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The Ill Man: An Exploration of Chronic Illness Disclosure within Masculine Culture

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A thesis

presented to

the faculty of the Department of Communication and Performance

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Master of Arts in Communication and Storytelling Studies

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by

Matthew Daggett

May 2019

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Dr. Christine Anzur

Keywords: Chronic Illness; Communication; Culture; Disclosure; Masculinity; Non-disclosure;

Pain; Privacy; Shame

## ABSTRACT

The Ill Man: An Exploration of Chronic Illness Disclosure within Masculine Culture

by

Matthew Daggett

Masculine culture is known for teaching men to be strong, independent, and in control; however, the presence of chronic illness creates challenges for men when attempting to uphold a dominant masculine identity and make disclosure decisions about sharing illness information. This study explores the intersection between illness related self-disclosure and masculine culture. Utilizing qualitative methods, it examines the challenges chronically ill men face when making decisions about self-disclosure. Semi-structured interviews were conducted with five men ( $N=5$ ) who have one or more chronic illnesses. Transcripts were analyzed and coded using grounded theory to identify emergent themes. The analysis revealed three primary themes and several secondary and tertiary themes. The three primary themes are: 1) participant expression of masculine culture; 2) communication challenges; and 3) disclosure strategies. Participants' accounts of their experiences with living with chronic illness are positioned within literature on chronic illnesses, self-disclosure, and masculine culture.

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## CHAPTER 1

### INTRODUCTION

#### **Purpose of Research**

Masculine culture teaches men to be strong, independent, and in control; however, the presence of chronic illness creates challenges for men when attempting to uphold a dominant masculine identity and make disclosure decisions about sharing illness information. In masculine culture, men are taught to remain silent and not talk about illness, disease, pain, or sickness. Men *need* to share their experiences of living with chronic illness. In a culture that prescribes that men be silent and strong regardless of illness, taking the opportunity to be heard could lead to strengthened illness and identity management strategies, feelings of connectedness, and feelings of empowerment. Talking about chronic illness with others helps in many ways, arguably making the illness more tangible. Talking about illness with others, especially those who share similar illness experiences, has a therapeutic and cathartic effect. There are benefits for men when disclosing, however, dealing with negative reactions from others when disclosing chronic illness information is a challenge that all chronically ill individuals must face. For many men, it can be the primary reason for nondisclosure (Barned et al., 2016). This project could help individuals develop strategies that help with the disclosure of illness information and help with the selfmanagement of chronic illnesses. Communication is imperative to men facing illness. Men are, however, constrained by masculinity norms and masculine social scripts; so many experience unique constraints to disclosure. This absence of communication magnifies the illness experience.

## **Chronically Ill Men**

This project emerged out of the lack of research on chronic illness disclosure within masculine culture. It builds upon established research in chronic illnesses and self-disclosure and ventures out to look at these through a masculine culture lens. There is literature finding that men do not disclose and keep illness information quiet, but what of the ill man's individual illness experience? What happens when he does disclose? Where did he learn what he knows about masculine culture, illness, and self-disclosure? What communication challenges do men living with chronic illness express facing when disclosing illness information, and how do they navigate those challenges? These are some of the questions this study explores. The goals of this study are: (1) To explore the intersection of masculine culture, illness scripts, and chronic illness disclosure; (2) To identify communication challenges that emerge when men disclose about a chronic illness; and (3) To identify communication strategies that participants express using when disclosing about a chronic illness.

This study explores the intersection between illness related self-disclosure and masculine culture. Utilizing qualitative methods, it examines the challenges chronically ill men face when making decisions about self-disclosure. Semi-structured interviews were conducted with five men (n=5) who have one or more chronic illnesses. Transcripts were analyzed and coded using grounded theory to identify emergent themes. The analysis revealed three primary themes and several secondary and tertiary themes. The three primary themes are: 1) participant expression of masculine culture; 2) communication challenges; and 3) disclosure strategies. Participants' accounts of their experiences with living with chronic illness are positioned within literature on chronic illnesses, self-disclosure, and masculine culture.

## CHAPTER 2

### LITERATURE REVIEW

#### **Illness in Masculine Culture**

Chronic illness is an individual experience; yet there are similarities across illness experiences. Charmaz (2000) states that chronic illness is:

the person's experience. [...] Chronic illness can be episodic or endless; it may have long plateaus or continual progression. It is at once subjective and social; it includes experiencing inchoate emotions and bodily sensations as well as making such experiences meaningful and responding to actual or imagined social responses. (p. 277)

As outlined in Charmaz's quotes, the illness experience is personalized and subjective; however, that deeply personal experience is rooted within a larger social system. Cultural masculinity norms prescribe certain behaviors when it comes to having an illness. Men in traditional masculine roles are expected to behave in specific ways. Kvigne, Kirkevold, Martinsen, and Bronken (2014) discuss these norms as:

the main characteristics of hegemonic masculinity are independence, physical strength, power, personal control, domination, aggressiveness, competitiveness, risk-taking, competence in specific social domains such as sports, hunting and alcohol and drug use, emotional toughness, rationality, self-reliance, sexual prowess and being the family provider while denying weakness and rejecting help. (p.199)

Connell (1990) defines hegemonic masculinity as, "the culturally idealized form of masculine culture" (p. 83). He goes on to say that hegemonic masculinity emphasizes, "the connecting of masculinity to toughness and competitiveness", "the subordination of women" and, "the marginalization of gay men" (p. 94). When culture accepts and reinforces this kind of

masculinity, it becomes hegemonic and teaches other men what it means to be a man (Connell, 1990; Kimmel, 2006; Moss-Racusin et al., 2010; Trujillo, 1990). When a man reveals to others that he has a chronic illness, arguably, he threatens his masculine identity, as well as his place in the masculine culture. Being ill is often very closely related to being weak. Men are expected to be strong and if illness is weakness, then the ill man is weak. Gibbs (2005) discusses how the “strong” masculine identity can be threatened by illness, stating, “Chronic illness can involve pain, fatigue, and reduced strength and flexibility, thus undermining the image of strength and independence that is associated with hegemonic masculinity and the factors that have previously sustained a man’s place in the gender order” (p.288). Subsequently, symptoms and byproducts of the illness experience, such as pain and loss of control over one’s body, potentially evidence the “ill” man’s inability to abide by his social contract with the masculine culture.

### **Be Strong**

There is a binary construct within masculine culture that says a man is either a strong man or a weak man. This binary directs men to be silent and not talk to others about their illnesses because the man who admits he is ill and discloses is weak (Kvigne et al., 2014, Courtenay 2000). Masculine culture teaches men that they are to be strong no matter the cost, no matter how much work must be put into maintaining that perception that he is strong (Charmaz, 1994; Kvigne et al., 2014). The “strong” identity is to be kept intact, even if it means making life harder on himself (Moss-Racusin et al., 2010). For example, a man with Irritable Bowel Syndrome may keep to himself the fact that he may have explosive diarrhea at any moment and sit in pain and discomfort rather than letting people know he has IBS and may need to run to the restroom at a moment’s notice (Bjorkman, 2014; Joachim & Acorn, 2000). By admitting his illness, the man with IBS is admitting a weakness, and men are not supposed to be weak. If a

man is silent and discloses nothing, he can be somewhat confident that others will see him as strong since there is no information given that suggests otherwise (Charmaz, 1994). When a man discloses, however, he is at risk of the information shared showing him as “weak”. Masculine culture teaches men that they are to be strong mentally, physically, and in any other way they may come to show their masculine “strength” (Charmaz, 1994; Gibbs, 2005; Kvigne et al., 2014).

Gibbs (2005) discusses the masculine expectation of silence surrounding health and illness as, “Hegemonic masculinity, like other masculinity constructs, may vary for different social groupings and shift over time and place (Connell, 1999). However, it is generally expected that men not show pain, be self-sufficient, and not appear weak” (p.288). Any deviance from that expectation could cause a man’s masculine identity to be at risk (Moss-Racusin et al., 2010). Many chronic illnesses bring with them pain, dependency, and weakness. This adds to the identity management work that must be strategically completed to keep the expected masculine identity intact.

### **Be in Control**

Men are supposed to control every aspect of their lives—and they are supposed to do that without any help from others (Connell, 1990; Charmaz, 1994; Kvigne et al., 2014). The ideal masculine man within the dominant culture accepts help from no one, because he does not need it; he can accomplish his goals all by himself. He is completely independent. Asking for help from others would be giving up some of that control, so men are inclined to manage life and daily tasks for themselves (Bjorkman 2014; Gibbs 2005; Kvigne et al., 2014). For example, Duck (2009) explored the reasoning behind African American men’s avoidance of HIV/AIDS screening. The delaying of health screening can lead to serious consequences, including late

stage diagnosis. The participants in Duck's (2009) study highlighted the masculine rule that men should be experts in the realm of sex, and that includes taking charge of sexual health knowledge by not getting screened. Ironically, then, the act of avoiding health screenings appear to help men feel a sense of control over self, one's body, and one's health (Taber et al., 2015).

### **Identity Management of the Ill Man**

Men who encounter chronic illness within their lives will engage in identity management to maintain a hegemonic masculine identity—especially when disclosing. They will try to preserve their senses of self by giving others the perception that they are leading normal lives despite their various illnesses. Charmaz (1994) discusses this preservation of self as:

they implicitly, and often explicitly, devote much effort to preserving self-aspects of a self known and valued in the past. Preserving self means maintaining essential qualities, attributes, and identities of this past self that fundamentally shape the self-concept.  
(p.278)

When chronic illness enters the life of a man, there will be role shifts and changes in identity (Charmaz, 1994; Martin, 2016). There may be certain activities that the ill man can no longer perform at the same capacity as before illness came into his life. He will have to manage his roles to accommodate for the new variables that come with his illness, each of which affect his sense of identity. Some men may even experience a loss of identity. Martin (2016) finds that individuals feel a loss of identity when adapting to their new roles within the community in which they are now a member. Kaushansky et al. (2017) found that not disclosing can affect one's identity as, "individuals with chronic illnesses consequently deviate from normative expectations, leading them to conceal their true identities in order to adapt to a world of 'normals'" (p.50).

If a chronically ill man fails to preserve his self, he may face many consequences. Joachim and Acorn (2000) write about the risks of having a chronic illness out in the open: “risks include being rejected and stigmatized, having difficulty handling the responses of others, and losing control” (p.245). Masculine culture teaches men to be strong, in control, and independent, compelling them to be silent about their illness experiences. There are benefits for men when disclosing, however, dealing with negative reactions from others when disclosing chronic illness information is a challenge that all chronically ill individuals must face. For many men, it can be the primary reason for nondisclosure (Barned et al., 2016). Discussed in the next section, then, are the consequences of the disclosure of chronic illness information include stigmatization, shame, discrimination, disbelief, and loss of control.

