focus of the present study on fibromyalgia. Because fibromyalgia is personal, it is important to understand why individuals may or may not make this personal information collective.

Regarding supposition three (control and ownership), Petronio (2002) discusses that private information is something that individuals perceive as owning. Because of this, individuals may choose to reveal or conceal private information. Petronio also admits that because there is a risk of disclosing information, individuals want control over their information. Because of these tenets, Petronio posits three levels of control that exist upon a continuum of thick boundaries to transparent boundaries: high control (secrets), moderate control, and low control (openness). Because individuals afflicted with fibromyalgia experience stigma (Arnold et al., 2008), they may be likely to exercise high control of this information. This high control leads to boundaries that are impermeable and thick. Individuals with this level of control are incredibly selective when determining who knows the private information, if anyone other than the self.

Supposition four reflects the rule-based management system of privacy management. In recalling the personal and collective levels of disclosure, it is imperative to understand how information is regulated among these levels. Personal-level control reflects information that we



individually own, while collective-level control involves co-ownership of the information (Petronio, 2002). Despite one's willingness to manage information appropriately, once the disclosure is made to another individual, this recipient of the information now has the responsibility to manage this information appropriately. Additionally, there is an expected protectiveness that comes with co-owning information that encapsulates boundary coordination. Because both individuals are now co-owners of the information, they regulate the further management of the information.

CPM relies on the assumption that an individual owns their private information (Petronio, 2002). When private information is disclosed, the individuals involved with the disclosure become co-owners of the information, and boundaries are created to ensure the information is negotiated among the parties involved. Venetis et al. (2012) examined how privacy rules are constructed within the context of health disclosures. They found that individuals disclosing health-related topics expect the listener not to disclose this information to another person; because of this implicit expectation, they rarely create explicit boundaries around the private information. The authors discussed the reasoning for these implicit boundaries as it "may be neither entertaining...nor the type of material that allows for relational development with others" (p. 360), meaning that people do not get relational benefits by disclosing someone else's health information to others. This holds true in the interpersonal context of the study. However, it is unknown whether the same holds true within organizations.

The fifth and final supposition reflects privacy management dialectics. Petronio (2002) asserts that there are various degrees of dialectics at play within the conversation and regulation of private information management: "The basic thesis of the theory is grounded in the unity of dialectics including disclosure-privacy, concealing-revealing, public-private, openness-

closedness, and autonomy-connectedness” (p. 12). With little medical understanding of fibromyalgia, an interesting dynamic may occur once this information is disclosed. Petronio (2010) notes that individuals may experience a need to disclose information they receive from another individual. Due to high uncertainty about the illness, the disclosed information may be too much for recipients to handle, and it could cast a negative light on the afflicted individual. This notion demonstrates a dialectical tension presented above of autonomy-connectedness. The individual is experiencing the tension of whether to relieve the stress of trying to maintain this private information or seek social support by disclosing the private information to another individual.

### **Privacy Rule Management Process**

Now that the suppositions of CPM theory have been considered, I will discuss the privacy rule management process. This process is important to consider when discussing CPM because “people use rules to regulate the degree of access to or protection of their private information” (Petronio, 2002, p. 23). The three privacy rule management processes are: “(a) foundations of rules ranging from the way they are developed to the elements that make up their attributes, (b) their boundary coordination, and finally (c) their turbulent nature” (p. 23).

In the first privacy rule management process, Petronio discusses the development and attributes of rules. When people construct rule management, she says they use the criteria of cultural expectations, gender, motivation, context of the situation, and risk-benefit ratio to create privacy rules. Related to the gender criterion, according to Petronio (2002), the literature supports that women disclose more to other women and same-sex partners than to male partners, and males, vice-versa. Additionally, men will disclose information that is perceived masculine while women disclose information that is perceived feminine (Petronio, Martin, & Littlefield,

1984). That is, women will disclose to be accepted, respected, warm, and open. Also, a man will likely disclose more information to a partner than a woman if future interaction is likely. Because women are more likely to have fibromyalgia and experience detriments at work (Buzzanell, 1995; Wrigley, 2002), they may not disclose such private information to workplace acquaintanceships.

The next process of information management is boundary coordination operations. Petronio (2002) notes an important tenet of this process “We become co-owners in many ways” such as when “we are drawn into a boundary when we are privy to information about a third party, when there is a mutual or reciprocal disclosure, and when we learn private information by accident” (p. 28). When individuals become co-owners of information, boundary coordination is regulated through boundary linkage, ownership rights, and permeability. First, boundary linkage occurs from boundary coordination. When one hears private information, no matter the setting, they become “linked” with that individual due to the knowledge of the disclosure. This can be based on attraction, status, gender, relationship, personality, and attachment style. Petronio mentions that boundary ownership dictates the levels of responsibility such that individuals may further disclose the co-owned information. There are dimensions to boundary co-ownership in determining the rights and privileges to the private information. These include mutually drawn boundary lines, fluidity of the boundary lines to meet the needs of privacy, and cohesion between the co-owners of the private information. If these dimensions are violated or not negotiated, it can lead to negativity within the relationship of the co-owners.

Additionally, boundary permeability is what Petronio (2002) highlights as “varying degrees of revealing and concealing” information (p. 31). Boundary permeability exists on a continuum ranging from open access to closed access boundaries. Open access information is

considered fully revealed when all rules are met and the boundaries are open. Petronio does note that secrets can still occur when co-owners follow all privacy rules. An example Petronio provides of this secret-keeping is hiding a health concern from others.

Finally, Petronio (2002) describes boundary turbulence as “clashes over expectations about privacy management” (p. 33). Examples she provides include intentional rule violations, boundary rule mistakes, fuzzy boundaries, dissimilar boundary orientations, boundary definition predicaments, and privacy dilemmas. When these occur, there are usually self-correcting actions in which the co-owners recreate or add new rules to the boundaries to negate and manage the turbulence properly. This leaves room for control of the information between the co-owners.

Petronio’s (2002) model of CPM theory as a self-correcting system illustrates how the process flows. In the beginning, boundaries of private information are coordinated through definitions of linkages, ownership, and permeability. As time goes on, boundary turbulence occurs. After the turbulence occurred, a recreation of boundary coordination ensues. The cyclical and self-correcting cycle represents the process of CPM theoretical constructs.

Petronio (2010) acknowledges a gap in the research in which “other kinds of conditions [may] lead to violations, miscalculations, and missteps” in privacy breakdowns (p. 178). The disclosure and management of invisible illness, particularly fibromyalgia, may be one of the instances in which privacy rules need to be more explicit. Individuals with fibromyalgia may not disclose to save face in an organization and avoid the effects of stigma (Arnold et al., 2008). Based upon the discussion of avoidance and privacy management, the following questions are posed to discover how individuals with fibromyalgia manage this information.

RQ1a: How do women with fibromyalgia decide whether and how to disclose information about their illness within the organization?

RQ1b: For women who disclose their illness at work, what is their process of boundary coordination with the targets of their disclosure?

### **Stigma, Stigmatized Health Issues, and CPM**

Stigma likely plays a role in decisions about disclosure and boundary coordination among women with fibromyalgia. Goffman (1963) states that stigma was initially used to describe an individual marked by a burn or cut because of moral corruption. Such examples included criminals, pirates, and enemies. The term then evolved into three types: physical (associated with death, garbage, etc.), social (associated with contact within marginalized groups), and moral (associated with sin or dubious activities) (Ashforth & Kreiner, 1999). Stigma is an undesired trait that separates a person from societal acceptance. Today, stigmatization often occurs without a physical sign. In regards to stigma within organizations, those with nonvisible stigma need support or they are likely to leave the job due to stressors because this occupational stigma is directly related to turnover rates (Ashforth & Kreiner, 1999).

Goffman (1963) appointed disclosure as an effective strategy for stigma management. Applying this, Thompson (1982) found that disclosing about a disability leads to an increase in comfort level within the organization. In addition, Mesenbach (2010) describes that “stigma disclosure can improve an able-bodied individual’s acceptance of a disabled individual, lessening tension and uncertainty” (p. 273). Because fibromyalgia is an invisible chronic illness (Berne, 2001), affected individuals experience stigma-related behaviors (Arnold et al., 2008), and disclosure is effective in alleviating stigma, it is important that stigma be reduced for individuals with fibromyalgia to help them have equal opportunity in the workplace.

