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# Exploring the Intersections of Stigma and Masculinity in the Illness Perceptions of Men Living with Fibromyalgia: An Interpretative Phenomenological Analysis

## Abstract

Fibromyalgia is a musculoskeletal condition characterized by widespread pain, fatigue and cognitive problems. While it affects between 2-7% percent of the population in the United States, the biopsychosocial impacts of the disease on the lives of those affected are so substantial that it is considered to have one of the highest cost burdens comparative to other chronic pain conditions. Fibromyalgia has historically been deemed a contested illness due to the complexity of its presentation and lack of clear etiology. As a result, people with fibromyalgia often feel misunderstood and stigmatized. Like other pain conditions, fibromyalgia is more commonly diagnosed in women. Therefore, existing research has centered on women's illness experience, and men's experiences appear to be more marginalized and less understood. Medical conceptualizations of fibromyalgia as a "woman's disease" coupled with the healthrelated stigma of fibromyalgia may make men with the disease vulnerable to multiple stigma experiences that intertwine with masculinity concerns. This study addressed a gap in the fibromyalgia literature by examining the experiences of men living with fibromyalgia through semi-structured interviews, with particular emphasis how men's experiences of stigma and masculinity strain intersect to impact their illness perceptions. This study utilized an interpretative phenomenological analysis approach to explore the question, "How do health-related stigma and masculine gender role strain influence illness appraisals, coping behaviors, and health outcomes in men with fibromyalgia?" Nine superordinate themes emerged: *Precipitating Events; Fibro Experience; Psychosocial Stressors; Emotional Impact; Impact on Identity; Social Impact; Adjusting to Physical Aspects of Fibromyalgia; Coping with Psychosocial Aspects of FM; and Coping with Stigma and Masculine Identity Threats.* Findings reflect how the illness perceptions and coping behaviors of men with FM are shaped by the psychosocial impact of stigma and masculinity strain across various contexts. These findings highlight the particular needs of men with FM, and provide considerations for improving social and healthcare systems, practices, and treatment to be more sensitive and responsive for this population.

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of Men Living With Fibromyalgia: An Interpretative Phenomenological Analysis

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A Dissertation

Presented to

the Faculty of the Morgridge College of Education

University of Denver

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In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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by

Christine L. Motzny

August 2022

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Title: Exploring the Intersections of Stigma and Masculinity in the Illness Perceptions of Men Living With Fibromyalgia: An Interpretative Phenomenological Analysis

Advisor: Trisha Raque, PhD

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### **Abstract**

Fibromyalgia is a musculoskeletal condition characterized by widespread pain, fatigue and cognitive problems. While it affects between 2-7% percent of the population in the United States, the biopsychosocial impacts of the disease on the lives of those affected are so substantial that it is considered to have one of the highest cost burdens comparative to other chronic pain conditions. Fibromyalgia has historically been deemed a contested illness due to the complexity of its presentation and lack of clear etiology. As a result, people with fibromyalgia often feel misunderstood and stigmatized. Like other pain conditions, fibromyalgia is more commonly diagnosed in women. Therefore, existing research has centered on women's illness experience, and men's experiences appear to be more marginalized and less understood. Medical conceptualizations of fibromyalgia as a "woman's disease" coupled with the health-related stigma of fibromyalgia may make men with the disease vulnerable to multiple stigma experiences that intertwine with masculinity concerns. This study addressed a gap in the fibromyalgia literature by examining the experiences of men living with fibromyalgia through semi-structured interviews, with particular emphasis how men's experiences of stigma and masculinity strain intersect to impact their illness perceptions. This study utilized an interpretative phenomenological analysis approach to explore the question, "How do health-related stigma and masculine gender role strain influence

illness appraisals, coping behaviors, and health outcomes in men with fibromyalgia?”