### **Consequences of Disclosure**

What emerges from a review of existing literature on disclosing chronic illness largely focused on the cost and consequences of the illness-related disclosures. Petronio (2000) explains that, “decisions to disclose are likely fraught with fear and anxiety” (pg.126). Petronio identifies additional risks such as “potential rejection and discrimination, and emotional distress for others” which may result in broad impacts “ranging from ostracism in interpersonal relationships to selfidentity crises, from threats to basic survival (loss of employment, housing, insurance or healthcare) to loss of social support” (p.126). Each time an individual discloses illness information to others, there are risks involved and consequences to consider. Some of the risks include stigmatization, stereotyping, prejudice, discrimination, disbelief, ignorance, and insensitivity (Vickers, 1997).

## **Stigma**

Some individuals may decide not to disclose of their chronic illnesses as a way to avoid receiving pity and being seen as different by others (Kaushansky, Cox, Dodson, McNeeley, Kumar, & Iverson, 2017). Those individuals do not want to be seen as weak, sick, or deserving of pity. They do not want to be defined or held back by their illness. One of the many possible consequences of disclosure of the illness is that the individual may experience social judgment (Barned, Stinzi, Mack, & O’Doherty, 2016; Goffman, 1963). Those individuals may be questioned by their friends or peers about an absence to an outing—maybe a dinner-date or planned outing to the movies and, since there is a chance peers may not understand the illness, they may judge the person and their illness. Rejection can sometimes be a consequence of telling others about a chronic illness and chronically ill individuals are often in fear of rejection from their peers when they are revealing such highly guarded personal information (Kelly, 1996). Kaushansky et al. (2017) further outline the potential costs to chronic illness disclosure as:

interest to this inquiry are the potential costs of disclosure an individual may experience, e.g. potential stigmatization, discrimination, self-consciousness, social avoidance or rejection, and potential physical harm. (p.50)

## **Vulnerability**

People often have their guards up and avoid vulnerability, but disclosure of the individual’s illness leaves that individual vulnerable (Kelly, 1996). As discussed above, (Gibbs, 2005) underscores that masculine culture prescribes that men are not to be vulnerable, because vulnerability implies weakness. Another consequence of disclosure that men must face and manage is the loss of control that comes with chronic illness and the disclosure of it.

## **Loss of Control**

As previously stated, one of the prescribed behaviors within dominant masculine culture is that a man should be in control (Charmaz, 1994; Gibbs, 2005; Kimmel, 2006; Kvigne et al., 2014). Chronic illness brings with it a loss and lack of control (Charmaz, 1994; Charmaz, 2005; Kvigne et al., 2014). For chronically ill men, a disclosure of chronic illness information is an agreement to give up a certain amount of control (Petronio, 2000). Some men choose not to disclose as a way to preserve this sense of control, thus perpetuating the cycle of masculine culture prescriptions of silence being synonymous with strength (Bjorkman, 2014; Charmaz, 1994).

## **Non-Disclosure**

Because of the risks of disclosure, some men with chronic illnesses choose not to self-disclose to others, largely, because they believe that others will not understand (Charmaz, 2002). Kaushansky et al. (2017) expand this point as they describe how the individuals in their study of male and female adolescents; specifically, participants reported that they would not disclose information about their illnesses for fear that others would not be understanding of the illnesses or circumstances surrounding them. In this study of young adults who live with chronic illness, the researchers found that not being understood, especially about something critical such as a chronic illness, is frustrating and creates a risk to the senses of identity and self for the chronically ill. Some will remain silent because they are in fear of having the information they share being disregarded, ignored, or minimized.

Some illnesses bring with them such a stigma that the individual with the illness is dehumanized and thought of in terms of the illness rather than as a person (Frank, 1995). Those who disclose illness information are at risk of being labeled as deviant or abnormal. Greene and

Petronio (2000) found that a label of being deviant is placed upon the disclosing individuals because their peers do not understand the illness or how it affects that person's life. Being seen as not normal and deviant can lead to social crises and, as Fry and Bates (2012) contend, to social ostracism. Some choose not to disclose at all because of the risk of being seen as not "normal" (Kaushansky et al., 2017). By withholding any or all information about the chronic illness, a man eliminates nearly all the risks of being labeled as deviant. Some individuals may choose to not disclose any information in hopes that others will think they do not have an illness at all.

### **Benefits of Disclosure**

There are many reasons for individuals with a chronic illness not to self-disclose information about that illness to others but there are also many reasons *to* disclose. Disclosure can benefit the ill man.

#### **Informing**

First, an obvious benefit is others being informed about the situation. Some decide to self-disclose because they want to inform others about their illness and their situation (Martin, 2006; Greene, 2003; Munir, 2005; Kelly, 1996). For example, chronically ill students will often times tell their teachers or school officials about their illness to inform them about what is going on and to avoid penalties from illness-related lateness or absences (Kaushansky, 2017). People may be confused and not understand the illness, and so disclosing information about the illness could help to explain the changes that the chronically ill are going through in ways that make sense to others (Martin, 2016).

## **Knowledge Control**

A second benefit is the control of knowledge. Chronically ill people can sometimes exercise control over other people's knowledge of their illness through strategic disclosures (Barned et al., 2016). People's knowledge of other people's illness depends, to an extent, on what the person with the illness has told them about it. The management of that knowledge is a very important part of the overall illness identity management (Barned et al., 2016).

## **Sharing**

A third benefit is that, when disclosing to someone with a similar illness, information may be shared that helps the teller gain knowledge about their illness which helps them with the self-management of that illness (Petronio, 2000). Some people will disclose to someone for the purpose of sharing insights in hope of helping with illness management (Kelly, 1996). Over time, the disclosures will help the individual understand their illness and the choices made as to who, when, why, and where to disclose (Kelly, 1996). Barned et al. (2016) discusses how chronically ill people may receive much needed help after disclosure (such as access to a bathroom or understanding of absences from work or school). If the individual never discloses, then there is no way to know if support is available (Vickers, 1997). Petronio (2000) explains that "a person must see benefits (and how they outweigh risks) before being willing to expose themselves by disclosing" (p.126). Without clear benefits from the disclosure of illness information, a chronically ill person is much less likely to disclose specific aspects of their illnesses and may not be willing to disclose at all.

## **Disclosure Decisions and Strategies**

Because of all the variables of masculine culture and the consequences of disclosure, disclosure decisions must be carefully made. Many men have developed strategies that may be used when making decisions about and performing the communication act of disclosing. These strategies include weighing the costs and benefits, incremental disclosures, and concealment.

### **Cost vs. Benefits**

Given the apparent tension when making disclosure decisions, it makes sense that individuals would form strategies to help manage disclosing. For example, in an earlier study Munir (2005) identified that a strategy which individuals with a chronic illness will often enact is a cost versus benefit analysis to help them decide whether or not to disclose in a particular setting or to particular people. These individuals are attempting to predict if exposing themselves and revealing information about their illness will be beneficial enough to face the possible risks of disclosure. As Petronio (2000) explains, “People must balance competing needs to obtain benefits from disclosure yet avoid negative consequences from sharing” (p.123). When the benefits of the disclosure outweigh the costs, individuals are much more likely to disclose information about their illnesses. Sometimes, a test of other people’s reactions to disclosure is a strategy which chronically ill individuals will use to gain insight into how people will think about and react to their illness, which then helps in implementing a more thorough cost-benefit analysis to make the decision of whether or not to disclose (Charmaz, 2002).

### **Incremental Disclosures**

Kelly (1996) discusses how people’s reactions have a significant impact on the disclosure of chronic illness as, “perceived reactions from confidant (listener) determine if the revelation/disclosure is beneficial to the teller” (p.450). Depending on the perceived reactions

and costs, keeping secrets and not disclosing can sometimes be more beneficial than telling (Kelly, 1996). Some will assess the situation, do an analysis of costs and benefits, and decide that disclosure should happen *only* when necessary (Barned et al., 2016).

Men can be selective in who to disclose to (Slepian, Camp, & Masicampo, 2015; Barned et al., 2016). Silence and disclosure can be directed toward particular audiences, often as a way to keep the illness out of view from certain people (Charmaz, 2002). Individuals are much more likely to tell about their illness when they are in a comfortable environment and when they are around certain supportive people (Slepian et al., 2015).

A chronically ill individual is more likely to self-disclose to others if that disclosure has already happened elsewhere (Munir, 2005). Positive experiences with the disclosure of chronic illness information increases the discloser's confidence and ability to articulate. People are much more likely to talk to others who share commonalities, which applies to those with chronic illnesses as well. For example, an individual is much more likely to disclose to someone who shares the same chronic illness or who knows someone with the same chronic illness (Kaushansky et al., 2017). Finding commonalities among others with similar chronic illnesses is a great way to gain knowledge about and become more comfortable with the illness and it also helps the individual with the management of their identity.

### **Concealment**

A partial disclosure strategy is sometimes used as a way to pick and choose which information about the chronic illness to disclose and which information to keep hidden (Fry and Bates, 2012; Munir, 2005). Through this, the chronically ill man will choose which information to tell that they believe will have the most benefit to them while leaving out the parts that they believe will harm how others view him. Munir (2005) explores how she believes that,

“disclosure is necessary for effective management of illness”, but that partial disclosure seems to be the best route for those who are more inclined to keep information to themselves (p. 177).

Many men have boundaries set as to what information is tellable and what information is off limits. Kelly (1996) found that secrecy helps people maintain their personal boundaries. A person’s boundaries help to give them a sense of identity, and a risk to that person’s boundaries is a risk to that person’s identity. Martin (2016) discusses how important communication was for her study participants as they managed those risks: “Participants recounted various ways that communication is central to the process of managing these threats to identity” (p. 315). Communication is not only essential for the management of the masculine identity, but also for the management of the illnesses themselves.

### **Summary**

An examination of the literature provided information on masculine culture, the consequences of disclosure, the benefits of disclosure, and disclosure strategies that the chronically ill use to navigate disclosure decisions. Men are taught to be strong, independent, and in control; however, chronic illness presents challenges in upholding a masculine identity. Consequences of disclosure of illness information include stigma, vulnerability, and loss of control. Benefits to this type of disclosure include informing, knowledge control, and sharing. Illness disclosure strategies include a cost versus benefit analysis, incremental disclosures, and concealment. There is a need for targeted, male illness-experience specific, research to be added to this body of literature. There is a lack of literature that focuses on the lived experiences of chronically ill men, especially regarding their illness-related disclosures. This study explores the intersection between illness related self-disclosure and masculine culture. Additionally, this

study attempts to fill in some of these holes by providing examples of men living with chronic illness navigating masculine culture, their illnesses, and disclosure decisions.