Because of stigma associated with the illness, women may adjust their behaviors to maintain their success and positive image at work. In addition, others may change the way they

behave and interact with the women due to the stigma of the illness. To uncover whether these changes occur, I posed the following two research questions:

RQ2a: How, if at all, do women afflicted with fibromyalgia change their own behaviors within the workplace?

RQ2b: What positive or negative changes in behaviors, if any, do women afflicted with fibromyalgia perceive in the workplace as a result of disclosing their illness?

CPM is often utilized in studies of health communication within interpersonal relationships. Of all illnesses and disorders, human immunodeficiency virus (HIV) tends to emerge in previous studies as one of the most stigmatized illnesses, and subsequently is one about which people struggle in terms of managing disclosures with others. Smith and Niedermeyer (2009) investigated HIV in Namibia, Africa, and wanted to examine how families with an infected individual manage the disclosure of such information because HIV carries a heavy stigma in Africa. Many times, the families refuse health care because other non-family members would see the health care worker in their house. The individual would indirectly disclose that the family had a member with HIV, and thus seclude them from the community. The stigma surrounding HIV-AIDS influences not only the individual's disclosure in this case, but that of the family and community as well. Horan et al. (2009) looked at disclosures of those with HIV and cancer, as well as by healthy individuals, to determine how relationships develop or collapse after the disclosure of an invisible illness. The researchers found that those with HIV have less communication with those with whom they had prior relationships after the disclosure, suggesting a stigma. However, those with cancer did not face the same issues. The researchers compared a non-self-generated stigma to a self-generated stigma. Cancer is perceived as non-self-generated as it is not necessarily caused by risky behaviors. However, people see HIV as

self-generated because it can be caused by risky behaviors. The researchers consider all chronic illnesses to fall into these two categories. The scholars suggest that participants may frame HIV as self-inflicted through sexual encounters and drug use and cancer as not self-inflicted, leading to this distinction. Although fibromyalgia is not self-inflicted, the Martín et al. (2014) and Arnold et al. (2008) articles frame fibromyalgia similarly to HIV in the Horan et al. (2009) study. To understand the stigmatization of those with fibromyalgia, the following research questions is presented:

RQ3: What role, if any, does perceived stigma play in women's decisions about privacy management regarding fibromyalgia?

## CHAPTER III: METHODS

### Participants

To understand the experiences that women afflicted with fibromyalgia face, I conducted nine in-depth interviews. Saturation of information and themes typically develop after eight interviews (McCracken, 1988), but I conducted an additional interview to ensure that no new information emerged. Participants were between the ages of 28 and 69 ( $M = 52.55$ ,  $SD = 14.71$ ) were diagnosed with fibromyalgia, and had work experience occurring simultaneously with the affliction of fibromyalgia. The participants were all white females, and the majority worked in academia ( $n = 7$ ); one worked in a human resources position, and one worked in the medical field.

Participants varied in their age of the initial diagnosis of fibromyalgia. Most participants received their diagnosis during their late thirties to middle forties ( $n = 6$ ). Two participants received their diagnosis at age 26, and one received her diagnosis at age 51. All participants mentioned that they believe they had the illness much longer than the age at which they received the medical diagnosis. All participants explained that it took years and several doctors (ranging from 5 to 17) to receive official diagnoses. Additionally, all participants disclosed that they have some type of chronic (e.g., irritable bowel syndrome) or mental (e.g., depression or anxiety) illness in addition to their diagnosis of fibromyalgia. None of the participants viewed their fibromyalgia diagnosis as a disability.

Treatment and management for the diagnosis varied among the participants as well. Three participants reported actively taking some form of medication. Most participants ( $n = 5$ ) mentioned some sort of therapy (e.g., physical therapy, water therapy, massage therapy) as



management for their fibromyalgia. Other management techniques included rest, nutrition, and avoiding caffeine, nicotine, and alcohol.

### **Procedures**

Prior to conducting the interviews, I obtained approval from the Institutional Review Board. Then I used criterion sampling (Lindlof & Taylor, 2011) to ensure that the individuals interviewed were female, diagnosed with fibromyalgia, and worked in an organization during the time they were diagnosed with fibromyalgia. Nonrandom participant recruitment occurred through posts on an online university research board, Facebook, and the National Communication Association listserv (see Appendices A through C for recruitment materials). The participants contacted me expressing interest in participating in the study.

I conducted all nine in-depth respondent interviews via telephone. Prior to the interviews, I emailed the participants the informed consent document. To express consent, the participants responded to my email with the following message: “I agree to participate in this study and have my responses audio recorded for transcription.” I also recorded their verbal consent in the audio recording of the interviews. I conducted all nine in-depth interviews using a semi-structured, informed interview guide using CPM as the guiding theory (Lindlof & Taylor, 2011). This interview guide allowed for questions to be shuffled, modified, and improvised to create the best interview fit for each individual. This interview protocol can be found in Appendix D. The average interview length was 40 minutes. Participants did not receive compensation for their involvement. I transcribed each interview, which resulted in 91 pages of double-spaced transcripts. I assigned each participant a pseudonym in the transcripts to maintain participant confidentiality.

## Data Analysis

To analyze interview data, I used Braun and Clarke's (2006) process of thematic analysis. Braun and Clarke offer six phases of analysis for data: 1) familiarizing with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. I will explain how I included each phase in my analysis.

To familiarize myself with the data, I listened to interviews as I transcribed them. After I completed transcription, I read each transcript while listening to the audio tape to ensure accuracy of verbatim transcriptions. Through these methods, I familiarized myself with my data.

Next, I read the transcriptions to identify codes that appeared interesting to me as the analyst (Braun & Clarke, 2008). I found various examples of the participants' experiences that felt poignant and important to the participants. The participants' experiences in the form of codes are reflected within each theme.

Then I searched for themes based on my research questions. Using CPM theory as the sensitizing framework (Bowen, 2006) for RQ1a and RQ1b, I read the transcripts looking for themes representing participants' disclosure of their private information regarding fibromyalgia. I then read the transcriptions to identify experiences related to boundary coordination. To identify responses related to RQ2a, I paid attention to any themes reflecting participants' own changes in behaviors. For RQ2b, I analyzed the transcripts for the codes that highlighted the behaviors from others. Finally, I read the transcripts to find themes related to stigma to answer RQ3.

In the fourth step (reviewing themes), I looked for how the subthemes worked with one another. In RQ1a & RQ1b, I found disclosure themes stemming from CPM in terms of

disclosure criteria: gender, motivation, context, and risk-benefit ratio. For RQ2a & RQ2b, behavioral themes differentiated enough to split into three subthemes: self-monitoring behaviors, supportive others, and unsupportive others. In RQ3, I examined issues related to participants' perceptions of their illness as stigmatized.

In the next step, I named the themes in terms of the essence of the experiences they represented. CPM theory and its criterion for disclosure created the theme of disclosure. The overarching theme of behavioral changes entailed subthemes that describe the various changes and emotional reactions that the participants experienced. Finally, various characteristics of stigma embodied the final theme.

The final step is producing the report, which occurs in the results section of this thesis. The themes have vivid examples that encapsulate participants' experiences. Additionally, each theme has a brief introduction and summary to properly introduce the reader to each section and transition into the next theme.

## CHAPTER IV: RESULTS

Through the analysis, three theme emerged. The organization of the results section reflects the three RQs and the corresponding major themes: privacy rule management process, behavioral changes, and the role of stigma in privacy management. The results for each research question build upon one another to create a whole picture of the participants' experiences. I included participant responses that illustrated their experiences.

### **Management of Private Information**

To answer the first research question, I explored participants' management of private information about their illnesses. In the following section, I describe criteria that guided privacy rule development, how the women coordinated boundaries, and how the participants experienced boundary turbulence.

### **Privacy Rule Development**

Participants' decisions about sharing information about their illness reflected four of Petronio's (2002) criteria for privacy rule development: gender, context, motivation, and risk-benefit assessment.