Nine superordinate themes emerged: *Precipitating Events; Fibro Experience; Psychosocial Stressors; Emotional Impact; Impact on Identity; Social Impact; Adjusting to Physical Aspects of Fibromyalgia; Coping with Psychosocial Aspects of FM; and Coping with Stigma and Masculine Identity Threats*. Findings reflect how the illness perceptions and coping behaviors of men with FM are shaped by the psychosocial impact of stigma and masculinity strain across various contexts. These findings highlight the particular needs of men with FM, and provide considerations for improving social and healthcare systems, practices, and treatment to be more sensitive and responsive for this population.

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## **Chapter 1: Introduction**

### **Introduction and Study Rationale**

Chronic pain is a significant problem in the United States. National estimates by the Center for Disease Control (CDC) indicate roughly 50 million adults (20.4%) have chronic pain and 19.6 million (0.8%) have “high-impact” chronic pain, or pain frequently limiting functioning across life domains (Dahlhamer, et al., 2018). In 2003, chronic pain was estimated to account for nearly 20% of medical visits, over 10% of pharmaceutical sales, and was the number one cause of absenteeism and disability, thus surmounting as one of the costliest medical problems in the U.S. (Max, 2003). Cost burden associated with chronic pain in the U.S. is estimated to be between \$560 and \$635 billion annually resulting from medical spending, loss of work productivity, and disability (Pizzo & Clark, 2012). In addition to the significant societal burden, chronic pain impacts the individuals suffering from it on a physical, mental, emotional, and social level.

Chronic pain has been a focus in the healthcare paradigm over the past few decades for several reasons. First, efforts to treat chronic pain historically drove the over-prescription of opioid medications, contributing to the opioid crisis plaguing the U.S. As the detrimental consequences associated with opioids has been widely recognized, healthcare providers have worked to curtail over-reliance on pain practices (Kampman & Jarvis, 2015; Darnall et al., 2017). Multidisciplinary treatment approaches

have gained traction, as well as the newly established subfield of Pain Psychology, which specializes in addressing psychosocial aspects of pain (Gatchel et al., 2014; Wandner et al., 2019). Additionally, chronic pain has gained attention because unlike acute pain which can be linked to an etiological factor, the underlying cause of chronic pain is often unclear and multifaceted. Thus, the complexity of the disease can make it difficult to understand and challenging to treat.

While many chronic pain conditions are classified as ‘invisible illnesses,’ Fibromyalgia (FM) is a particular type of chronic pain that has often been labeled a ‘contested illness’ due to it typically not having a clear cause (Barker, 2011, 2008). FM also fits the classification as “high-impact” chronic pain due to the pervasive limitations it imposes on a person’s functioning across life domains. FM is a musculoskeletal condition characterized by chronic widespread pain (CWP), fatigue, neuropathy, headaches, sleep disturbance, and associated cognitive symptoms, including concentration and memory problems [National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS, 2019)]. Although FM impacts a small percent of the U.S. population (2.0 - 6.4%), the nature and impacts of FM are severely disabling. It ranks as one of the most expensive conditions in terms of health-care utilization cost, primarily due to the repeated medical visits and tests required to arrive at an accurate diagnosis (Chen & Mackenzie-Brown, 2015). The cost burden of FM is also attributed to absenteeism, productivity loss, hospitalizations, countless medication and treatment trials, out-of-pocket expenses for informal care and household help, and the high comorbidity of FM with other physical and mental health conditions– which increase the severity of

the illness and escalate overall health care expenditures (Sanchez et al., 2011; Skaer, 2014). One population study comparing ten chronic diseases found that FM was ranked highest in terms of pain, long-term disability, and self-rated health (Kasman & Badley, 2004). Within a sample of patients with CWP, patients having a diagnosis of fibromyalgia demonstrated the greatest disease burden due to poorer health status, function, and sleep; lower productivity; and more pain-related medications and comorbidities, all substantiating to higher costs (Schaefer et al., 2016). Given the profound disease burden, medical and mental health comorbidities, and cost related to fibromyalgia, FM research warrants further attention.