## CHAPTER 3

### METHODOLOGY

Given the sensitive nature of this topic, a qualitative approach was chosen by the researcher to examine the experiences of men who live with chronic illness. The use of qualitative methods in this study was useful because qualitative research attempts to gain a better understanding of the lived experiences of people and it takes a deeper dive into unknown phenomena (Berg & Lune 2007; Charmaz & Belgrave 2007; Strauss & Corbin 1990). Drawing on Berg and Lune (2007), the researcher developed an initial research question; though, that question changed over time as the study provided emergent data. The final research question became: What communication challenges do men living with chronic illness express facing when disclosing illness information, and how do they navigate those challenges?

#### **Participants**

The participants ( $N=5$ ) in this research study of chronic illness self-disclosure all identify as men. The sample included individuals who attested that they are at least 18 years of age, identify as male, and have one or more chronic illnesses. The ages of the participants range from 21 to 59 years. To find men who were willing to participate, the researcher used the online discussion forum Reddit. Internet-based research was employed given the sensitive nature of the topic. Additionally, as Mann and Stewart (2000) explain, “In the online environment, there are fewer of the constraints associated with conventional research as many of the difficulties of accessing multiple, and geographically disparate, real-life sites disappear” (p. 79).

Reddit is a social media website that contains forums of various topics. Users create an account and choose a username, which leaves the users anonymous. Mann and Stewart (2000) discuss the anonymity that internet-based usernames provide as, “It is possible to circumvent

social cues which might be suggested by names or email addresses by, for instance, opening an ‘iname’ account. This allows the user to choose a context-free username (which can be almost anything)”, arguably making the users more likely to share information that they would not normally divulge in other settings (p.80). The users engage in discussions and sharing on the various forums. The community is self-regulatory, in that the users upvote or downvote posts depending on whether or not they like them, which highlights the posts that people like the most.

Following granting of approval by the Institutional Review Board, permission from the site’s moderators was sought by the researcher, per the study protocol. After permission was secured and documented, the researcher posted information about himself, this study, IRB approval, and a recruitment request letter. The researcher targeted forums about chronic illness and chronic conditions. The researcher contacted eight different subreddits. “Subreddit” is the name Reddit uses to call an individual discussion forum. Reddit is the main website, while subreddits are the many various discussion forums on the website. Of the eight subreddits targeted, two were willing to allow the researcher to post a recruitment letter. There was resistance met, with some moderators not allowing the letter to be posted due to privacy and confidentiality concerns—as Reddit is a guarded and highly involved community. The researcher used purposive sampling to gather participants, selecting the participants “on purpose” (Berg & Lune, 2012; Mann & Stewart, 2000). This study uses this approach of purposeful sampling, targeting specific discussion boards, to remain focused and to find individuals who, as Mann and Stewart (2000) state “have experienced the phenomenon under study and are prepared to be involved” (p.78).

## Data Collection and Procedures

In fall, 2018, recruitment letters were posted to Reddit, with 21 males responding to the recruitment posts (see Appendix D) on Reddit, and five of them committing to and participating in an interview. The interviews were conducted via telephone, allowing for additional layers of protection of participants. Interviews lasted between 29 minutes and 1 hour, 40 minutes.

Drawing on existing literature (DiCicco-Bloom & Crabtree, 2006), a semi-structured interview schedule was constructed (see Appendix A) and used for each of the interviews. Utilizing a semistructured interview schedule is useful because it provides the researcher with a guide of questions while also allowing for conversation that may stray from the guide, probing questions, and open-ended questions. Including open-ended questions and probing topics that may diverge from the interview guide provides an opportunity to identify new ways to see and understand phenomena (DiCicco-Bloom & Crabtree, 2006). The interview schedule contained questions ranging from those about demographics to those about the disclosure of illness information, how that disclosure is handled, and how masculine culture effects these. Table 1 provides some sample questions from the interview guide.

Table 1

### *Interview Schedule*

---

#### Sample Questions

---

Tell me about how the usual conversation about your illness goes.

Talk to me about how being a man affects how you talk about your illness.

Imagine you are talking to a man who has been newly diagnosed with (chronic illness), what tips might you give him on talking about it?

---

Participants were informed about the research project. Each of the participants were asked to verbally attest to an informed consent document after having the research explained to them. Participants were then asked if it is okay that the conversation be recorded. Then, the participants were asked to confirm again that they agree to the informed consent document and that it was okay to audio record the interview to attest that consent had been given on audio record. Each participant received a sheet of guidelines (see Appendix B) which explained the process of the interview and gave some general rules. Each participant was ensured that there were no right or wrong answers to the questions being asked, but that the researcher was looking to hear their experiences of being men with a chronic illness and how they disclose about those illnesses to others. As this researcher asked participants to share some more personal information and stories, adequate privacy was provided and ensured. Transcripts, coding, memos, and anything containing information about this research project and its participants were stored on a password protected computer. The participants were informed that a thesis would be written from the findings through the analysis of transcripts from the interviews and that a presentation would be given on that thesis. Pseudonyms are used in place of names and all personal identifiers have been omitted from all parts of the project to ensure participant confidentiality. The names of specific locations have also been omitted.

### **Data Analysis**

The interviews were audio recorded after receiving permission from each of the participants. The audio recordings were transcribed verbatim to allow for deep analysis and coding. Transcription resulted in a total of 85 single-spaced pages. Field notes were written directly after each interview. Each transcript was read entirely so that the researcher could get a general feel for what the participants were saying. The transcriptions were analyzed and coded,

informed by the Grounded Theory approach (Charmaz & Belgrave, 2007; Strauss & Corbin, 1990; Strauss & Corbin, 1997). Data were analyzed in many different ways and the researcher took multiple approaches, utilizing initial coding, line by line coding, in vivo coding, focused coding, axial coding, and memo writing. Memo writing allowed the researcher to take the data and coding that had been broken apart and form it back together while writing a high order analysis that built the results section. The use of qualitative methods for analysis allowed the researcher to analyze and see the data in various ways, each providing a deeper perspective and understanding (Berg & Lune, 2007).

Through the coding and thematic analysis, common themes emerged and were explored. Those themes include the participants expression of masculine culture, the communication challenges chronically ill men must manage, and the communication strategies that participants report using to navigate those challenges. This study was not driven by a theory. Rather, the researcher let the data reveal themes and categories as they emerged. To promote flow and conciseness, some of the participants' quotes have been edited for clarity. While no change was made to the words that the participants said, some sections of quotes were omitted to promote clarity.

## CHAPTER 4

### RESULTS

The analysis and coding of the data from interview transcripts uncovered three primary themes emerged within this study. The first primary theme reveals how participants characterize being a man within hegemonic masculine culture. The second primary theme, then, highlights the disclosure related challenges they have had to navigate while living with chronic illnesses within that masculine culture they identified. The third and final primary theme that emerged was disclosure strategies. The participants talked about the various disclosure strategies that they enact in different situations. They highlight how disclosure decisions are based on the visibility of their illnesses and the source that provokes their disclosures.

#### **What is a Man?**

The participants in this study expressed their perceptions of what masculine culture is, and, more specifically, how a man is supposed to behave within the context of that culture. Participants talked about how the presence of chronic illness affected them within hegemonic masculine culture. Hegemonic masculine culture is the legitimization of powerful men's dominant position within society and finding ways to justify the subordination of the average male, women, and other non-dominants, including those living with chronic illness (Connell, 1990; Gibbs, 2005; Kimmel, 2006; Kvigne et al., 2015; Moss-Racusin et al., 2010; Trujillo, 1990). Through analysis of this primary theme of masculine culture, three secondary themes were found in participant descriptions of masculine culture. Participants expressed being aware of masculine culture and upholding it in the following ways: 1) remaining strong; 2) remaining independent; and 3) remaining tough. These findings echo the findings of previous research, as well as extend them, as discussed below.

## **Men are Strong: “men should be tough”**

Underscoring previous research (Kvigne et al., 2014), participants in this study revealed that a defining trait of masculine culture is that of strength. For example, Thomas expressed:

They're this strong, we are perceived as the stronger gender even though you know science has pretty much disproven that.

This is a particularly interesting quote in that Thomas reflects an understanding of the larger masculine culture while also rejecting it; however, like over half of participants, Thomas acknowledged concealing his chronic pain because of those same cultural norms he critiques, also dictates that he be strong.

What appears to be a prescriptive outcome is that men conceal their weakness, including pain. Rather, men are to keep information about such aspects of life to themselves. A man is viewed as ‘too strong’ to be in pain, and thus if a man acknowledges that he is in pain, he is considered weak—and in being weak, he is less of a man. Jeffrey expressed that this view on men keeping such information to themselves is not only a belief that he holds, but that it is part of masculine culture. He said, “your, um weak, or you look weak”.

Similarly, John echoed:

I think that most men, definitely me included, is that you don't really talk about pain that much.

Later, in the interview, John further explained this connection between masculine culture and the hiding of pain.

You know some men maybe they did have the pain there but they just didn't want to admit it you know...And they want to tough it out, they want to look strong, whereas you know they've got crippling pain inside of them...And you know this is the reason that we've been hidden for so long. (John)

Repeatedly, participants signaled the prescriptions advanced by masculine culture, particularly prescriptions related to the expression of pain. As Thomas said, "You know a man is not supposed to scream out in pain, cry, you know or even really acknowledge more than an oh it hurts." Richard pointed to stigma as he said, "Well there's obviously a stigma, men should be tough." Participants spoke of the stigma surrounding men, specifically men who violate the gender-specific disclosure prescriptions. Participants talked about the reactions of others to hearing that they are in pain. They expressed that even though some do not say it, they felt that others are at least thinking of him as someone who is just complaining. Richard said, "Yeah, I'm not going to whine about it 24/7, but it's true you know I am in pain."

Men are not supposed to be in pain in the first place, let alone be seen crying because of pain (Courtenay, 2000). But, men *do* have pain, they do have feelings, and sometimes no matter how hard a man tries to follow masculine culture prescriptions and be the 'manly man', he will not be able to always hide it. Other men, do not try to hide it at all; however, they risk receiving unwelcoming responses when they violate the basic tenets of masculine culture. Thomas revealed that there were times his pain had been evident, noting that:

People look at you really really weird...and it's really hard because you know, its uh obviously you can't take the pain, you know you're not strong enough, you're weak.

Subsequently, as indicated by John, men who experience pain, therefore violating the norm of strength, risk being stigmatized. He said, “I know that there's a lot of stigma and there's a lot of just kind of you know prejudice around the idea of men with chronic pain and chronic disorders like that”. John expresses that men have been hiding their pain so that they can look strong and adhere to the masculine principle of being tough.

### **Men are Independent: “the man brings home the bacon”**

Participants expressed that men are supposed to be independent. Men are to be able to handle everything on their own without the help of others. This responsibility of independence permeates beyond the realm of caring for oneself and encourages men to provide for others, such as loved ones. John revealed:

I feel even worse because there is the whole concept of you know, the man brings home the bacon, and all that.