**Gender criterion.** Each participant discussed their gender as a criterion for choosing whether to disclose their private information. Most of the women in the study expressed concerns over discussing their diagnosis with a male colleague, particularly if he was a superior at work. As Jenna, a forty-eight-year old administrative assistant and fitness instructor, described that "even though I've been at my university for 17 years, and I'm a well-established employee with an excellent education, meeting a new boss and having this conversation is very unsettling because you don't know how they're going to react" (6: 130-132— *note: numbers after quotations reflect interview number and transcript line numbers*). Except for one participant

whose boss had a wife with fibromyalgia and was very understanding of her illness, most women described unsupportive male superiors, including Diana, a fifty-one-year old human resources manager, whose boss terminated her when she asked for accommodations. Eliza, a thirty-seven-year old instructional designer, also provided insight into her negative experience of two male superiors treating her poorly because of her diagnosis:

About a year and a half ago, we moved buildings, and instead of being on the ground floor, I had to get up 18 floors with old elevators. I could not stand long enough to get up all the floors via the elevator. I began to look into accommodations, and my direct supervisor and director of where I worked were not open to accommodations. They were somewhat aggressive and hostile about it. I did have to go to HR, and I went through about 4-5 months of seeing doctors and specialists to try to get medical documentation to say that my symptoms had become worse, and this was their recommendation for accommodations. During that time, I felt harassed because it was an everyday occurrence asking me if I had the documentation yet. They were coming to my office and saying, “Maybe you need to exercise more” or “Maybe you need to lose weight, have you tried disability?” Things like that. It was very judgmental to be honest. (4: 174-183)

After she received accommodations including FMLA (Family Medical Leave Act) days, flexible hours for doctor’s appointments, and the ability to work from home some days, Eliza explained:

The department agreed to it, but they’ve been very passive aggressive about it...It’s gotten to the point where they wrote me up for job negligence, which came from when I had two laptops fail, and the system that we use was down for four days. Everyone was behind in their work, but they wrote me up for it, but not anyone else, despite keeping my direct supervisor in the loop. (4: 194-195; 199-205)

It appears that the lack of support came from the boss's judgment and later, his refusal to welcome the accommodations she received. Overall, these negative examples support women's fears that male supervisors would react negatively to their private information.

Further related to gender issues, many participants explained that they would not want to tell a male colleague of their illness because of the perception of being a "weak woman." As stated earlier, fibromyalgia affects mostly women (Lawrence et al., 2008). Because of this fact, the women in the study found that others perceive this disease to enhance the stereotype of the "weak woman." Fiona, a twenty-eight-year old student and instructor, encapsulated a common experience of the participants as she explained:

Weak woman, that's all it's about. I talked about how I'm always proving myself, especially with male faculty and male supervisors. I probably don't tell them as often because I feel like as soon as they know that, it could be used against me even though it can't be used against me according to education rules or whatever. That doesn't mean that unconsciously or unintentionally, it wouldn't be anyway. I want to have the same opportunities, but they may see me as not as capable. There's a lot of misinformation 'bout fibro, and I think that it can definitely harm, especially for women because we are already perceived as the weaker sex. If I'm already an emotional, oh God that narrative, and now you know that I have fibro, they may not ask because now she's weak. It's funny, now that I think of that, there's a lot of male faculty that I would never tell that to.

(5: 263-282)

Many participants echoed Fiona's explanation that others perceive them as feminine and weak for having this illness. This perceived opinion led to decisions to withhold private information.

In addition to their own experiences as women impacting their disclosure, participants often discussed their views of men with fibromyalgia and acknowledged struggles men go through when deciding whether to share information about their illnesses. For instance, Jenna said:

Oh gosh, I feel sorry for the men that have fibromyalgia because they're not supposed to ever complain. You're supposed to often suck it up. As a female, I feel enough of that pressure, and I'm really good at sucking it up. I've talked with a few men who have fibro, and I honestly don't know how they do it. I can't imagine the emotional pressure that they are under. (6: 162-165)

This example shows that the participants were aware that men may also experience various degrees of isolation and job loss because of the feminine nature of fibromyalgia.

As fibromyalgia appears to enhance the idea that femininity translates to weakness and undesirability in the workplace, participants are less likely to disclose such an illness in the workplace. It is important to note the amount of strength and perseverance each participant felt that they had to bring to work each day. As reflected in earlier examples of pain and fatigue, there are many symptoms to overcome and in addition, they experience degradation in terms of undesirability and weakness.

**Context criterion.** The workplace as a context was pivotal when deciding whether to disclose. Many participants distinguished between supportive and unsupportive workplace environments, as reflected earlier in the results. Whether the context of the workplace was supportive impacted their decisions about sharing information about their illness. When asked about advice they would give others about disclosing their illness, identifying the type of workplace environment emerged as one of the most important factors to take into consideration.

Even participants who disclosed openly noted that others may not be as fortunate if they have to disclose in an unsupportive environment. Eliza explained:

I don't feel like I can give advice on when to disclose it because it is very personal depending on personality type and type of job they're in. Whether you made your supervisor aware of it or not depends on your situation. (4: 317-321)

She directly expressed the need to view the various aspects of the whole context prior to disclosure. Additionally, Diana added:

I think my advice would be to make sure that they go in, prove themselves to be good, reliable workers, good producers. Then, once that is established, if they trust the people they work with, then it's fine to disclose. I wouldn't disclose it early because, again, I think it taints the ability to objectively view someone else's work. (7: 168-171)

Diana's perspective combats the gender context of the perception of the "weak woman." She advises to go into the context (i.e., the organization) and prove how much that the individual can make a difference prior to disclosure to a trusted colleague.

Beyond whether the workplace is supportive or not, participants also discussed the job interview as an important context in which to assess whether to disclose. Diana and Eliza shared perspectives regarding the interview. Diana said:

I would never do it [share information about fibromyalgia] in an interview ever. I truly believe that would put me in the bottom of the pile in a candidate process. Once you're hired, again my concern is that people, I don't know if it's discrimination, but they can relate everything back to the fact that she said she has fibromyalgia, and it's because of that. I don't want to be judged or graded or my expectations to be outlined by the illness. I want everything to be based off of what I do, not what I have. (7: 137-141)



Eliza also explained her experiences:

I thought that was a big hindrance as far as me being competitive in the job market. It also caused a problem because I wasn't sure when to disclose it. Do you disclose it in your application, interview, or afterward? It's like if you tell them after you get a job offer, then it almost felt like you lied to them about your limitations. They may discriminate even though they're not supposed to. (4: 139-143)

As reflected in these examples, women with fibromyalgia struggle deciding whether to disclose the information in various hiring contexts. These women feel that they may be discriminated against despite legal protection from the ADA. However, they feel that they should eventually disclose because they want to seek accommodations to assist with limitations. The tension between disclosure and nondisclosure in the various contexts became apparent in participants' responses.

**Motivation criterion.** Participants reported various motivations that impacted their decisions whether to disclose their illnesses at work. For instance, some participants disclosed for accommodation purposes. However, the most prevalent motivation for deciding whether to disclose was education. Participants seemed to experience the tension between disclosing for the purposes of educating others and not disclosing due to others' lack of education.

Some participants mentioned that they chose to disclose their diagnosis openly at work to enhance the education of others. Jenna gives an overview of why:

I am a big advocate for educating people that this is out there, and it's very real. For most people, I think it's manageable, but this is what's going on. It would be great if people could just remember that this isn't my choice, and I am very open about it because when I was diagnosed nobody talked about it. That's not serving the community at all. If nobody

talks about it, it will never be understood. I tend to be a little more up front. I do a lot of videos, and I am passionate about showing that fibromyalgia is not the end to a healthy and active lifestyle. (6: 146-152)

In addition, Fiona also decided to disclose to educate:

I talked about the pain and what was going on a lot more [after I received my diagnosis]. Beforehand, if I complained about my pain, there was no explanation or label on it. I didn't feel like I could actually complain about it. So now, I feel like I can actually talk about it and tell people what's going on. Even if they can't understand and empathize, they can still say, "Oh, okay, I've heard of that" or "What is that again?" You know what I mean? It opens a dialogue. It's my own little pet project to educate people. (5: 152-157)

Some participants firmly believe that open disclosure creates a healthy dialogue about the illness. It allows others to see successful women managing the illness daily.