As noted, FM is a particularly esoteric type of chronic pain, typically lacking a clear etiology or course of treatment. Illnesses that fall outside the scope of a clear biomedical explanation are often misunderstood by the medical community and society at large and may carry a greater psychological burden in light of such perplexity (Armentor, 2015; Mengshoel et al., 2018). As a result, health-related stigma is a common phenomenon experienced by patients with unexplained chronic pain conditions such as FM. Health-related stigma is typically characterized by the social devaluation of individuals who are identified with a particular health problem (Weiss, Ramakrishna & Somma, 2006). Moreover, FM is a condition that results in consequences representing a deviation from American cultural values of hard work and independence, rendering FM patients more susceptible to societal criticism and stigma (Paxman, 2019).

While there is considerable research affirming the experience of stigma in patients with chronic pain (De Ruddere & Craige, 2016) and fibromyalgia (Armentor, 2017;

Åsbring & Närvänen, 2002; McInnis et al., 2015; Sabik, 2010), studies have predominately consisted of women participants and research related to the stigma experiences of men with chronic pain and FM is lacking. For example, a recent review of 18 studies on chronic pain and stigma from 1989-2015 pointed out that the total participant ratio was 14,073 women and only 256 men (Aste, 2016). While this is reflective of the fact that chronic pain is disproportionately more common in women (OCA, 2010), accounts of men's experience are needed to inform more gender-sensitive pain management interventions, including gender-inclusive healthcare materials and culturally responsive approaches to interacting with men experiencing FM. Of note, most FM research has used the gender binary, and not yet explored the experiences of people who identify as non-binary. As a next step in expanding our understanding of how gender intersects with the experience of FM, this study focused on individuals who identify as men with FM. However, there is a need for future research to expand beyond the gender binary to more fully capture the continuum on which gender identity may fall.

It is also important to consider social and contextual factors that are particularly salient to the experience of internalized stigma in men with FM. Since fibromyalgia is primarily diagnosed in women, men diagnosed with the condition may experience greater masculinity threats that relate to the experience of internalized stigma. Thus, men living with fibromyalgia may be a particularly useful group to explore these phenomena. The purpose of this study was to examine the experience of stigma in men living with FM. Specifically, this study aimed to gain an understanding of how masculine ideologies, or internalizations of and adherence to traditional masculine gender norms, and stigma-

induced identity threat intersected to shape the health and illness experiences of men living with FM. My primary research question was: How does health-related stigma and masculine gender role strain influence the illness appraisals, coping behaviors, and health outcomes in men with FM.

Research sub-questions include the following:

1. What are the illness perceptions of men with FM?
2. What is the experience of stigma in men with FM?
3. How does FM-stigma threaten men's sense of self or masculine identity?
4. What coping strategies do men with FM use to navigate FM, stigma, and masculine identity threat/gender role strain?

### **Literature Review**

The remaining portion of this chapter consists of an empirical research review on fibromyalgia (FM) and literature related to stigma and masculinity concerns in men with FM. The first section will address background information on fibromyalgia (pathology, diagnosis, prevalence, comorbidity, impact, and treatment) in general and more specifically in men. The second half of the literature review will detail the theoretical frameworks shaping this study including the Common-sense Model of Self-Regulation, or Illness Perception Model (Leventhal et al., 1992), Stigma-Induced Identity Threat Model (Major & O'Brien, 2005), and the Gender Role Strain Paradigm (Levant & Richmond, 2016; Pleck, 1995). Lastly, the literature review will conclude with scholarly work specifically addressing the experiences of men with FM. Each section was

developed to outline important contextual information related to the lived experiences of men with FM.

## **Fibromyalgia**

### **Pathology**

Fibromyalgia (FM) is a chronic musculoskeletal condition characterized by widespread pain and a multitude of associated physical and cognitive symptoms. Individuals are typically diagnosed around midlife (Chen & MacKenzie-Brown, 2015). FM is classified as a Rheumatological condition because its etiology was originally thought to involve pathology of fibrous muscle tissue (Gowers, 1904). However, research indicates that muscle pathology in FM is more likely a consequence of pain, inactivity, and atrophy, rather than a cause (Sarzi-Puttini et al., 2011). The development and maintenance of pain and dysfunction related to FM is regarded as resulting from a nervous system process known as “central sensitization” (Jensen et al., 2009; Sarzi-Puttini et al., 2011). Other factors theorized to influence the onset of FM include – genetics (Buskila, 2007; Buskila & Sarzi-Puttini, 2006); traumatic experiences (physical or psychological) including the compounding effect of multiple or chronic stressors; infection or immune dysfunction; and hormone imbalance or overload – yet central sensitization is thought to be an outcome of each of these, thereby permeating pervasive pain in FM (Chaitow, 2010, p.113).