John spoke of the idea that the man in relationships should be the one who makes the money—or at least more of it. He explains how these masculine ideas perpetuate themselves and how it can be difficult to push back against them because they are so deeply part of masculine culture and of who many men are. John states:

And the other of course is the whole breadwinner, man of the house type thing [...] I very much understand that is kind of some toxic cultures in our past, you know and I uh, but but there is an extent of it, like its ingrained and it can't necessarily be pushed out.

John talked about his feelings of not being able to support his and his fiancé's relationship financially. He mentions the views that others have expressed having of him because of not being the main provider of his family and violating masculine culture norms. He said, "So, like, someone came up to me and was like 'oh, your fiancé is the breadwinner, wow you must feel emasculated.'" John reveals that men are supposed to financially support their families. He said:

We're not rich, we're not independently wealthy so its, I feel bad because I'm not supporting us when we need it.

The participants add that not only are there general negative feelings they have about the financial instability, but that there is an added layer of shame and guilt because of not living up to masculine culture's standards. Richard revealed:

I do have the negative feelings just because I am not providing and [...] most people would assume if anything it would be her stay at home not me, you know...I know that other people think that as the man in the relationship, I'm basically leaving my partner out to dry.

John spoke of the dependency that has come along with his chronic illnesses. He explains that he has lost independence because of his illnesses and that he has had to make sacrifices in many aspects of his life such as with significant others, with education, and with living arrangements. This focus on independence appears to impact illness-related disclosures, as will be discussed further below. John also spoke of the expectation that he has that others will look down on him because of being less independent. Through this, John is highlighting

masculine culture's prescription that a man should provide for his family (Bjorkman, 2014). He said:

I know that expectation is there, so even if they've gotten over it, even if they're convinced that yeah no matter how hard he can try he can never hold down a job [...] that its reasonable for me to be where I am, I would feel convinced that they should be thinking less of me.

This independence appears to translate into the participants expressing the feeling of being compelled to protect their loved ones. Thomas said, "Well generally in society men are seen as the people that protect, um you know, women, children." Underscoring this point, John talked about the negative feelings brought about by not being able to uphold the masculine image of being independent. He believes that others see him as less of an adult and less of a man because of the dependency brought about by his chronic illness.

I feel that way with just about everyone, you know, that probably the first thing that they think about when they see me is how I live at home without a job. And I will always remain so, not only in concept or family like latter, but in just who I am, just a kid who lives at home without a job. (John)

John expressed shame for not upholding the masculine prescription of independence and providing for others as he said: "But it's hard for me to think that largely that they would be over them, because I haven't gotten over them. I still feel like crap for not really supporting us financially." He also highlights the inability to drive as one of the main sources of his shame regarding his dependency. He revealed:

I don't drive because of my legs and vision, and a lot of reasons...So, no driving.

Don't have my own place. Don't have a job. You know, so I've missed like a lot of adult milestones that I'll probably not get to hit...So I have a lot of negative feelings toward myself and I, it's hard to imagine that you know close family doesn't as well.

What John's quote suggests is that masculine cultural prescriptions dictate that men should provide and be providers—especially of monetary well-being and wealth, and when a man is incapable of meeting those prescriptions, he will judge himself as insufficient, as will those closest to him. Henry expresses shame when not adhering to that prescription. He said, “The reason I personally have a problem with it now is because we are not financially stable (laughs)...We're not rich, we're not independently wealthy, so it's, I feel bad because I'm not supporting us when we need it.” Hegemonic masculine culture dictates that the man of the relationship is the one who should provide financially for it. John expressed the shame he feels because he and his wife are not financially independent, and because of his chronic illness, she is the one who supports their family. The shame John expressed stems not only from not being able to heavily contribute to their family's financial well-being but also from not meeting masculine cultural norms. John also talked about how important driving is for independence and image within masculine culture as he said:

Driving is huge for people. Driving is such a big thing for independence you know, you can just get up and go wherever the hell you want anytime you want, when you have a, own a car that you can drive. Like not only can you do things on your own but it's a, there's the image behind it. It's a very machismo thing of like oh I've got this you know modded out car you know, I've got this baby gets up to 200 you know like (laughs).

He continued: “But this whole image...So not only do I not have the image, I don’t have the actual functionality either”. John revealed that, because of his illnesses, he is unable to drive. He expressed that his inability to drive inhibits his freedom and independence, which undermines his ability to uphold masculine cultural norms and prescriptions of independence and control.

### **Men are Resilient: “Suck it up and deal with it buttercup”**

According to the dominant masculine culture, the masculine man deals with the hand he was dealt. He takes what he is given and finds a way to work with it. If a man is born with a chronic illness, then he should find a way to work around it while keeping his mouth shut about it. Men are molded to believe such ideals and let them guide their lives, as Jeffrey expressed:

I think that as a man, sometimes we’re expected to [...] toughen up and you know take whatever we’re dealt, right. At different times I can feel that.

All five participants spoke directly or indirectly about the resilience that men are expected to have within this society. Men are supposed to keep going no matter what obstacles he may run into—no matter the illness or pain. Thomas stated, “I’m from the rub some dirt in it, man up, you know...Keep on going...But it's not quite as simple as that unfortunately.” Arguably linking the emergent findings about pain and resilience, participants revealed the reactions of others regarding disclosure of pain. Richard said:

And telling people that I'm in pain 24/7, they're usually surprised by that, and a lot of people’s reaction is [...] just deal with it, you know everyone hurts somewhere, everyone has got some pain so you gotta just deal with it.

Henry spoke of masculine culture as being the “old way”, while still revealing that those old ways have permeated through generations and still very much exist today. He mentions the masculine ideals that men should keep their own personal information to themselves and just find a way to deal on their own. He said, “The old way these types of things was to you now, keep your mouth shut, nobody needs to know your business, and it's, you know, find a way to suck it up and deal with it buttercup.” Then, Henry explained that just because masculine culture views certain things in certain ways, does not mean that that’s the way they really are, as he says, “You know, that’s the way that its viewed. And the thing is, just because we’re guys, doesn’t mean that we don’t have struggles.” Henry went on to say:

Those emotional things that they don't want anybody to know about...But, you know just because, a lot of it is because of the stigma of you know hey you know you're a man and you should just deal with these things and you're not supposed to have those problems.

Henry revealed, “You're not supposed to have, you know be emotional, that’s a woman’s job, and that's something that women do, that’s, men don’t do. And you know we are supposed to be rough, tough, and able to handle it...But, that’s not always the case.” Henry pointed out the masculine prescription that men are not to be emotional—only women are allowed to talk about and show their feelings. A man is supposed remain stoic, without telling anyone or asking anyone for help, even though they may be in dire need. The intersection between chronic illness and masculine culture brings about unique challenges for men when disclosing and trying to adhere masculine norms.

## **Disclosure Challenges**

Given the cultural prescriptions of being a strong, tough provider, it is hardly surprising to find that the participants' illness-disclosure experiences were informed by these prescriptions. Participants expressed that there were numerous challenges to disclosing chronic illness information to others within the hegemonic masculine culture. Through analysis of the primary theme of disclosure challenges, secondary themes emerged that shed light on them. The main challenges to disclosing chronic illness information expressed by the participants were: 1) the barriers of pain; 2) dependency; 3) loss of control; and 4) the visibility and evident-ness of the illness.

### **Barriers to Maintaining Masculine Norms/Prescriptions**

**Pain: “they want to tough it out, they want to look strong”.** The men in this study were concerned about the aspect of pain within their chronic illnesses and within their lives. They spoke about how pain presented one of the major challenges and barriers to maintaining masculine prescriptions and upholding norms. Thomas, who lives with multiple chronic illnesses causing much pain, said:

So when, you know, something happens and it causes me to be in pain that I literally curl up in a ball and start crying, people look at you really really weird.

Pain, or more likely the expression of pain, is equated with weakness within masculine culture. The men in this study express that they go through much effort to conceal their pain so that they are not seen as weak and so they do not violate masculine norms. As John expressed, men will try to look strong, even in times of immense pain, “Some men maybe they did have the pain there, but they just didn't want to admit it you know...And they want to tough it out, they

want to look strong, whereas you know, they've got crippling pain inside of them." Within masculine culture, pain is kept so concealed, that it can be shocking to others to hear a man disclosing that he has pain. John talked about this as he said, "And telling people that I'm in pain 24/7, they're usually surprised by that." Richard brought up the visibility and evident-ness of his pain. He expressed that, when the pain becomes visible, it can no longer be hidden. Others take notice and thus Richard's masculine identity is at risk because he has deviated from masculine cultural norms. He said:

I have tremors from the pain time to time, with some medications [having] made that a lot worse and it's been like, so it's something you can't hide, you're like shaking all the time you know.

Sometimes pain cannot be concealed, no matter how much effort an individual puts into hiding it. During times of acute pain, others are more likely to notice. John spoke of a time when he had intense pain that could not go unnoticed, "And everybody got dead silent and I, the pain just came on so like intense that I fell forward off of the chair I was sitting on onto the deck of the patio." Living with chronic pain can take its toll on people, both physically and mentally. Putting in large amounts of effort to conceal that pain to adhere to masculine culture norms can greatly exacerbate that toll. Richard spoke of pain and how it affects a person's mental health as he said, "I'm in a lot of pain and its affected me you know, my mental health quite a bit."

**Dependency: "from the stages of being independent" to "sometimes there were times I could barely do anything for myself"**. The participants in this study revealed that a second barrier to maintaining masculine cultural norms is depending on others. Relying on others for help is in direct violation of the masculine prescription of independence. A man

should not need assistance in any matter of life. Thomas expresses that, when the independence prescription is violated, a man not only deals with that deviation of that norm but must also navigate shame. For example, he reveals that, when he and his wife met, he was independent, but as time went on and his chronic illness worsened, he began to rely on her more and more.

It took its toll on her [my wife], it really did, um she had to deal with me from the stages of um being independent, sometimes there were times when I can barely do anything for myself and she had to go to work, take care of our son, and help me. So, it put a lot of pressure on her, and it did fracture our relationship for quite a while. (Thomas)

Thomas expressed the feeling of shame for being dependent upon others, his wife in particular, because of his chronic illness. He explained that his dependency and feelings of shame have increased since the onset of his illness. He explained that his dependency upon his wife has put a tremendous amount of pressure and responsibility on her, and it has taken its toll on their relationship.

I know that I'm judged frequently because of that. Like people I meet and even friends, um and I feel bad too because like, my parents we live out in the woods you know...So say if all our friends wanted to get together, somebody's gotta go out to the woods to pick me up...And get me to the place, and then somebody's gotta go out to the woods to drop me off...So I feel bad about it all the time.