The lack of education also motivated some participants not to disclose. Betty, a sixty-seven-year old retired academic clinical psychologist, gave her statement that reflects the general acknowledgement regarding invisible illness:

I dealt with the discrimination that you deal with when you have a visible disability, and I didn't want to feel that by admitting to other issues because already, if you have a visible disability, you're on trial. If you have something that's invisible and poorly understood, that is not something I would disclose. (2: 45-47)

Basically, those who did not disclose due to a lack of education did not want to receive any form of maltreatment due to the illness.

Education as the motivation for disclosure serves a multifaceted approach to the illness: does one disclose to educate about the illness or does one not disclose because of potential

repercussions due to lack of education? There does not seem to be one common experience based on the responses of the participants.

**Risk-benefit ratio criterion.** The risk-benefit ratio criterion seemed to be an overlying criterion that impacted the other criteria previously discussed. In regards to gender, the women had to decide whether telling a male superior about their illness was worth the need for potential accommodations or not. As mentioned earlier, Jenna and Eliza found this risk worth the benefits, yet other participants did not. When discussing context, the supportive environment was perceived as less risky with more benefits than the unsupportive environment was. Additionally, participants believed that disclosure on job applications or at interviews was too risky. They wanted to wait until they could prove themselves in an organization, as Diana described. Finally, the motivation of education seemed to benefit the community more than the risk of stigma as perceived by Jenna, but Betty explained why this risk may not be worth it.

Participants relied on combinations of the criteria to determine privacy management decisions. Most questions of disclosure stemmed from a risk-benefit ratio of disclosure. Should one disclose despite perceptions of gender? Should one disclose in a particular workplace environment? Should one disclose to educate? It appears that participants perform risk-benefit analyses when answering these questions.

### **Boundary Coordination**

Boundary coordination occurs once people share private information and develop collective boundaries. Once they form these collective boundaries, they may negotiate explicit boundary rules to determine how both parties should handle the information. Among all nine participants, only one recalled creating explicit boundary rules, and in that one instance, both parties managed the information appropriately. Thus, most participants did not attempt to

coordinate boundary rules explicitly with the confidant. I directly asked all participants whether they told the individuals with whom they disclosed what to do with the private information. The common answer was a simple, “No.” However, if this information is as sensitive and threatening as these participants claim the illness to be, why are explicit boundaries absent from the data?

Data suggest that perceived support plays a significant role in decisions to disclose. Participants only disclosed to someone they trusted in the workplace. Because they trust this person, they may assume that this person will handle the information appropriately, and thus, participants relied on implicit privacy rules to guide boundary coordination. For example, Diana said, “The person to whom I disclosed, I felt, was trustworthy enough to keep it at the upper levels of the organization” (7: 101-102). Next, I discuss participants’ experiences with boundary turbulence.

### **Boundary Turbulence**

Boundary turbulence did not occur often, even though participants did not create explicit rules to guide boundary coordination. Petronio (2002) defines turbulence as a violation of expectations with disclosed private information. The co-owner of the information does not manage the private information appropriately or as intended. When turbulence did occur, it appears that it was not in the form of confidants sharing the information with others but instead when people did not respond to the disclosure the way that participants expected. For example, Diana’s job loss demonstrated turbulence as she did not expect termination to result from her disclosure; she expected accommodations. Eliza’s hostile workplace was similar: she expected accommodations, but she received hostility.

Participants explained that *anticipated* turbulence impacted their decisions not to create collective boundaries with coworkers and supervisors. For instance, Betty decided not to disclose

out of a fear of turbulence because of the nature of her hostile work environment. Alice, a forty-four-year old professor, did not disclose out of the fear of turbulence from the standards her affected coworker set in her workplace. Cara, a sixty-nine-year old retired healthcare professional, did not disclose in her workplace because she saw the turbulence that her coworker experienced from her chronic conditions. Thus, they feared turbulence would result from their disclosures.

Overall, various tensions arose in the experiences of the women in this study. In wanting accommodations, the participants weighed the various disclosure criterion heavily, particularly the gender criterion. Additionally, the motivational criteria embodied the tension of whether to disclose this private information. Finally, the implicit boundary coordination demonstrated organizational trust for instances of disclosure in the organization. Knowing the various obstacles that these women faced in terms of their disclosure, it would come as no surprise that these participants would experience behavioral changes.

### **Behavioral Changes**

In response to RQ2a and RQ2b, participants reflected on changes they made to their own workplace behaviors after diagnoses and behavioral changes they perceived from their coworkers after participants shared information of their diagnoses. Participants spoke frequently about their self-monitoring behaviors. In addition, they shared experiences with coworkers who engaged in supportive and unsupportive behaviors. Each of these changes in behaviors will be explained in detail.

### **Self-Monitoring Behaviors**

Participants changed their own behaviors to make their workplaces better for themselves. For instance, some participants changed their diets, sleep schedules, and social behaviors to

ensure productivity at work. To change diets, some participants made sure to eat healthier. For sleep schedules, participants recognized the need for more rest to combat fatigue. Some participants stressed the need to take naps or sleep for a regular amount each night. As far as social behaviors, participants limited drinking, smoking, and social interaction. Some noted that avoiding social interaction allowed them to focus the little energy they had on work. Betty noted her decision to reduce social interactions:

The energy to do the little extras just wasn't there. The energy to go sit in somebody's office—a colleague's office—to chit-chat and stuff when I was having a flare was not there. I came in, did my job, and I didn't have the energy to do the little extras. (2: 69-71)

Gloria, a sixty-two-year old professor, who also chose to limit her social interactions, explained how her illness directly affects her work environment:

It can be very isolating for sure. Even the social events through the department—those are just as important as the department meetings. When I don't go to those events, it kind of leaves me on the fringe. I'm going up for promotion this year, starting the cycle in July. You know, those loose ties are just as important as the ones when it comes to doing the business stuff that department does. So, I always worry about that. It's always in the back of my mind when I can't make social events or happy hours. (8: 278-289)

Additionally, participants described a phenomenon known as “fibro-fog” or “brain fog.” Diana explained fibro-fog as “a confusion that makes it hard to think of what you just said or what you're going to do next” (7: 27-28). Additionally, Heather, a sixty-six-year old professor, experienced similar feelings:

I do want to stress that I told you I'm tired, I really am tired all the time. It does fog up my brain. I'm having more trouble now remembering things in short-term memory. I will

stand in front of the class, start a sentence, and then forget where I was going with it. It's a problem. (9: 40-43)

Jenna also expressed her situation with the brain fog:

I really have a hard time focusing. I think that's due to the lack of sleep. I'm sure since you're researching fibro, you've heard about brain fog. I would say by far that's my biggest challenge because I'm not stupid. I can look at something I've done 100 times, but if the brain fog is bad, it's very difficult to accomplish or remember it. That gets frustrating. (6: 92-95)

The prevalence of brain fog led to some changes in participants' behavior, including taking extra time to respond to emails, taking a brief nap, or taking a small break to clear their minds.

Participants noted that despite the brain fog, their work quality did not diminish.

The participants continued to succeed at the various jobs they were in if the workplace accommodated their illness. They did end up eventually limiting their behaviors to make sure that they continued to succeed, but not at first. For example, Diana noted her desire to stretch herself beyond her capabilities after her initial diagnosis: "I think maybe I overachieved a little bit for a while, but I think it was more to prove to myself that I could do it" (7: 61-63). Other participants expressed this same overextension after diagnosis.

The participants changed their own behaviors to manage the illness better, but a few mentioned that they wanted to keep working at the pace they had before diagnosis to show themselves that they could do it.