According to the Institute for Chronic Pain (2017), central sensitization occurs when the central nervous system (CNS) “gets regulated in a persistent state of high reactivity,” thereby lowering the pain sensitivity threshold. With this high reactivity and



lowered pain sensitivity, central sensitization is marked by two main characteristics – hyperalgesia and allodynia. Hyperalgesia is when a painful stimulus is perceived as more painful than it should be. For example, something such as a minor bump, which would be mildly painful, would be interpreted as extreme pain. In a study comparing the brain activity of FM patients with controls using magnetic resonance imaging (MRI), hyperalgesia was observed in FM patients, as they showed greater neuron activation under a low-intensity painful stimulation compared to the control group (Nebel & Gracely, 2009). Allodynia involves experiencing pain from tactile, thermal, or mechanical stimuli that are not normally painful (IASP, 2017) – such as slight touch, which is often reported by individuals with FM to be extremely painful. Patients with FM are often noted to have hypersensitivity to various stimuli including light/visual and auditory stimuli (Geisser et al., 2008), as well as temperature (e.g., heat, cold) (Petzke et al., 2003). Thus, while increased sensitivity to pain is one feature of FM, central sensitization in FM can also manifest by a heightened sensitivity in other sensory processing domains.

Differences in biological processes and brain structures observed in patients with FM are one factor theorized to explain the overamplification of pain and sensory processing systems. For instance, studies have indicated elevated levels of neurotransmitters that tend to promote pain or pain perceptions (e.g., Substance P, glutamate, nerve growth factor, and brain-derived neurotrophic factor) and/or reduced levels of neurotransmitters that inhibit pain transmission (serotonin, norepinephrine, and dopamine) in patients with FM (Larson et al., 2000; Gracely et al., 2002; Russell et al.,

1992). Additionally, studies of FM patients have shown structural deformities in forebrain areas involved in pain processing (Schmidt-Wilcke & Clauw, 2011). In a meta-analysis of brain activation in patients with FM, structural and functional differences were found in the primary and secondary somatosensory cortex, amygdala, insula, superior temporal gyrus, and lingual gyrus of FM patients (Dehghan et al., 2016). Biopsychosocial perspectives emphasize how changes in these brain structures and functions regulate more than merely the bodily sensations experienced in FM.

In addition to their role in pain processing, these areas are implicated in several aspects of cognitive and emotional processing (Dehghan et al., 2016). This may help explain why FM is highly comorbid with depression, anxiety, fatigue, and often marked by cognitive problems (Borchers & Gershwin, 2015). Likewise, cognitive and affective processes contribute significantly to the momentary perception of physical pain, as explained by the gate control theory (Melzack & Wall, 1965, 1982). Research shows how thoughts and feelings about physical pain (e.g., apprehension, hypervigilance, pain catastrophizing) affect one's ultimate pain experience by way of increased pain intensity, pain interference (i.e., functional impairment across life domains), and poor health outcomes (Jensen et al., 2017; Mun et al., 2019). It stands to reason that troublesome thoughts internalized about the self/others, and feelings arising from difficult intra/interpersonal experiences could also play a significant role in pain perception. Of particular interest is how stigma induced identity threat in men with FM can potentially shape illness perception.