(John)

John spoke about the shame he feels from not being able to drive and having to depend on others to get from place to place. This goes to show how chronic illnesses are not just

physical and mental, but they are social illnesses as well. Chronic illness permeates beyond the individual's private life and into the public and social life (Charmaz, 2000). It affects a person's relationships—their ability to retain them and make new ones. Because John must rely on his friends for a ride to and from gatherings, there is a strain and tension on their relationships together because if he did not have his chronic illnesses, he would not be depending on them for rides.

**Lack of control: “I've missed like a lot of adult milestones that I'll probably not get to hit”.** As already discussed, masculine culture prescribes that men be in control of every aspect of his life (Charmaz, 1994). Thomas clarifies the challenges to disclosing that arise because of this emphasis on control. Because Thomas has lost his independence over time, he has also lost control over time. He explained how he has gone through great and varied measures to regain some of that control. He said, “I went to the Chinese community herbalist and everything, acupuncture and all that, and I was still not leading an independent life. I was still bedridden most of the time.”

Likewise, John expressed the lack of control due to his chronic illness:

I didn't continue my education, I didn't even finish my education. My fiancé moved to continue her education because [...] she still could. So that forced my relationship to become long distance for three years. It forced me to stay at home with my parents instead of moving out.

John explained how he lost control over the directions his life has been taking due to his chronic illnesses. He has had to discontinue attending school, he has had to navigate a longdistance relationship, and he has had to remain living with his parents rather than moving

out on his own. This lack of control has brought about great shame to John and he explained how that shame has led him to assume that others view him poorly. He said, "I feel that way with just about everyone, you know, that probably the first thing that they think about when they see me is how I live at home without a job." John revealed his missing out on life milestones because of his illness. The lack of control he has over the completion of those milestones leads him to shame. According to masculine culture, a man who is in control would have no problems reaching life milestones regardless of illnesses, when in reality it is not that simple. As John's explanation goes to show, chronic illness and the lack of control that comes with it, can hinder one's ability to reach those milestones. He said:

I've missed like a lot of adult milestones that I'll probably not get to hit...So I have a lot of you know negative feelings toward myself and I, it's hard to imagine that, you know, close family doesn't as well.

Some participants expressed that the lack of control within their lives not only makes them less of a man within masculine culture, but also makes feel less of an adult. John spoke of this as he revealed, "And I will always remain so not only in concept or family like latter, but in just who I am, just a kid who lives at home without a job." Being seen as less of a fully operating adult within society comes with its own various communication challenges. Henry revealed the struggle he has with the lack of control in his life because of the stigma that surrounds his chronic illness, he stated:

But if me being diagnosed with depression reaches a certain level, then legally they can come and strip me of my guns and strip me of my right to bear arms and my ability to be able to stand up and defend and help my community...So there is

quite a bit of negativity that comes with even discussing having a mental disorder such as depression...And there's a serious threat to even, I would say my way of life, just by simply talking about it.

Henry talked about the lack of control that comes with having a mental illness. He explained that the disclosure of his illness information poses a serious threat to the way he lives. Being able to bear arms is part of his masculine identity, and the potential of having them taken away at any moment creates a lack of control over his life and in some ways a lack of control over himself and his life, because of his chronic illness. Participants pointed out the stigma and negativity that surrounds mental health, mental illness, and mental disorders. Most mental illnesses are not visible, and the less visible an illness is, the more difficult it is to gain sympathy and empathy from others.

**Visibility: “You can't see it. That's probably one of the things that's worse”**

The visibility of a chronic illness effects how it is disclosed about and the illness experience altogether. Disclosure decisions are sometimes based off the evident-ness of an illness (Charmaz 2000). The men in this study expressed the challenging nature of navigating their disclosures based on the visibility of their and illnesses. For example, Thomas points out that with his ankylosing spondylitis, that the, “average person wouldn't notice.” Subsequently then, disclosure decisions became trickier. If their illness is evident, the disclosure of that illness, or at least the symptoms, may be compelled, leaving the men to sense that they have lost additional control over their lives and illness experiences. On the other hand, if their illness is concealable, then they must decide among possible disclosure strategies, as will be revealed in more detail later.

The men in this study talked about the challenges they run into with the visibility of their illnesses. Chronic illnesses are often not visible to most people and so it is sometimes required of the chronically ill man to self-disclose so that others will know that they have the illness. Because others do not see the illness, they may assume that there is nothing wrong at all. Jeffrey, for example, highlights this challenge with visibility, saying:

You can't see it. That's probably one of the things that's worse. If it was a broken arm or something like that, people can see it.

Jeffrey spoke of the challenge of gaining empathy for his less-visible illness. It is easier for others to empathize with the chronically ill individual if the illnesses are visible and others can clearly see them. If the illnesses are invisible and not clearly able to be seen, it is more difficult to gain empathy from others. Jeffrey expressed, "But when it's something that's nerve related, you can't see it. The only thing they can see is I'm in pain or I kind of get this stabbing and my head kind of jerks back." Jeffrey links concerns about being stigmatized with this quality of evidentness of an illness. He said, "You feel a little bit judged...I think it, really it's the thing where you can't see it." Jeffrey expressed about how he feels that he is judged by acquaintances, such as coworkers, because of his illness. He expressed that he believes this judgement comes from the fact that his illness is nearly invisible. Others cannot see it, and so they may not believe that he has a chronic illness at all. He explained that an invisible illness brings about much more judgement of the individual than one that is visible as Thomas said:

If it was a broken leg or arm, its super easy to see, and people kind of understand that...But because it is something that's unseeable, there just seems to be a little

more judgement about it. You know, is he really in pain or you know that type of deal.

John expressed the challenge wanting to hide the side effects of his illnesses, but not always being able to. He said, “When I am able to hide the side effects, I try to. I would hide a lot more if I didn’t have to use a cane...because having a cane, people come up to you, you know, and obviously something’s wrong.” John also talked about using his cane. He expressed that his use of a cane is one of the main reasons why he cannot hide his illness. He also mirrors other participants’ thoughts in that the more visible an illness is, the more others will sympathize and empathize with the ill individual.

Other than the cane, it's really not visible, so um its, maybe I'm wrong on this but I feel like if you, so if your legs are out entirely and you're paralyzed from the waist, and you're in a wheelchair, people would be more immediately sympathetic, no matter what causes your condition. (John)

Richard expressed his fear of others noticing the side effects of the medication he is taking—making his illness visible. Others often make assumptions and make up their own minds about what they think is going on before gaining any input from the primary source. Richard revealed, “You're kind of afraid that oh if they make you sleepy maybe you will mess up at work or something or people will notice and then that’s a tough conversation because, you know if people, maybe people think you're on drugs.”

**Disclosure decisions.** Participants expressed that careful attention must be paid to the disclosure decisions that are made—especially when the disclosure is linked to the evident-ness of the chronic illness. Echoing earlier work (Joachim and Acorn, 2000), participants talked

about how disclosures were often compelled when the illness is visible and further decisions would need to be made as to how to disclose and what strategies to use. If the illness were invisible, however, there is an inclination to concealment, nondisclosure, and faking it.

***Compelled disclosure: “If I’m getting a haircut, I have to tell the person who cuts my hair because they can’t touch that area at all”.*** Emergent findings revealed that men were compelled to disclose information about their illnesses, in effect challenging established gendered prescriptions and rushing disclosure decisions. Questions and thoughts arose about this theme, such as can anybody actually *make* someone disclose? What if an emergency were to pop up and an individual *had* to disclose to save their own life—and could that even be considered compulsion? Is *having* to disclose the same as being *compelled* to? Where would that line be drawn—if there even is a line. Participant’s accounts of some of the challenges show that compelled disclosure—a disclosure that the sharer is not ready for or keen to—is one of the main challenges faced by men when they navigate their chronic illnesses. Jeffrey said:

If I’m getting a haircut, I have to tell the person who cuts my hair because they can’t touch that area at all, you know. Uh, or if I, well I haven’t gotten one in a while, but if it’s a massage or...or anything around that area, you kind of have to tell them what’s going on and I just give them a brief history that you now, shingles, misdiagnosis, extremely sensitive so just like avoid that area completely.

What is particularly powerful about the quote above is that it shows a lived situation in which a man may have to disclose even when he does not necessarily want to. Jeffrey talks about disclosing chronic illness information to others such as barbers or masseuses, even when he does not necessarily want to. In some ways he has to, because if he does not, something could happen

that triggers a flare up of his nerve pain. The visibility of an illness changes how the chronically ill individual approaches self-disclosure. If an illness is visible to others, there is no doubt that that person has the illness, but if it is not visible to others, disbelief and the need for a more thorough explanation may be encountered. The chronically ill person is likely to be in situations when disclosing to others to inform them of the illness is necessary. Thomas spoke of being compelled to disclose, he said:

I'll bend over and I'll fracture a vertebra or slip a disk...Or I start having muscle spasms that last over 15-20 minutes. People notice that there is something that's not quite right and they're quick to pull the trigger to call for um emergency services.

Thomas spoke about hiding his illnesses when he could, but that there are times when he has no choice but to disclose. Even though he may be able to hide the invisible parts of his illness, the tremors make his illness visible which compels him to disclose. Others will notice that something is going on, and to avoid letting them jump to conclusions or prematurely call emergency services, he will disclose some of his illness information. Thomas also talked about the first time he disclosed information about his chronic illnesses. He revealed:

It actually happened to be a fraternity brother. I was at the house and there was about 4 or 5 of us hanging out and we were on the back patio. And I bent over to grab a lighter and I just heard this snap. I mean everybody in the room pretty much heard the snap. And everybody got dead silent and I, the pain just came on so like intense that I fell forward off of the chair I was sitting on onto the uh deck of the patio...And that was when I had to have a discussion about what was going

on and basically, you know, they were like do we need to take you to the emergency room, what's going on.

Challenges of compelled disclosures are further highlighted by participants' discussion of medication side-effects. John described the side effects of some of the medication he is taking.

The side effects of his medication are visible to others. This makes the side effects, in a way, their own disclosure. He also talked about using his cane, which can be seen as a form of forced disclosure as well. He said, "because having a cane, people come up to you, you know, and obviously somethings wrong." John is not actively trying to disclose that he has a chronic illness to others, but his cane does not allow him to hide. His cane is a form of disclosure in itself. If he did not have to use a cane, the average person would likely look at him and see nothing wrong on the surface. Using the cane, however, signifies that John needs a form of assistance, which signals that there is something wrong with him. Without saying a single word, the fact that he has a chronic illness is disclosed. Richard also talked about being compelled to disclose as he said:

If I ever have a conversation with people, I would say about half the time is because someone noticed me uh turning and cracking my neck.

Richard spoke of others noticing the "tick" he had developed as a way to relieve some of the pain and pressure he has in his neck. Others notice him twisting and turning his head and ask him about it. The tick, when noticed, is compelling him to disclose illness information. Once others notice him doing this, his invisible illness becomes visible. Richard also talked about others noticing the side effects of some of the medication he is taking. While the communication

challenges for men living with chronic illness are numerous, there are several strategies that ill men report using to navigate and manage those challenges.