## Supportive Behaviors

The participants did not only change their own behaviors but also observed changes in behaviors from others after disclosure. While only three participants disclosed involvement in actual support groups, all participants found support from others, including coworkers, romantic partners, medical groups (e.g., an arthritis foundation), and therapists. For the majority who found support outside of the workplace, they found this information too private and sensitive to disclose within their work environment. However, some participants did recall support from coworkers after revealing their illness. They explained that having supportive coworkers was pivotal in helping them cope with the diagnosis through work flexibility and coworker empathy. For example, Eliza explained the role that her coworkers had in supporting her:

Before I had mobility issues, my coworkers were very positive and supportive. When I couldn't find a parking spot on campus, one of my coworkers would go park my car in a lot that was really far away. They would go get my car for me at the end of the day. . . . They would get me coffee if they were going to the Starbucks near our building. They were very nice, accommodating, and concerned. They would ask me how I'm feeling and that kind of thing. They really wanted to understand what I was going through as much as they could. (4: 230-238)

Those who reported support from coworkers felt they could be more open about their fibromyalgia in future situations as well. For instance, those participants who worked in an organization that they perceived as supportive prior to their diagnosis also perceived positive behavioral changes from their coworkers after sharing their diagnosis. For example, when Jenna experienced a transition in superiors, she notified her new boss immediately of her diagnosis. Although they recognized that they would not disclose to certain coworkers, especially superiors



because of the concern that supervisors would use the information against them, they felt that they could be open with the information overall to some fellow employees. Most women maintained some level of privacy with their information, but a few were completely open with their disclosure.

### **Unsupportive Behaviors**

Although participants provided examples of receiving support from coworkers, many also experienced a lack of coworker support, and in some instances, negativity after disclosing their diagnosis. It is important to note, however, that despite unsupportive others, all participants disclosed their fibromyalgia to at least one coworker at some point.

Lack of support emerged in many different forms, ranging from a coworker dismissing the seriousness of the illness to managers firing the participants. For instance, when Betty shared her illness with one coworker, the coworker replied by saying, “Oh, I get tired, too. You know, it’s a part of getting older. Don’t worry” (2: 74-75). In a more extreme case, Diane recalled being terminated when she asked her previous boss for accommodations:

It was in a capacity that I disclosed to a director that I may be needing accommodations due to a disability. It was more of just one professional to another, and I told him that I wasn’t sure if it was going to be necessary. I asked for this because my workplace was very restrictive, making it hard for me to get to appointments and get time off when I needed it. I felt like I might have to take the route of getting disability accommodations. I just wanted to give him a heads up that it may be coming, and I would let him know.

Within a month, they had terminated me, and that’s what happened there. (7: 87-93)

Participants often gauged how supportive their workplace would be of their disclosure by comparing the perceived overall level of support among employees and supervisors. For

instance, Alice stated that her coworker, who also had fibromyalgia, portrayed herself as a martyr in the workplace, and others saw her as a martyr too. Alice did not want others to perceive her the same way. To avoid being judged as such, Alice said that she is fairly open about her illness, but she is careful not to go down the same road as her coworker (1: 108-109). This means that she makes sure not to complain frequently or use her illness as a scapegoat so that she can avoid being perceived that she is like her coworker. Cara also noted that she had a coworker who had lupus, diabetes, and fibromyalgia, and her coworkers treated this individual poorly. Because of this, Cara has never directly stated that she has fibromyalgia, but she does not deny it either (3: 99-101). Betty described her boss as hostile and berating to everyone at work, so when he asked her about her illness (that he learned about from one of Betty's coworkers), she said she never confirmed nor denied that she had fibromyalgia to him because, she explained, she did not want him to use it against her (2: 99-103).

Because of situations like these, women with fibromyalgia may become apprehensive to disclose their illness in the workplace. Some participants overcame this lack of support through reliance and trust in the other coworkers who supported them in their work environment. While particular bosses or coworkers may have been unsupportive, participants seemed to find at least one confidant in the workplace with whom they could talk about their illness.

In summary, it was apparent that participants adapted their own workplace behaviors and noticed both supportive and unsupportive changes in their coworkers' behaviors after disclosing their illness. Participants made changes in their own behavior to continue living a standard quality of life and performing well at work. Participants who experienced supportive environments seemed to have a better attitude about their workplace and felt less stigmatized. I discuss the role of stigma in privacy management next.

## Role of Stigma in Privacy Management

In the final research question, I investigated the role of perceived stigma in decisions about privacy management. Data revealed that stigma was a common concern of participants, and participants believed that their experiences of being terminated, being perceived as a “weak woman,” and being bullied by coworkers, stemmed from the stigmatized nature of the illness. To understand the stigma they perceived, it is important to first understand how they felt about their diagnoses. Their feelings seemed to reflect the stigma associated with the invisible nature of their illness.

When asked how they felt after the diagnosis, participants revealed experiencing multiple emotions at the same time. Many times, their responses started with “I was relieved, but...” followed by emotions like frustration, anger, sadness, and despair. The emotional reactions stemmed from living many years without a diagnosis, experiencing disbelief about their symptoms from others, and managing the illness long term. The relief came from having evidence to support that they were not making up their illness in their heads. Fiona highlighted these experiences:

All these years, I've known something wasn't quite right. I knew I couldn't take tests, I knew that my legs got stuck, I knew that smoking a cigarette made my body hurt in weird ways, and I knew that pounding a bunch of Red Bull at a party resulted in more pain. I knew all of this stuff, but there was no label on it. Once I had the label [of fibromyalgia], I could pinpoint it. That felt like a small victory. It felt good that I finally had a name to put on what was going on in my body. That's a very affirming thing. That's the positive side. But then, at the exact same moment, the hope goes away because we know that they don't even know what the hell causes this let alone how to fix it... So at the same time

that I'm like, "Yes! I finally have a label on it, it makes sense, and I can put words onto paper," all hope for it every going away vanishes" (5: 59-71).

The participants consistently expressed these concerns. They finally had a name of an illness after years of tests, doctors, pain, and fatigue, but three of those things would never change: doctors, pain, and fatigue. Because of this constant, ongoing management of the illness, the participants felt frustrated, angry, and hopeless. They realized that they had to continue managing an invisible illness that was poorly understood by the public.

Stigma seemed to center on the invisible nature of the illness. Fiona recognized this when she explained:

I would never disclose this to my students. This is sad because if I had a visible disability, I couldn't not talk about it because it would be the elephant in the room. Maybe that's the privilege I have of having an invisible illness. (5: 253-256)

Fiona is not reflecting that she is lucky to have her illness; instead she considers it to be positive that she can conceal her illness from others. Participants can hide the illness if they wish which decreases the chance of being stigmatized by it; however, the hidden nature of the illness often contributes to stigma because people do not understand the illness. As many participants expressed, one cannot understand the illness without experiencing it because of its lack of visibility. Others expressed that the diagnosis process also contributes to stigma. Participants felt that the long nature of the diagnosis as well as a lack of a consistent way of testing for fibromyalgia leads some of their coworkers to challenge the legitimacy of the illness.

Participants attributed hostile work environments and termination of employment, in part, to stigma. For instance, participants perceived that people's lack of education about fibromyalgia led to the stigma that they could not perform well at work. As Diana described:

I don't tell people initially because I don't want a stigma attached to me. People may say, "Oh, she can't do this," "She can't do that," or "She's leaving early because she's sick. I guess maybe I felt that I had to conceal that, but I was internally apprehensive about balancing work full time and the illness. (7: 45-48)

Diana wanted to show that she can combat the stigma that may impact perceptions of her abilities in her workplace. Hostility, job loss, and illness uncertainty stem from the invisible nature of the illness, which created the stigma.

The results demonstrated that the women in this study were aware of a stigma regarding fibromyalgia. Whether the stigma came from a lack of understanding, the "weak woman" idea, or the invisible nature of the illness, the participants explained the various scenarios in which the stigma existed for them. These results provided an in-depth look at what these women experienced in terms of fibromyalgia stigma at work after their disclosure.

Taken together, the results demonstrated the multifaceted issues that women afflicted with fibromyalgia face: decisions about disclosing, behavioral changes, and stigma. The participants experienced struggles determining appropriate self-disclosure about the illness, changes in their own and others' behaviors, supportive and unsupportive behaviors from colleagues and supervisors, and instances of stigma. It appears that the biggest influence on the participants' privacy management process was the level of perceived support in their workplaces. Further, the perceived associations of the illness with "weak woman" and a lack of education about the illness inhibited participants' desire and willingness to disclose their illness. The results of this study provide various implications and directions for future research, which I discuss in the next chapter.