### **Diagnostic Information**

### ***Diagnostic Criteria***

Given the complexity of FM, it can be helpful to understand its diagnostic criteria. Classification criteria for the condition were first established in 1990 by the American College of Rheumatology (ACR) (Wolfe et al., 1990), and was updated in 2010 (Wolfe, et al., 2010) and 2016 (Wolfe et al., 2016). According to the Wolfe et al's updated 2016 criteria, the following three conditions are required for a diagnosis of fibromyalgia: 1) Generalized pain (i.e., pain in at least 4 of 5 regions); 2) Widespread pain index (WPI) greater than or equal to 7 and symptom severity scale (SSS) score greater than or equal to 5, or a WPI of 4–6 and SS scale score 9 or greater; 3) Symptoms present and at a similar level for at least three months. Lastly, the new criteria specify that FM is a valid diagnosis irrespective of other chronic illnesses or diagnoses (Wolfe et al., 2016, p. 319).

According to the ACR, widespread pain involves both left- and right-sided pain, as well as upper and lower segment pain. The WPI Index score is yielded based upon patient's reported pain in 19 areas (score can range from 0-19). The symptom severity (SS) score is based on the sum of the severity of three symptoms - fatigue, waking unrefreshed, and cognitive symptoms - plus the severity of somatic symptoms in general. For each of the three main symptoms, patients are asked to indicate the level of severity using the following scale: 0= no problem, 1= slight or mild problems, generally mild or intermittent, 2= moderate, considerable problems, often present and/or at a moderate level, and 3= severe: pervasive, continuous, life-disturbing problems. Other general somatic symptoms may include muscle pain, tenderness or weakness, numbness/tingling, cardiovascular issues, gastrointestinal problems, neurological

problems such as headache, dizziness, blurred vision, or problems with thinking or remembering, sleep problems and fatigue, mood problems, fever- or cold-like symptoms, skin problems, auditory problems, or problems with urination (see Table 1). These are rated using the following scale: 0= no symptoms, 1= few symptoms, 2= a moderate number of symptoms, 3= a great deal of symptoms.

Table 1  
*Fibromyalgia Criteria*

Fibromyalgia criteria—2016 revision

<p><b>Criteria</b> A patient satisfies modified 2016 fibromyalgia criteria if the following 3 conditions are met: (1) Widespread pain index (WPI) <math>\geq 7</math> and symptom severity scale (SSS) score <math>\geq 5</math> OR WPI of 4–6 and SSS score <math>\geq 9</math>. (2) Generalized pain, defined as pain in at least 4 of 5 regions, must be present. Jaw, chest, and abdominal pain are not included in generalized pain definition. (3) Symptoms have been generally present for at least 3 months. (4) A diagnosis of fibromyalgia is valid irrespective of other diagnoses. A diagnosis of fibromyalgia does not exclude the presence of other clinically important illnesses.</p>		
<p><b>Ascertainment</b> (1) WPI: note the number of areas in which the patient has had pain over the last week. In how many areas has the patient had pain? Score will be between 0 and 19</p>		
<p><i>Left upper region (Region 1)</i> Jaw, left<sup>a</sup> Shoulder girdle, left Upper arm, left Lower arm, left</p>	<p><i>Right upper region (Region 2)</i> Jaw, right<sup>a</sup> Shoulder girdle, right Upper arm, right Lower arm, right</p>	<p><i>Axial region (Region 5)</i> Neck Upper back Lower back Chest<sup>a</sup> Abdomen<sup>a</sup></p>
<p><i>Left lower region (region 3)</i> Hip (buttock, trochanter), left Upper leg, left Lower leg, left</p>	<p><i>Right lower region (Region 4)</i> Hip (buttock, trochanter), right Upper leg, right Lower leg, right</p>	
<p>(2) Symptom severity scale (SSS) score Fatigue Waking unrefreshed Cognitive symptoms For the each of the 3 symptoms above, indicate the level of severity over the past week using the following scale: 0 = No problem 1 = Slight or mild problems, generally mild or intermittent 2 = Moderate, considerable problems, often present and/or at a moderate level 3 = Severe: pervasive, continuous, life-disturbing problems The symptom severity scale (SSS) score: is the sum of the severity scores of the 3 symptoms (fatigue, waking unrefreshed, and cognitive symptoms) (0–9) plus the sum (0–3) of the number of the following symptoms the patient has been bothered by that occurred during the previous 6 months: (1) Headaches (0–1) (2) Pain or cramps in lower abdomen (0–1) (3) And depression (0–1)</p>		
<p>The final symptom severity score is between 0 and 12 The fibromyalgia severity (FS) scale is the sum of the WPI and SSS</p>		

The FS scale is also known as the polysymptomatic distress (PSD) scale.