### **Disclosure Strategies**

Participants spoke of using various strategies when disclosing chronic illness information to others. They expressed that strategies are situational—that no one disclosure strategy is best for all encountered situations. While it is up to the individual when, where, and how to use disclosure strategies, the men in this study revealed their main strategies of: 1) quick-fire disclosure; 2) disclosing symptoms rather than diagnosis; 3) swapping a complicated diagnosis for a simpler; 4) faking it; 5) mediated disclosures; 6) managing the privacy of information after it has been disclosed; 7) disclosing to educate; and 8) intimate disclosures. These strategies are explored in the following section.

#### **Quick-Fire: “it's just a nerve pain that I deal with”**

Participants expressed advantages to giving disclosures that were quick, containing few details about the illness or broader illness experience. This strategy was revealed to be used when disclosing to strangers or to those who seem hostile and unwilling to empathize. This strategy links with the masculine cultural prescription of keeping quiet to uphold the norm of being strong, helping him to achieve some minor disclosure-related goals while minimizing the threat to his place in the masculine community. The fewer details a man discloses about his illness, the less likely it is that others will view him as weak. Jeffrey revealed:

You know it's very rare that I do [disclose]. But when it is, I would just say I had a bad case of shingles and the shingles got misdiagnosed and that's left me with some nerve pain in my forehead.

As Jeffrey expressed the way he discloses to strangers, he began to reveal the strategy of a rapid-fire response. He would give short explanations with no details—somewhat adhering to masculine prescriptions of not talking about illness and pain. This allowed him to disclose some of his chronic illness information without incurring as much risk as going into depth about his illness to every single person. John echoed Jeffrey’s thoughts on disclosure with minimal detail. He said, “Be careful with um, fibromyalgia. Use, use the term “chronic pain disorder” or um, discuss that you have a nerve syndrome, or something along that line.” Jeffrey talked about not going into depth when he is disclosing information about his chronic illness. He expressed his concern with how others may feel when he discloses to them. He does not want to bring the mood down or cause others to be sad for him. He said:

Normally I wouldn’t tell them the depth of it [my illness and the challenges it causes for me] just because it’s kind of depressing...So you might just say its, you know, it’s just a nerve pain that I deal with. But, I just don’t go into what the depth of it is or the history.

Jeffrey talked about giving a rapid-fire explanation of his chronic illness. He said: “Just say, okay, I have an area that’s extremely sensitive, you know”. Rather than going into depth and throwing out biomedical terms and language with his trigeminal neuralgia, he seemingly drops in a simpler version, such as the quote above, “nerve pain”. Thomas mirrored other participants’ thoughts on the quick-fire strategy of disclosure. He expressed that it is not necessary to give detailed information about chronic illness when disclosing. A short explanation with no details is what he highlights as he said:

Most of the time I just tell them that I uh have a, I have a neurological disorder from birth and I have arthritis, is basically all. You know, I don't really delve into much of it because I don't feel that it's quite necessary.

Echoing Thomas' explanation of the rapid-fire approach, John said, "Usually I just answer that I have a, I'll either say that I have a chronic pain disorder, I'll say I have a chronic nerve syndrome or disorder...because it's usually much easier and more accepted than fibromyalgia." John speaks of the stigma that surrounds his chronic illness as a primary motivator to disclose with as little information as possible. Rather than giving others the complicated name of his diagnosis, John tells others simply that he has a chronic pain disorder. This rapid-fire explanation that has little to no details brought about fewer invasive questions from others. He said:

I often just say a basically either I have a generic pain disorder or generic nerve disorder, and then sometimes I loop in my arthritis. In public usually that's enough for a person to be like "oh okay sorry" you know, whatever and move on. I usually limit it to the I've got a chronic pain disorder and it makes so that I have difficulty walking.

Participants indicated that prior to using a rapid-fire approach, they assess various factors, including setting and motivation of the question. John said:

I try to gauge, if I end up talking to someone about it more in depth, I try to gauge how receptive they would be to it...and if they seem more open then I'll go with fibromyalgia, but that's something very less often. I don't usually advertise or

offer up that information very easy. I just typically go with that I have a nerve disorder.

John spoke of gauging what he perceived others' reactions would be to his disclosure. The more receptive the other individual seems to be to listening, the more detailed information he is willing to offer. If the others being disclosed to seem less open, the rapid-fire strategy is used to keep details given and questions asked to a minimum. To further express the use of gauging others, John said:

Just try to do your best to gauge people. Um, as to how responsive they will be to and like it usually, it's usually pretty easy to tell mostly from the beginning of the conversation whether someone is looking to criticize you, [...] or if they're trying to be sympathetic and trying to understand more.

This finding underscores previous research about disclosers trying to obtain a feel for others' before disclosing (Petronio, 2000). John offers advice to others living with chronic illness that they should not feel obligated to disclose any more information than they feel comfortable with. The chronically ill man can pick and choose who to disclose to and when. "So, try to gauge, and if you find the people who are outright, they're just being aggressive and uh that want to bump heads or act in hate, just give the minimal advice or, minimal details you feel comfortable with and move on." Richard highlights the exhaustive nature of answering others' questions about chronic illness. He said, "Don't do more than is good for you, because if you try to answer every person who has questions, you're going to run out of energy really really quickly." Answering questions from others takes energy—which the chronically ill often have less of. It is easy to grow tired from gauging others, choosing strategies, implementing those strategies, and dealing with those people who are aggressive, nonbelieving, and not asking

questions for anyone's benefit. The chronically ill individual already must spend tons of energy managing the illness itself, so the quick-fire disclosure that leaves out details may arguably be an effective strategy for the self-disclosure of chronic illness information, as it helps save time, energy, and his place in the larger masculine community.

Some of the participants brought up the toll that managing both a chronic illness and its disclosures can take on one's mental health. The participants expressed that the quick-fire strategy of disclosure helps to alleviate some of that toll. Richard spoke about the sleep disruption that his illness has caused and how it has affected his mental health. He stated:

Because its, it's sleep schedule disruption had, it's had probably one of the largest effects on me mentally...Uh its taken a pretty big mental toll, with the lack of sleep just because you know I can, its pretty noticeable when you aren't getting enough sleep and you're very tired and in a lot of pain and its affected me, you know, my mental health quite a bit. Um, so I mean that's just like the dark side of it maybe.

Richard talked about the mental toll and sleep disruption as being the most protected information about his illness. He expresses protecting this information because he believes that it is highly sensitive and that others often make assumptions and have their own ideas about mental health. He goes on to point out the severity of the toll his chronic illness has been taking lately. He said, "I've had, I've had some pretty rough times mentally recently, uh that have been, that are just different from anything I have gone through in my life."

**Disclose Symptoms rather than Diagnosis: “if you have the kind of fibro symptoms where your skin flares and you can't touch anything, explain that”**

Participants talked about a strategy of disclosing symptoms rather than diagnosis. Thomas describes it as one of his go-to strategies when disclosing about his chronic illnesses to others. He said:

People, what they wanna know is what the symptoms are, so that's usually one of the go-to's. So I'll easily give out the symptoms.

The participants expressed that the disclosure of symptoms is much easier for others to understand, accept, and sympathize with than biomedical terms and language is. Often, biomedical language is difficult for others to understand, which adds to the confusion others may feel when learning about someone's chronic illness. They said that explanations should be given as to what symptoms actually *feel* like for the individual so that others can get a better grasp on what it is really like to live with chronic illnesses. John said:

So, if you have the kind of fibro symptoms where your skin flares and you can't touch anything, explain that. If you have nerve pain that like I do that shoots and you know it disables limbs randomly, explain that. That is always going to be much more sympathetic and understandable than a than a clinical term is.

Once again then, these men seem cognizant of the need to manage both the illness experience and the illness disclosures, all while abiding by the prescriptions of masculine culture.

### **Illness-Swap: “this is a temporary thing or, even you know a urinary tract infection”**

Similar to the other disclosure strategies outlined above is the strategy identified here as *illness-swap*. The researcher coined this term to represent this strategy of swapping out diagnoses. Specifically, when communicating about their illness, participants took a complicated diagnosis and changing it out with one that they feel would be easier for others to understand. In doing so, they are holding on to the power of the knowledge and information about their illness by altering it and offering a different version to others in hopes of simplicity. Participants expressed that others are more accepting of illnesses with diagnoses that they can easily understand. The more complicated the diagnosis, the more complicated the disclosure is and the more difficult it is to gain others' understanding. Jeffrey revealed, “I would just say I had a bad case of shingles and the shingles got misdiagnosed and that's left me with some uh nerve pain in my forehead.” In his own words, Jeffrey describes using this illness-swap approach, exchanging a better-known condition (i.e., shingles) for one that is lesser known, and therefore, would require more energy to explain trigeminal neuralgia. Rather than disclose that he has trigeminal neuralgia, Jeffrey offers up a more easily digested diagnosis of shingles that led to nerve pain. In doing so, his disclosure may be easier for others to understand and empathize with.

Participants expressed that they may omit clinical terms completely; hence, they exchange the medical diagnosis for one that seems more recognizable, and perhaps, less stigmatizing. Jeffrey mentioned worrying about how disclosing a complicated diagnosis may make others feel, and so opts for a simpler explanation, saying that he deals with nerve pain. He said, “So you might just say it's, you know, it's just a nerve pain that I deal with. But, I just don't go into what the depth of it is or the history.” Thomas echoed Jeffrey with the use of this

strategy as he said, “Probably that it's just um, you know stomach issues that are, you know, acting up

[...] I’m gonna be fine but this is a temporary thing or, even you know a urinary tract infection.” Thomas explained his strategy of swapping a complicated diagnosis with a simpler one when disclosing chronic illness information to others. Rather than disclosing a diagnosis that may be confusing or raise numerous questions, he took a shortcut, so to speak, focusing on stomach issues or a urinary tract infection.

John talked about swapping his complicated diagnosis with a simpler one when disclosing as a way to gain more understanding and sympathy. He stated:

I don’t offer up the fibromyalgia diagnosis very often...Arthritis is super easy for people to understand and accept, especially when it's in your knee, you know...so that’s an easy one for me to just throw out there and people can mostly be sympathetic and understanding.

When someone hears the term fibromyalgia, they may likely be confused, however, the term arthritis is much more widely understood by many people. Because people may not have ever come into contact with fibromyalgia, as an illness or a word, they may not have any life experiences to put to the word—thus making it a foreign concept that is nearly impossible to understand. Arthritis, on the other hand, is much more common and many more people may have life experiences to put to the word—possibly personal experiences with arthritis or maybe someone in the family has lived with it—thus making the word much more relatable and understandable. By telling others that he has arthritis, John is able to gain more acceptance from others.