## CHAPTER V: DISCUSSION

The purpose of this study was to identify the process through which women with fibromyalgia managed private information about their illness at work, behavioral changes that these women face in the workplace from their disclosure, and the instances of stigma that they experienced from their disclosure in the workplace. Although Arnold et al. (2008) reported various outcomes of living with fibromyalgia such as disrupted relationships, isolation, and loss of or lack of advancement in an occupation, they did not provide further depth into why these outcomes existed. I chose to focus on the workplace because women with this illness should receive protection from discrimination at work and be provided accommodations, per the Americans with Disabilities Act; however, as Arnold et al. uncovered, employees with fibromyalgia face many obstacles when trying to work with this illness. Additionally, to receive workplace accommodations, individuals with fibromyalgia must disclose their illness. Without this disclosure, the illness is virtually invisible in the workplace, but revealing this information is risky and has possible repercussions. In this chapter, I summarize my findings from the results, explain the implications from the data, and provide directions for future research.

### **Summary of Findings**

The privacy rules criteria of gender, motivation, context, and risk-benefit ratio played significant roles in participants' disclosure of private information about their illnesses. Participants expressed fibromyalgia as a feminine illness. This classification further perpetuated the ideology of the "weak woman." Many participants expressed that going into the organization and making a name for oneself without the label of "weak woman" prior to disclosure helped alleviate some risk of that label after disclosure. Additionally, others' education about the illness motivated participants' decisions whether to disclose at work. In some instances, they believed it

was their job to educate others and self-disclosing allowed them to do that, and others reported that the lack of education motivated them to remain silent about their illness. Those who disclosed to educate did so because they wanted to show others that they can complete their work well with others knowing about the illness. Those motivated to not disclose wanted to prove that they were worthy of the position as a person, not seen as an individual with fibromyalgia.

Although Petronio (2002) classifies the risk-benefit criterion as separate from the others, it appears in the data that this criterion impacted the other criteria. For instance, risk-benefit assessment emerged when participants considered, “Should I disclose to combat gender norms, or will I be perceived as weak?” Additionally, risks and benefits impacted motivations and gendered criteria when participants considered: “Should I disclose to educate, or will I experience hostility from a lack of education?” “Should I disclose to my employer even though it may hurt my chances of landing the job?” If the workplace was supportive, the benefits tended to outweigh the risks. In an unsupportive environment, the risks tended to outweigh the benefits.

Although participants framed their illness as poorly understood and often stigmatized, it was surprising that, when sharing private health information to coworkers or managers (thus creating collective boundaries), they often did not develop explicit rules for boundary management. It appears that participants only disclosed to coworkers they trusted and relied on implicit expectations that this trusted confidant would not mishandle their private information. In a few instances, participants experienced boundary turbulence, but it was not as common as one would assume considering that they rarely discussed explicit boundary management expectations.

The participants from this study identified various ways that they changed their own behaviors to ensure success at work after diagnosis as well as behavioral changes they

experienced from others in their workplace after their illness disclosures. Participants changed many of their unhealthy habits (e.g., less sleep, drinking, smoking) into healthy ones (i.e., proper nutrition, more rest and exercise). The impetus for these changes was the desire to maintain the normalcy of their lives prior to their diagnosis. Maintaining their strong work performance after diagnosis was important to participants as well.

The participants witnessed changes in others' behaviors after their disclosure; participants tended to classify these behaviors as supportive or unsupportive. With only one question tailored to support in the interview (i.e., "Did you have any support in place, such as a support group?"), the context of the workplace as either supportive or unsupportive seemed to significantly impact people's talk about their illness at work. While some participants recalled receiving support from their colleagues, others received a lack of support from their disclosure. Those who did receive support were more likely to disclose this information in the future. If a workplace was unsupportive, however, participants became weary of future disclosure of the information. It appeared that disrupted relationships, isolation, and loss of or lack of advancement (Arnold et al., 2008) in the workplace occurred more often in unsupportive workplace environments.

Lastly, the stigma regarding fibromyalgia manifested itself in all interviews. The most common way that this stigma arose was participants' views that others saw fibromyalgia as made up or all in the participants' heads. Participants perceived that others were hostile and failed to support them due to this stigma. However, not all participants experienced this negativity. In instances of supportive behaviors, participants had positive interactions with colleagues and superiors who either knew about the illness, experienced it themselves, or knew someone else with the illness. If an individual with fibromyalgia knows that their colleague or superior has



experience with fibromyalgia in one these ways, they may find comfort in disclosing such information.

This information taken together leads to three important conclusions related to support, boundaries, and stigma. These take-aways embody what the participants experienced in regards to their fibromyalgia disclosure in the workplace.

## **Support**

Numerous scholars have posited that organizational support to be innovative and create change leads to more productive and innovative employees (Cullen, Edwards, Casper, & Gue, 2014; Young, 2012), and conversely, lack of support can lead to apathy, dissatisfaction, or isolation, as was the case of whistleblowers in McGlynn and Richardson's (2014) work. However, the literature does not appear to address organizational support when discussing invisible illness. The literature describes various aspects of social, community, and familial support with health-related topics such as breastfeeding, HIV/AIDS, aging, and cancer (Horan, Martin, Smith, Schoo, Eidsness, & Johnson, 2009; Kuehl, Drury, & Anderson, 2015; Oetzel, Wilcox, Archiopoli, Avila, Hell, Hill, Muhammad, 2014). Most invisible illness support literature explores the role of computer-mediated support through online informational support, online support groups, and blogging (Batenburg & Das, 2015; Chung, 2014; DeAndrea, 2015; Dutta & Feng, 2007; Hether, Murphy, & Valente, 2014; Mein Goh, Gao, & Agarwal, 2016; Rains & Keating, 2011; Wright & Rains, 2013; Wright & Rains, 2014; Ye, 2014). Because of the previous research on organizational support and invisible illness support do not intersect, this study highlights the intersection of these two branches of study.

Within the context of women with fibromyalgia, it appears that in an ideal scenario, employees would feel free to disclose their illness without negative repercussions and employers

would provide functional support (i.e., accommodations, non-discrimination) and emotional support. However, while most of the organizations for which the participants worked provided functional support through accommodations, some failed to provide emotional support, which seemed to be very important to the participants. None of the participants' workplace organizations refused to provide accommodations, but some did so within an otherwise hostile and unsupportive work environment. This begs the question: Which type of support is more important for women with fibromyalgia and in a broader sense, employees with invisible illnesses?

Participants who received perceived support in their organization that included accommodations, non-discrimination, and emotional support, believed that they were more productive and innovative employees in their workplaces. Those who received some form of unsupportive behaviors, termination, or hostile work environment reported experiencing isolation and/or dissatisfaction in their workplaces. Because women expressed their own uncertainty about the illness and how it would impact their work performance, it appears that emotional support is very important and employers should consider ways to convey emotional support for their employees beyond providing accommodations, which were also very important to participants.

In providing accommodations, participants disclosed reaching out to human resources or a superior to ask for these. This is especially important for employees with invisible illnesses because the existing literature (Cullen, Edwards, Casper, & Gue, 2014; Young, 2012), and the findings of this study indicate that supported employees are more successful. In regards to the specificity of fibromyalgia, the supportive environment is pivotal because support can help an individual perform their job duties successfully. When an employee discloses their fibromyalgia,

management should take precautions to best support the employee. First, make sure the employee contacts the appropriate office or department to discuss accommodations. Second, ask the employee if they would be willing to share how the illness affects them to garner a better understanding of the illness. Finally, fulfill accommodations without bias. From the data, it seems that drawing excessive attention to the illness or making the accommodations seem burdensome will contribute to an unsupportive work environment.