<sup>a</sup> Not included in generalized pain definition.

## ***Diagnosing Fibromyalgia***

Because there is often no clear etiology, receiving a diagnosis of FM is often a long drawn-out process of repeated medical visits and rule out tests. FM is diagnosed by a physician based on an assessment of clinical history and a physical evaluation of pain

and other symptoms to determine if they meet the threshold set forth by the diagnostic criteria described above. Additionally, laboratory tests and additional evaluations of mood, sleep, and neurological problems may be used to rule out other possible causes of pain (Chen & Mackenzie-Brown, 2015). Diagnosis of FM can be received in a primary care setting, though a referral to a Rheumatologist may be warranted if there is uncertainty. The cut-off for diagnosis remains difficult to determine since polysymptomatic distress in FM populations can be viewed as falling along a spectrum, rather than marking a discrete group (Wolfe et al., 2013).

Another reason FM can be difficult to diagnose is that the complex presentation of symptoms in FM can often mimic or be difficult to distinguish from other diseases, such as autoimmune disorders, cognitive disabilities, and/or mental health disorders. Patients with FM often present with co-morbid conditions (Weir et al., 2006), therefore it can be confusing and difficult to identify a subsequent diagnosis of FM when other conditions coexist. Unfortunately, there are no specific labs or tests associated with identifying FM, but lab tests are often helpful to rule out other specific diseases, as well as to identify possible co-morbid conditions that could be exacerbating symptoms (Imrie, 2017). Recommended blood tests include: full blood count, urea and electrolytes, liver and thyroid function tests, calcium, phosphate, and c-reactive protein or erythrocyte sedimentation rate (Imrie, 2017). If there is suspicion of an autoimmune inflammatory disorder, autoimmune screenings are also suggested.

While the updated FM criteria and advances in best-practices for diagnosing FM have become better established, the complexity of symptoms and high symptom overlap

with other diseases/disorders can delay the diagnosis of FM. Patients may experience symptoms for years before an official diagnosis of FM is made. This prolonged process can cause substantial psychological distress and impact the quality of life as patients spend a significant amount of time and money attempting to navigate multiple facets of the medical system to find longed for answers (Annemans et al., 2009; Knight et al., 2013). Moreover, without a diagnosis to help patients explain and make sense of their experiences, patients may feel as if providers do not believe their pain is real, that they are exaggerating, that it's "all in their head," and experience a sense of stigma or shame. This may make them more likely to lose hope and possibly disengage from healthcare treatment, which may only serve to further erode their physical and mental health.

### **Prevalence**

Due to the 2010 and 2016 ARC diagnostic revisions, definite prevalence rates of FM in the United States are relatively unknown as they widely vary. Prevalence estimates based on the 1990 ARC criteria were first examined by Wolfe and colleagues (1990) using a sample of 3,006 adults from Kansas. They found that 36 individuals met the diagnostic criteria for FM, leading them to conclude an estimated prevalence of 2% in the general population, with a greater prevalence in women than in men (3.4% vs 0.5%). The authors also found a sharp increase in FM rates for women after age 50, and for both men and women, FM rates peaked in the 70-79-year-old age group. A slight decrease in the gender ratio gap has been observed in specialty clinics, where FM is about six times more common in females than males (Macfarlane et al., 2009). Another study examining FM

prevalence among individuals referred to tertiary pain clinics estimated that over 40% of patients met the 1990 FM diagnostic criteria (Brill et al., 2012).