This strategy would have to be navigated and used carefully, because each chronic illness comes with its own stigmas, and one may place a more severe stigma on himself if he does not pay close attention to which diagnosis is being switched with which. Additionally, illness conditions that are invisible continue being “erased”, in effect, by this illness-swapping technique.

### **Fake It: “fake it ‘til you make it”**

Participants expressed the use of a strategy of faking it—acting as if there is nothing wrong and no illnesses present at all. Faking it, and concealing illness information, allows for men to uphold masculine prescriptions of strength, independence, provider, and toughness.

Henry revealed:

I’m really good at faking it, you know I’m really good at being able to smile and to go through and do the things that are expected of me...And to do them with a smile so that nobody else really even knows what I’m going through, and I think that you now stereotypically, that’s what a lot of men do.

Henry talked about faking that he is completely fine, that there is nothing wrong at all, while having a smile on his face as a way to hide his illness from others. This underscores the findings of Fry and Bates (2012) regarding the concealment of chronic illness information. Henry also mentioned the fear and real possibility of others using their illness, feelings, and emotions against them, and how hiding or faking it can be a helpful strategy for adhering to masculine culture’s norms.

They are able to you know, either, like the saying goes “fake it ‘til you make it”

[...] or they just fake it so that nobody else knows, so that nobody will look down on them, nobody will put them down for having these types of thoughts and feelings...So I have the same, I guess say the same feelings, the same concerns that a lot of guys do about people looking down on them because of these types of things. (Henry)

**Managing Privacy of Information Post-Disclosure: “they can turn around and use that against you”**

Participants brought up the issue of managing the privacy of information after it has been disclosed. Once a chronically ill individual discloses information about that illness, how much right does the disclosed-to individual have to that information. Can the other person tell other people? What information is okay for them to share? What information is not okay for them to share? How would ground rules even be set for such secondary and tertiary disclosures? If that person does tell someone else, how much right then does the third party have to that information? These questions could lead down a rabbit hole that scares some into not disclosing at all. However, with clear communication and understanding—which can be very difficult to achieve—the privacy of information that has been disclosed to others can be managed (Greene et al., 2003). Henry revealed:

Well I think, uh, if I'm talking to somebody I don't know, I'm going to leave out a lot of the detail. Um, just because, you know people, you know we want to believe that people are good, but the truth is, we're not. People in general, you now, are very evil towards each other, very malevolent towards one another, and certain facts with what you're dealing with and going through makes it difficult to

share with people that you aren't comfortable with and don't trust fully...Because they can turn around and use that against you.

Henry talked about others using people's sensitive information against them. Managing the privacy of information after it has been disclosed is one of the ways chronically ill men control certain aspects of their lives, which helps them to hold onto some power. In doing so, they are adhering to hegemonic masculine norms. When asked what others could do better or different to make talking about chronic illness easier, Henry said:

Being more open themselves about what they go through. Uh, and also, just loving people. I mean not putting them down and tearing into them, and using their problems against them.

Sometimes, individuals who have been disclosed to will share that information with others, regardless of the intimacy of the information. John brings up that his fiancé shares a lot of his chronic illness information. She is in some ways disclosing for him in his place in certain situations. He said, "My fiancée shares a lot of my information so that they can kind of understand more of what I'm going through."

**Disclosing to Educate: "to educate and to kind of clear up some of this inaccurate data that they've gotten from news and other people"**

Three out of five of participants expressed in some way the desire to inform and educate others about their illnesses. It allows for the spreading of knowledge from firsthand sources—the people with the chronic illness—rather than a passing down of what others think living with the illness is like.

Those are the people that I generally will talk to them about um, and its more or less to educate and to kind of clear up some of this inaccurate data that they've gotten from news and other people. (Thomas)

Thomas indicated that he felt he had a duty to inform and educate others. He felt that many people were poorly informed about his chronic illnesses and what he deals with on a daily basis. He expressed that by educating others, he could alleviate some of the confusion about those that live with chronic illnesses.

John expressed the need to inform others, particularly as a means to confront the stigma that surrounds those with chronic illness and pain. He expressed concern in the reasons for peoples' interest in asking others about chronic illness. He said:

I wish the only way that people would be interested wouldn't be to ask the dude at the mall with a cane, other than that, what would make it easier to talk to people, definitely tearing down the whole stigma, both the stigma of chronic pain in general and um the stigma for men having chronic pain and the stigma for young people having chronic pain.

With an increased understanding and respect for the illness, others will be much more capable and likely to empathize and sympathize with the chronically ill individual. Charmaz (2012) explores and discusses the idea that chronically ill individuals will often self-disclose to educate others and to increase the understanding of others about their illnesses. These findings underscore her work.

Disclosing to educate is also a form of power control. These men are admitting that, yes, they do have these chronic illnesses, and, yes, that illness does potentially diminish their power

within masculine culture. Regardless of that diminishment, however, the average non-chronically ill person does not have the same knowledge. Knowledge is power, and since these men hold knowledge that others do not, they hold power that others do not. They exercise this power by having complete control over that knowledge and deciding when, where, how, and to whom to bestow it upon.

### **Mediated Disclosure: “where people are there to listen”**

Participants spoke of the ease of computer mediated communication. On many online discussion websites, the users are anonymous, with no real names attached to their virtual user names. This anonymity allows for added confidence with disclosing chronic illness information. John said, “I’m on uh different subreddits about chronic pain, and there it’s an easy space to talk because you know that’s what it’s for.” John expressed being able to find support through disclosures on websites for those with chronic illnesses. So there is no name, and no self, attached to the disclosures; they are made with much more ease than in face to face interactions with other people. He revealed, “So, when I have the energy to, I do my I try to do my part to be outward and open about it, at least uh online, where people are there to listen.”

### **Intimate Disclosures: “if it’s within a personal relationship, I think it’s very helpful”**

Perhaps not surprisingly, participants in this study expressed that in-depth disclosures are easiest with those people who are the closest. The increased intimacy reduces the uncertainty about disclosing illness information. Participants also revealed that those who are close are more empathetic and understanding. Jeffrey expressed, “If its close friends to best friends I’ll share completely openly about it, but past that, um not very much at all.” Jeffrey talked about disclosing information about his chronic illness to those who he is close to, such as a very close

friend, girlfriend, or mother. He expressed that he was fully open with them, but he does not disclose much information to others. This finding suggests that the intimacy of a relationship minimizes the influence that masculine culture has over disclosures. He said:

If it's my girlfriend, same level, uh my sister or my mother, the same level, but if its someone that's again, uh not a close friend then I don't, I don't talk about it, I typically don't disclose anything.

Ricard echoed Jeffrey as he said, "I think if it's within a personal relationship, I think it's very helpful. Um, but I think if its outside of um my close circle, I think it is a negative." This further evidences that the intimacy of a relationship has an effect on the amount of control masculine culture has over disclosures. Jeffrey expresses that in-depth information is only given to those who are close. He said:

Inside my personal circle I think it is helpful, because you get some empathy, some sympathy, people understand what you're going through, and they really truly care. But if it's just the average Joe, that I may have a work relationship with...They don't care, they've got their own problems you know that type of deal, so they just don't have as much sympathy as what someone that's close to me does.

Jeffrey expressed seeing benefits to disclosing information about his chronic illness, but only to those who are within his close personal circle. Outside of that close circle of trusted people, he saw no benefit, and actually saw it as a negative, potentially harmful thing to disclose to those outside one's trusted circle of individuals. He perceives that others do not care about his

illness and would rather not hear about it. When asked what advice he would give other men on disclosing information about their chronic illnesses, Jeffrey said:

Even if I was telling them to share as much as possible with close intimate, close nit-pick friends...past that I would do the exact opposite, say I would keep it pretty close to the chest, especially at work. People at work can kind of get a little bit funky about thinking that you're disabled or that you are taking time off when you shouldn't be.

Participants expressed that there are times when it is best to keep illness information to oneself. They highlight closeness and close relationships as bringing about more in-depth disclosure. Strangers and work acquaintances, on the other hand, should be disclosed to carefully, if at all. John said:

I usually hide the fibro from people I don't know, like absolutely, like that's a go to. If I don't know you, you don't get to know the name of my diagnosis, because I don't need that.

John talked about hiding his diagnosis from people who he does not know. He is protective of the name of his diagnosis and only reveals it to those who are very close who or to those who he perceives would be receptive and open to listening to him. This highlights the heavy weight that is given to the diagnosis, the name of a chronic illness. For him, there is also a real threat to his health when disclosing, as he talked about some people kicking his cane out from underneath him because of disbelief in his chronic illnesses. He said, "I've had people like come up to me in public and try and like kick my cane out."

I usually just tell people hey yeah, I mean I've got this neck pain, it's pretty bad, its going on about 3 years and uh they go oh yeah that sucks and that's usually all the conversation we have about it, you know, unless its someone I'm close to and it's gonna be like uh effecting them too because it's got to the point to where you know it doesn't just affect my life, now it has, you know, it has affected the people around me. (Richard)

Richard spoke of some of the social challenges that his chronic illness brings about. His illness affects not only him but those around him, and especially those closest to him. He talked about disclosing much more information about his illness to those who are close to him, especially if his illness is somehow affecting them.

For the most part, uh most of the time whenever I am struggling with depression, uh most people don't even know about it except for my family. Uh, I'll tell my wife I'm struggling, you know I'm having a rough, rough time or something like that. But outside of that most people don't know about it. (Henry)

Henry talked about hiding his chronic illness and faking it as a way of passing as normal. Rather than risking being labeled as deviant (Kaushansky et al., 2017), he acknowledges that he conceals and discloses to nearly no-one. He has, however, disclosed to those who are closest to him, such as his wife, to let them in on what is really going on behind the façade he puts on in everyday life. Henry expressed the benefits of disclosing chronic illness information to others that are close. He expressed the feelings of connectedness with those he disclosed to. For some that he disclosed to, he found out that they were struggling with some of the same things, and thus found support through telling others about his illness. A man that self-discloses to someone with the same illness is likely to gain insight into that illness that helps with the overall self-

management of the illness. The chronically ill individuals are likely to share their experiences with the illness with each other. This may give each of them helpful insight on how to manage their own illness through talking about it with someone who struggles with the same types of illness management. Henry said:

I think it helps. I really think it does. Um, number one it helps to know that you know I'm not the only one going through it. I've got some guys at the church that I'm close to that I'm friends with, and I'm, they struggle with the same types of things. And the thing is if we never talked about it, we'd never know that each other have the same problems and we wouldn't be able to support each other through it.