### **Boundaries**

Participants did not create explicit boundaries when disclosing health information to people at work. This was surprising given how private participants were about their illnesses and concerned with people at work, particularly supervisors, finding out. Venetis et al. (2012) discussed that people with a health condition often do not create explicit boundaries within non-workplace interpersonal relationships because they assume that the confidant understands the sensitive nature of the information and the need for privacy. It appeared that participants chose to disclose to people with whom they had already established interpersonal trust and disclosed this information to garner emotional support. Previous research supports that women tend to seek emotional support in organizations, particularly those with whom they trusted (Myers & Johnson, 2004; Sias & Cahill, 1998). They also were more willing to disclose to supervisors who oversaw other employees with this illness or who had personal experiences with the illness. In short, they seemed to reveal to those they trusted, and hence, also believed that this confidant would not share the information with others. Thus, although there are interpersonal motivations to workplace gossip such as gathering work information, venting, building relationships, and interconnectedness (Blithe, 2014; Blithe & Tracy, 2009; Cowan & Horan, 2014; Dillard, 1987; Ellwardt, Steglich, & Wittek, 2012), participants were selective in who they confided in and did

not believe there were risks of that person sharing information inappropriately with others and/or to gossip. But because workplace gossip often targets those low in informal status (Ellwardt, Labianca, & Wittek, 2012) and can be used for social capital in the organization (Hafen, 2004), women with an illness that they believe is stigmatized and can impact their workplace performance should use caution when revealing information and not creating explicit boundary rules. It is not clear if the women in this study got “lucky” that confidants did not share their information with others, or whether the supportive environments in which most of the participants worked led to a culture of trust and privacy. Participants considered the few organizations in which turbulence did occur to be hostile and unsupportive, and thus, women working in environments like these should consider creating more explicit boundaries due to the various violations of legislation, trust, and privacy that may occur regarding the illness.

Additionally, considering the American socialization of private health information through HIPPA, or the Health Insurance Portability and Accountability Act of 1996, may explain the desire to keep health information private. Under HIPPA, individuals have some level of control for whom gets access to their health information (Health and Human Services, 2017). Medical staff are not allowed to discuss patients’ information outside of the hospital environment or those not directly involved with the patients’ care. This idea could translate to the workplace in terms of privacy and health information, but more research should be done to identify whether this correlative or causative relationship exists.

### **Stigma**

Participants considered fibromyalgia to be a “feminine illness” which they believed contributed to the stigma surrounding it. The perception of fibromyalgia as feminine seems to further the organizational narrative of the “weak woman,” the participants’ hesitation to disclose

such information openly would be justified. However, these results proved contrary to Petronio et al. (1984) who noted that women tend to disclose information to feel accepted, honest, and liked. On the contrary, the results showed that women with fibromyalgia might instead choose to conceal this information to feel accepted and liked and to avoid judgment. This discrepancy between these findings and Petronio's claim may be explained through Buzzanell (1995), who examined glass ceilings in organizations. Buzzanell noted that women experience fewer opportunities in the workplace than men, and being a woman who is experiencing a chronic illness perceived to be "feminine" may only compound the glass ceiling.

As the women in this study concluded that fibromyalgia is a feminine illness, this study provides more of a context for disclosure of fibromyalgia to employers. Women with fibromyalgia should be aware of their organization's expectations of women. Because women already lack job clarity, tend to leave organizations, experience organizational frustration, struggle to manage work-life balance, and attempt to achieve workplace equality with men (Clason & Turner, 2011; Greenstreet & Frederick, 2000; Krouse & Afifi, 2007; Petersen, 2014), the addition of fibromyalgia may exacerbate these issues, particularly in unsupportive environments. To determine whether to disclose their diagnosis, women with fibromyalgia should gauge their organization's treatment of men and women at work.

These conclusions reflect the participants' advice when asked to provide suggestions to women wishing to disclose fibromyalgia in the workplace. While the participants understood the importance of education and awareness of the illness, they cautioned women, particularly those in unsupportive and/or hostile workplaces, to be selective in sharing health information.

## Limitations and Future Research

This thesis serves as initial research in exploring the various experiences that women with fibromyalgia face in the workplace. There are various ways to expand this work in the future. One such way is to include more participants and perspectives. Although the qualitative study included nine in-depth interviews, more research can be conducted to bring the experiences of women with fibromyalgia to light.

Additionally, there are privacy and stigma scales that would capture the experiences of more women with this illness and allow scholars to test outcomes of their workplace experiences. Scales such as the Self-Stigma of Mental Illness Scale (as cited in Boyle, 2013) would provide an in-depth look at the perceived stigma of those with fibromyalgia. The scale would be effective in “demonstrating negative associations between internalized stigma and self-esteem...as well as self-efficacy” shedding light on how individuals afflicted with an illness perceive others to perpetuate stigma (p. 1524).

This thesis only looked at women with fibromyalgia due to the high ratio at which women are afflicted with this illness (Lawrence et al., 2008). However, the perspective of men afflicted with this illness should not be discounted, particularly because participants discussed the obstacles men face when dealing with having a “feminine” illness. Knowing that certain themes arose in this thesis regarding the women’s perspectives, conducting this study with male participants would provide insight into managing a masculine identity while managing a perceived feminine chronic illness.

In regards to Communication Privacy Management, scholars should further explore boundary management processes related to disclosures of invisible illness. Although I looked at the various criteria regarding disclosure of private information and boundary coordination, and

considered whether participants developed implicit or explicit rules once they shared information with others at work, I was unable to describe the full boundary coordination process as Petronio (2002) suggested that it occurs. Specifically, Petronio described that once turbulence occurs after attempts at boundary coordination, co-owners renegotiate boundary coordination. Because there were only few issues of turbulence, and participants did not recall any sort of renegotiation afterward, I was unable to explore how renegotiation may fit into the disclosure of fibromyalgia or in the larger sense, disclosure of invisible illnesses at work.

As Petronio (2002) noted, the boundary coordination process includes boundary linkage, ownership rights, and permeability. Because boundary linkage occurs when the information is disclosed to another individual, this aspect of boundary coordination occurred in every instance that the participants disclosed their illness to another individual. However, participants did not seem to address ownership rights and permeability. This lack of discussion regarding ownership rights and permeability may indicate a key misstep in the disclosure of fibromyalgia. Future studies should examine the roles of ownership rights and permeability to see if these provide any significant data regarding fibromyalgia disclosure at work.

Another option to consider for future research would be to replicate the methods of studies that examined other invisible illnesses (see Horan et al., 2009; Smith & Niedermeyer, 2009) to investigate any consistency in various themes throughout invisible illness studies. If consistent themes can be found, the results would create a holistic view of invisible illnesses. If not, then important, nuanced distinctions among invisible illnesses would be considered for future research endeavors and implications.

## Conclusion

Overall, this study provided an initial look at how women afflicted with fibromyalgia managed their disclosure of the illness in the workplace. Using a theoretical lens of Communication Privacy Management Theory, literature on stigma, and a context of organizations, the study provided a framework for disclosure in the organizational context.

The study showed how some aspects of interpersonal communication theory translate into interpersonal workplace relationships differently such as gossip and boundary coordination. As Venetis et al. (2012) described the purposes for interpersonal implicit boundary coordination regarding health disclosures, this study adds an organizational perspective for the logic behind organizational implicit boundary coordination experienced by those disclosing fibromyalgia. The various implications in this thesis also provided tangible advice for both employers of employees affected with fibromyalgia as well as those afflicted employees.

The three intertwining themes of organizational support, implicit boundary coordination, and the feminine stigma of this illness, told the story of women with fibromyalgia in the workplace. This project opened a line of research for under-researched chronic illness, shedding light on the nuances that each chronic illness may have, particularly in a workplace environment.



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## APPENDIX A: RESEARCH POOL RECRUITMENT

### Studies

<b>Home</b>
<a href="#">ISU SoC Research Pool</a> <a href="#">Home Page</a>
<b>Student Area</b>
<a href="#">Available Research Opportunities</a>
<b>F.A.Q.</b>
<a href="#">Frequently Asked Questions</a>
<b>Rights</b>
<a href="#">Rights &amp; Responsibilities of Research Participants</a>
<b>Researcher Area</b>
<a href="#">Information for Researchers</a>
<a href="#">Study Submission</a>

**STUDENTS:** Below is the list of available research studies. Please check back often.

As studies become available throughout the semester, they will be posted.

**\*You can only receive credit for ONE communication course per study. Any attempt to receive credit for multiple courses for your participation in the SAME study will result in a penalty of NO CREDIT for participation in the study at all.**

The amount of extra credit you can earn depends on your professor. You'll earn 1 research participation credit for each 60-minute study (or 0.5 research credits for 30 minutes). Each instructor determines how much extra credit one student can earn and how much for each study. Refer to the course syllabus or contact your instructor for the amount of extra credit you can earn.