In a later study by Vincent et al., (2013) using the 2010 ACR criteria, the overall prevalence of FM in the U.S. was estimated at 6.4%, with 7.7% prevalence in women and 4.9% prevalence in men. Again, this study was conducted in one region of the U.S. and thus generalization to the larger population should be deemed with caution. However, collective research on FM prevalence points to estimates ranging from about 2-4% in the general population (Chen & Mackenzie-Brown, 2015) and up to 6.4% in some regions (Vincent et al., 2013; Wolf et al., 2013). Fibromyalgia continues to be disproportionately more common in women than men, with a ratio of about 7–9:1, respectively (Bartels et al., 2009). Prevalence of FM in clinical populations is estimated to range from 2-22% (Chen & Mackenzie-Brown, 2015). In a 2017 literature review of global fibromyalgia prevalence from 2005-2014, FM rates in the U.S. were found to be high in comparison to other countries (Marques et al., 2017).

In a later study by Vincent et al., (2013) using the 2010 ACR criteria, the overall prevalence of FM in the U.S. was estimated at 6.4%, with 7.7% prevalence in women and 4.9% prevalence in men. Again, this study was conducted in one region of the U.S., and thus generalization to the larger population should be deemed with caution. However, collective research on FM prevalence points to estimates ranging from about 2-4% in the general population (Chen & Mackenzie-Brown, 2015) and up to 6.4% in some regions (Vincent et al., 2013; Wolf et al., 2013). Fibromyalgia continues to be disproportionately more common in women than men, with a ratio of about 7–9:1, respectively (Bartels et

al., 2009). The prevalence of FM in clinical populations is estimated to range from 2-22% (Chen & Mackenzie-Brown, 2015). In a 2017 literature review of global fibromyalgia prevalence from 2005-2014, FM rates in the U.S. were found to be high in comparison to other countries (Marques et al., 2017).

While prevalence rates of FM in the U.S. are noted to be high, these figures may underrepresent actual prevalence. For example, the significant change in prevalence rates captured by the 2010 ACR criteria compared to the 1990 criteria suggests that FM rates in the U.S. may be much higher than previously thought. Additionally, Walitt and colleagues (2015) used data from the U.S. National Health Interview Survey (NHIS) and the modified 2010 American College of Rheumatology ACR preliminary fibromyalgia diagnostic criteria to identify individuals who met the diagnosis based on their survey answers. They found roughly 73% of those who met the criteria had not received a clinical diagnosis of fibromyalgia (Walitt et al., 2015).

Lastly, the 2016 diagnostic revisions negate the 2010 criteria that FM be diagnosed in the absence of other disorders that could explain the pain, which can also conceivably underestimate current prevalence rates. High variability in prevalence estimates of FM across sex has also been noted, which is likely due to the use of different criteria and sample biases in research (Wolfe et al., 2018). For instance, because FM is more commonly found in women it is typically conceptualized in medical practice as a women's health condition, which can also contribute to under-diagnosis and treatment of FM in men (Briones-Vozmediano et al., 2018; Katz et al., 2010; Vozmediano & Tula, 2017). It stands to reason that if providers are more reluctant to diagnose FM in men, men



may have more prolonged physical and psychological suffering associated with delayed diagnosis. Moreover, there is substantial evidence that men are more reluctant to seek out health services, which can also factor into the gender discrepancies seen in FM diagnoses and prevalence (Galdas et al., 2005). Together, gender-bias in diagnoses and men's low help-seeking make it less likely for medical providers to refer men for studies, and thus underrepresented in prevalence estimates. For example, Wolfe and colleagues (2018) discuss how some FM epidemiology studies include participants based on self-reported clinical FM diagnosis or a provider referral, rather than assessment using validated criteria. The former can cause selection-bias in studies and substantially skew prevalence estimates to overestimate FM prevalence in women, and underestimate it in men (Wolfe et al., 2018). The authors estimated that in an unbiased/unselected sample or a general population survey, about 60% or less will be women.

### **Comorbidity**

Another factor that may contribute to the under-diagnosis of FM is its high comorbidity with other conditions, making FM difficult to differentially diagnose. Like many chronic pain conditions, FM is highly comorbid with other chronic diseases and mental health conditions. Patients with FM often have one or more co-morbid condition than the general population (Weir et al., 2006). Physical conditions commonly comorbid with FM include rheumatoid conditions (Fitzcharles et al., 2019), autoimmune diseases (Kadamban, 2018), neurological diseases (Fitzcharles et al., 2018), and other pain conditions including visceral pain syndromes (e.g., irritable bowel syndrome, intestinal or

urinary pain, ischemic heart disease), craniofacial and myofascial pain, and various types of headaches (Affaitati et al, 2019).