Participants revealed these strategies they use when disclosing chronic illness information to others. These strategies included: 1) quick-fire disclosure; 2) disclosing symptoms rather than diagnosis; 3) swapping a complicated diagnosis for a simpler; 4) faking it; 5) managing the privacy of information after it has been disclosed; 6) disclosing to educate; 7) mediated disclosure; and 8) intimate disclosures. Participants expressed that each strategy varies in its usefulness depending on the situation, the evidentness of the illness, the closeness to the listener, and the perceived receptiveness of the listener. These men expressed taking action to navigate communication challenges through developing disclosure strategies. Arguably, participants were engaging in agentic behavior by disclosing in ways that did not threaten their masculine identities.

## CHAPTER 5

### DISCUSSION

This project emerged out of the lack of research on chronic illness disclosure within masculine culture, helping to build upon established research in chronic illnesses and selfdisclosure and looking at these through a masculine culture lens. The objectives of this study are: (1) To explore the intersection of masculine culture, illness scripts, and chronic illness disclosure; (2) To identify communication challenges that emerge when men disclose about a chronic illness; and (3) To identify communication strategies that participants express using when disclosing about a chronic illness.

Specifically, this study yielded three primary findings. First, the participants expressed what it means to be a man within dominant masculine culture. Within that theme, participants underscored that men are supposed to be strong, independent, and tough. Second, participants expressed challenges that emerge around disclosures and disclosure decisions. Within that theme, participants highlighted pain, dependency, and lack of control as barriers to maintaining masculine norms. Participants also expressed challenges with visibility of their illnesses and challenges navigating compelled disclosure due to the evident-ness of those illnesses. Third, strategies used to manage disclosures and disclosure decisions were revealed. Within that theme, participants underscored strategies of: 1) quick-fire disclosure; 2) disclosing symptoms rather than diagnosis; 3) swapping a complicated diagnosis for a simpler; 4) faking it; 5) mediated disclosures; 6) managing the privacy of information after it has been disclosed; 7) disclosing to educate; and 8) intimate disclosures.

## **Implications for Ill Men**

This research study further develops an understanding of what masculine culture is and what it looks like from the eyes of men. It further develops an understanding of what it is like to be a man, extending the literature on masculine cultures (Connell, 1990; Kimmel, 2006; MossRacusin et al., 2010; Trujillo, 1990). Research has revealed that navigating disclosure decisions is challenging for a chronically ill man. For example, men must negotiate their masculine identity and the upholding of dominant masculine norms when making disclosure decisions to protect their sense of self. This extends the ill man literature (Courtenay, 2000; Charmaz, 1994) by underlining the identity management work that chronically ill men do. Failing to meet masculine norms and follow masculine cultural prescriptions because of chronic illness further complicates the navigation of disclosures. The desire not to violate the dominant masculine norms implies that shame is felt when they are violated. This conflict may explain why men put their health at risk to maintain traditional gender roles. This also implies that men will remain silent as a way of maintaining the masculine identity. This research extends and clarifies the ill man literature (Gibbs, 2005; Kvignee et al., 2014) by highlighting the prescribed behaviors within dominant masculine culture. The lack of disclosure and sharing of information could be detrimental to future generations of men as it perpetuates and continues the cycle of hegemonic masculine culture. A surprising finding that emerged within this study was that mothers were the ones who had a major influence in shaping a man's view of masculine culture. Mothers are the primary agents of enculturation for their children, so it would make sense that they are instilling masculine cultural ideals in their sons. This implies that boys are not learning what it means to be a man only from other men, but that women take a crucial role, if not the primary role, in teaching boys masculine culture.

## **Implications for Illness Disclosure**

This study further develops our understanding of what the lives of those living with chronic illness are like. Research has revealed that making disclosure decisions is challenging for individuals living with chronic illness and that there are consequences to disclosure that must be managed. This underscores and extends the illness disclosure literature (Greene et al., 2003; Kaushansky et al., 2017; Petronio, 2000) by highlighting the challenges that surround illness disclosure decisions. Chronically ill individuals do disclose; however, they do so while making careful disclosure decisions. This suggests that those living with chronic illness use strategies to manage disclosure decisions, which this research supports. This study is useful in the identification and development of disclosure and communication strategies for those living with chronic illness. This research extends the illness disclosure literature (Barned et al., 2016; Charmaz, 2002) by illuminating and underscoring various disclosure strategies that might be implemented by those living with chronic illness. Chronically ill individuals may read this study and find connections between the words and their lived experiences, arguably making their illnesses more tangible. Participants revealed that one of the primary challenges surrounding disclosure decisions is the visibility of their illnesses. This research further extends and clarifies the illness disclosure literature, specifically illness disclosure literature related to the visible or invisibility of an illness (Bjorkman et al., 2014; Joachim & Acorn, 2000; Vickers, 1997), through the analysis and displaying of participant's expressed challenges with visibility and compelled disclosure.

## **Implications for Medical Practitioners**

Medical practitioners could read this and gain a better understanding of those who live with chronic illness, allowing them to empathize with the chronically ill individual on a deeper level. This could allow medical practitioners to develop more individualized care and management plans with the chronically ill—benefitting both the practitioner and the patient. Medical practitioners could develop well informed relationships with their patients, taking into account the social and communicative aspects of illnesses as well as the physiological. This research could help medical practitioners to better understand where their patients are mentally and socially, so they can ask the right questions to get the information they need to develop the best care plan possible. If practitioners understand why their patients do not want to talk about certain information, they can ask different questions so the patients feel more comfortable sharing sensitive information. This research could help practitioners strategize and reframe questions in ways that illicit thicker information. This research could further develop communication strategies of medical practitioners during the collection of sensitive information.

## **Limitations**

The major limitation in this research study was time. Time was limited for this project as it is a thesis for a graduate program. With more time, I could have gathered a larger number of participants, which would have allowed for a more varied and comprehensive collection of data. More time would have allowed me to access a wider range of men, and a wider range of chronic illnesses. It would have also allowed me to conduct member-checking. Member-checking, arguably, would have allowed me to give the participants the opportunity to review the coding I conducted on their interview transcripts and let me know if they agree with my findings and how

I am representing them. The sample size in this research study was small. Due to limitations of time, only a few participants were able to be gathered, which provided only a small amount of the data that could have been collected with more time to do so.

### **Future Research Suggestions**

Based on the findings from this thesis, four future research avenues can be identified. First, further research could be conducted on men's chronic illness disclosures. There might be an exploration of chronic illness within relationships with significant others. Second, the way in which men navigate disclosure and overall management of chronic illness within significant relationships could be investigated. Third, there could also be an exploration of chronic illness disclosure in the workplace. Participants expressed that the stakes are much higher when disclosing chronic illness information at work or to co-workers. Researchers could look at how chronic illness is managed in places of employment and whether or not disclosure at work is beneficial to the individual. Fourth, a larger scale project could be conducted that examines the origins of masculine culture. Such a research study could ask men where they learned what they know about masculine culture—where they learned what it means to be a man. A study the origins of masculine culture, and mothers' place as enculturation agents for boys, could examine the cycle of perpetuation that keeps masculine culture in its dominant position within society.

### **Conclusion**

This study explores the intersection between illness related self-disclosure and masculine culture. Utilizing qualitative methods, it examines the challenges chronically ill men face when making decisions about self-disclosure. Transcripts from semi-structured interviews were analyzed and coded using grounded theory to identify common themes throughout. Participants'

accounts of their experiences with living with chronic illness are positioned within literature on chronic illnesses, self-disclosure, and masculine culture. The primary themes participants expressed of masculine culture, disclosure challenges, and disclosure strategies are analyzed and examined in this study. Masculine culture is known for teaching men to be strong, independent, and in control, however, the presence of chronic illness creates challenges for men when attempting to uphold a dominant masculine identity and make disclosure decisions about sharing illness information. Men *need* to share their experiences of living with chronic illness. In a culture that prescribes that men be silent and strong regardless of illness, taking the opportunity to be heard could lead to strengthened illness and identity management strategies, feelings of connectedness, and feelings of empowerment. Talking about chronic illness with others helps in many ways, arguably making the illness more tangible. This study suggests that further research is needed in the area of chronic illness and illness communication to gain a better understanding of the experiences of men living with chronic illness. This research shows the communication struggles that these men living with chronic illness navigate and the strategies they utilize to manage illness disclosures.

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- b) What type of things do you tell?
- c) What type of things do you protect/not tell?

cc) Why is that information protected?

- d) Are there only certain things that you tell certain people?

**4) Have you ever said anything about your illness that you wish you hadn't said?**

- a) What do you wish you would have said instead?
- b) How might that situation have been different if you had said that instead?

**5) Could you talk to me about how being a man affects how you talk about your illness?**

*(Feeling)*

- a) How often do you discuss your chronic illness with other men?
- b) How often do you discuss your chronic illness with women?
- c) Who do you feel most comfortable to talk with about your chronic illness?
- d) Give me an example of the first time you talked to someone about your illness. What was said?
- e) Do you think talking about your illness helps you? (or hurts you)

*(Feeling)*

**6) Imagine you are talking to a man who has been newly diagnosed with (chronic illness), what tips might you give him on talking about it?**

**7) What could other people do better/different to make talking about it easier?**

*Closing:*

**Is there anything about your (chronic illness) we haven't covered that you would like to share with me?**

Thank you for sharing this information with me.

Appendix B  
Interview Guide

***Goals:***

1. To explore how masculine culture affects chronic illness disclosure.
2. To identify communication challenges and strategies that might arise when men discuss a chronic illness with others.
3. To explore the identity management processes of men who have a chronic illness.

***Research Question:***

*Individual Interview:* What challenges do men with chronic illness face when discussing that illness with others?

***Rules:***

**1. Participation:**

- I will avoid interrupting you.
- If I ask you a question and you aren't ready to answer, it's okay to pass.
- Let's make as much effort to let stories flow.
- You are welcome to keep this guide as a reference during the interview.

**2. Not about knowledge:** This day is not about testing your knowledge. There will be no judgement of opinion. This interview is about you and your story.

**3. Time:** We will talk for approximately 30 minutes.

**4. Bathroom:** If you need to excuse yourself to go to the bathroom, please do so.

Appendix C  
Recruitment Letter

Hello, my name is Matthew Daggett. I am a graduate student at East Tennessee State University (ETSU). I am currently working on my thesis, a research study that explores how chronically ill men talk about their illnesses to others. The process consists of a short interview (approximately 30 minutes). The interview will be conducted over the telephone.

Your confidentiality will be ensured during the process. I will not ask for your name or other identifying information. Before I write the transcripts, I will assign pseudonyms to all interviewees. Participation is voluntary and you can choose to stop at any time. Any question may be skipped.

To be eligible for the interview, you must (a) be at least 18 years old, (b) identify as male, (c) and have one or more chronic illnesses. I will be asking questions about your experiences with talking about your chronic illness(es) with others. These interviews will be audiotaped.

If you choose to participate, I will send you more detailed information about myself and the project. I look forward to hearing your different perspectives. If you have any questions please contact me at (....., ....., or .....).

VITA

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