#### How is research credit calculated?

Credit is pro-rated based on how many "half-hour units" the research thinks the study will take. For example, a 100-item online survey can typically be done within a single half-hour. In contrast, scheduling an experimental dyadic interaction involves travel time to the site of the interaction, the time of the interaction itself, and the time of the surveys that might be administered before and after, so this might involve an hour-and-a-half total. Credit will be rounded up to the nearest 1/2 hour increment (e.g., If your study only takes 15 minutes to complete, it will be rated at a 1/2 hour of credit time; if your study takes 45 minutes to complete, you will receive 1 hour of credit).

#### Spring 2016 Research Opportunities

	Study Name	Description of Study	Researcher (email)	Research Credit	Dates & Restrictions	Instructions
	EXAMPLE	This is just a test protocol. No credit assigned.	Name (ILSTU email)	0.0	CLOSED  None may participate.	Those over the age of 18 should go to the following link for more information on the study: <a href="https://survey.lit.ilstu.edu/example">https://survey.lit.ilstu.edu/example</a>
1	Fibromyalgia in the organizational context.	This study looks to see how individuals manage the disclosure of private information (fibromyalgia) in	Hall (rdhall5@ilstu.edu)	0.5	Open. To participate, the participant must be female, above 18, and have organizational experience	E-mail the researcher (Robert Hall) at <a href="mailto:rdhall5@ilstu.edu">rdhall5@ilstu.edu</a> if you are interested in participating in the study and meet the criteria described to the left.

## APPENDIX B: SOCIAL MEDIA RECRUITMENT

Facebook Post:

You have been invited to participate in a qualitative study conducted by myself, Robert D. Hall, a graduate student in the School of Communication at Illinois State University, under the guidance of Dr. Aimee Miller-Ott. The study focuses on fibromyalgia disclosure in the workplace. I would greatly appreciate your participation in this study. Your participation would be in the form of a one-on-one confidential interview.

To participate, you must be over the age of 18, female, and have experience in the workplace as an individual diagnosed with fibromyalgia. If you choose to participate in this study, please contact me using the information provided below to set up the interview, which is expected to last approximately 45 minutes. Your responses will be confidential. I will not share your identity or anything you say to others in a way that will identify you. This interview will ask you to respond to a series of questions relating to your experiences with fibromyalgia disclosure or non-disclosure and your emotional responses to the experiences. The interview will be audio recorded on the interviewer's voice recorder, which is password protected; however, we can do the interview without audio recording if that is your preference.

Your participation is completely voluntary, and anything you answer during the interview will remain completely confidential. There is no penalty for choosing not to participate in this study. Furthermore, you have the right to decline to answer any question or withdraw from the study at any time without penalty or adversely affecting your relationship with myself, Dr. Miller-Ott, or Illinois State University.

To move forward with participating in this study, please contact me by email at [rdhall5@ilstu.edu](mailto:rdhall5@ilstu.edu).

Sincerely,

Robert D. Hall

## APPENDIX C: EMAIL RECRUITMENT

Dear \_\_\_\_\_.

I am a graduate student in the School of Communication and am conducting a research study on fibromyalgia management in the workplace for my master's thesis. If you are/have been involved in a business or organization (of any kind), are a female who is at least 18, and are diagnosed with fibromyalgia, then I request your participation.

You are invited to participate in a face-to-face interview study regarding the communication processes that take place when you are/were involved in an organization. Particularly, this study seeks to assess treatment and role of individuals in the organizational context. This study is very relevant, as college students on a diverse campus may be involved in any number of organizations with a myriad of backgrounds regarding fibromyalgia.

The interview will take about 45 minutes. It will be confidential (I will not share your identity with others). I will change your name on the final paper for this project. Your participation will be completely voluntary. You may decide not to answer any question, and you can stop the interview at any time. .

Please direct any questions and/or comments to Dr. Aimee Miller-Ott (aeott@ilstu.edu) or to me.

If you would like to participate, please email me at the e-mail address provided below. I will be accepting participants until November 1<sup>st</sup>.

Sincerely,

Robert D. Hall  
Graduate Student, School of Communication  
Illinois State University  
rdhall5@ilstu.edu

## APPENDIX D: INTERVIEW PROTOCOL

### Preview

Thank you for your participation in my study. I'm Robbie, your interviewer for today. This interview will take about thirty minutes to an hour. I am going to ask you a series of questions about information disclosure about fibromyalgia in the workplace. I'm going to divide the interview into three sections. First I want you to talk about who you are and your diagnosis. Second, we will discuss your experiences in the workplace regarding your fibromyalgia. Finally, I will ask that you discuss your interpersonal experiences regarding your diagnosis. What questions do you have so far?

Now that you have signed the informed consent form, I just want to remind you that I will keep all of your responses confidential. The form you signed will remain separate from your interview responses. Also when I write my final report, I will change your name to protect your identity. To ensure that the information is obtained accurately and completely, I will be recording the interview. You may shut the tape-recorder off at any time during the interview. Only I or a hired transcriptionist will ever hear the tape for purposes of preparing a written transcript. Once the interview is transcribed, I will erase and/or destroy the audiotape of this interview. What questions do you have?

As I stated beforehand, I want to ask some questions about who you are and your fibromyalgia diagnosis.

- 1) Demographic information
  - a. Age?
  - b. Race?
  - c. Religious Affiliation?
- 2) Fibromyalgia diagnosis
  - a. At what age were you diagnosed with fibromyalgia?
    - i. Confirm the time diagnosed by subtracting current age with age provided.
  - b. What industries have you worked in while diagnosed with fibromyalgia?
  - c. What is your current treatment/management for your fibromyalgia?
    - i. PROBE: Why do you or don't you find this effective?
  - d. What symptoms do you tend to experience the most?

Now that I have an idea of who you are and your diagnosis, I'm going to ask you some questions regarding your workplace experiences you had while you were diagnosed with fibromyalgia.

- 3) Once you received your diagnosis, what thoughts went through your head?
  - a. What emotions did you feel?
  - b. What were your biggest concerns?
- 4) When you were diagnosed with fibromyalgia, what did you feel about going to work?
  - a. Did you have any fears about your job? Please explain.
  - b. Did you have any support (for instance, support groups) in place to help you continue working with this illness?
- 5) How if at all did your behaviors at work change after the diagnosis?
  - a. How did these behaviors either continue or stop as time went on?
  - b. How do you believe that they affected your work quality, if at all?

- 6) How has fibromyalgia affected your experiences in various workplace environments?
- 7) What obstacles at work do you face on a daily basis that you believe are related to your illness?

Next I am going to ask you some questions about talking with others at work about your illness. First, in your workplace or in the company, can you tell me about a time when you intentionally disclosed your illness to someone?

- 8) Please tell me who you talked to about your illness.
  - a. When did you tell them? How did you decide when to tell them?
  - b. How did you tell them? How did you decide how to tell them?
  - c. Why did you tell them?
- 9) What concerns, if any, did you have in telling this person about your illness? Did those concerns come to light?
- 10) Once you told them, did you talk to them about what to do with the information? (for instance, not to tell anyone, to keep it a secret, etc.)
- 11) Did they ever handle the information in a way that you wish they hadn't? If so, please explain what happened and how you responded.
- 12) Can you tell me of a time when revealing about your illness changed your relationship with an individual for the better?
- 13) Can you tell me of a time when revealing about your illness changed your relationship with an individual for the worse?
- 14) Can you think of instances when you believe that telling someone about your illness impacted your experiences at work? (for instance, how people treated you, the work you were given to do, etc.)

Can you tell me about a time when you intentionally did not disclose your illness to someone?

- 15) Why did you decide not to disclose this information?
- 16) What were your main concerns preventing you from disclosing this information?
- 17) Do you ever plan to disclose this information? Why or why not?
- 18) How, if at all, has your workplace experiences been impacted by not telling people about your illness?

**Ask everyone:**

- 19) How, if at all, does specifically being a woman in the workplace with fibromyalgia affect the way you manage this private information that you think might be different if you were a male?
- 20) What advice would you give other people with fibromyalgia about talking or not talking about the illness at work?

Thank you again for agreeing to participate in this study. The experiences you provided me with today will help shed light on the experiences that individuals with fibromyalgia manage. Is there any other information we didn't address that you would like to add now before we end?