FM has also been found to occur more frequently in individuals who suffer from non-restorative sleep, mood disorders (e.g., anxiety, depression), or who have experienced trauma; and these factors have been acknowledged as being an antecedent risk factor for FM, a cause, or an exacerbating factor that can increase the severity of FM (Chen & Mackenzie-Brown, 2015; Fitzcharles et al., 2018). Up to 75% of patients with FM complain of impaired sleep (Paul-Savoie et al., 2012), and sleep disturbances can contribute to developing muscle pain and lower the threshold for pain (Moldofsky, 1986). One study found that poor sleep quality was a major predictor of the onset of FM-type widespread pain in older adults (McBeth et al., 2014). Several studies suggest that sleep disturbances related to FM may be more frequent and severe for men than women. For instance, in one study, sleep quality was inversely related to QOL in men with FM, but not women (Buskila et al., 2000). Another study showed more sleep complaints by men than women (Prados et al., 2013). Men have also reported greater sleep latency compared to women, which is often associated with poor sleep efficiency (Segura-Jiménez et al., 2016). Sleep disturbances can contribute to mood dysfunction - which individuals with FM often experience, though mood and pain can also disrupt sleep.

Fibromyalgia is also highly comorbid with mental health conditions. Individuals with FM have a lifetime prevalence of comorbid psychological conditions of between 75-88%, and psychological disorders were associated with heightened distress and worse functional outcomes for patients with FM (Epstein et al., 1999). Similarly, patients with

FM are more likely to report psychological distress and symptoms consistent with PTSD than those without FM (Näring et al., 2007). Again, it is not entirely clear if the trauma is a direct cause of FM, but trauma experiences seem to increase susceptibility to chronic pain conditions and worsen their overall impact. Studies comparing the psychological statuses of men and women with FM are not entirely conclusive. While studies tend to find no significant gender differences in levels of depression and anxiety across FM patients (Häuser et al., 2011; Miró et al., 2012; Segura-Jiménez et al., 2016), greater differences observed in men with FM compared to those without FM (vs. FM and non-FM women) raise the question as to whether the emotional aspects of FM have a more profound impact on men. Thus, further exploration of masculine specific psychological factors is warranted.

### **Impact of Fibromyalgia on Men**

The physical and psychological impact of FM can negatively affect psychosocial functioning and quality of life (QOL). Studies have shown a greater detriment of pain symptoms on men with FM compared to women (Segura-Jiménez et al., 2016) and FM symptoms appeared to have a greater overall impact on men (Aparicio et al., 2012). This includes poorer health perceptions (Hooten et al., 2007), more severe deficits in physical functioning (Buskila et al., 2000; Aparicio et al., 2012; Castro-Sánchez et al., 2012), and worse social functioning (Hooten et al., 2007). For instance, in a phenomenological study examining the biopsychosocial impact of FM on African American men, men reported substantial physical challenges/limitations and cognitive and emotional issues. Moreover, they reported lacking support from friends and family (Callier-Perry, 2017).

FM may disrupt men's social relationships as they may avoid social activities due to pain, physical limitations, or fear of being misunderstood or judged based on their FM (Paulson, Danielson & Soderberg, 2002; Mengshoel et al., 2018). Additionally, men with FM report problems related to intimacy. Compared to healthy controls, men with FM scored significantly lower across domains of sexual functioning including erectile and orgasmic function, sexual desire, and intercourse satisfaction (Batmaz et al., 2013). Moreover, for many men, work-related activities provide a sense of purpose and accomplishment. When FM limits their ability to work it can disrupt their self-esteem and sense of identity (Ferguson, 2014; Sallinen & Mengshoel, 2019). Adjusting to living with FM appears to be difficult for men as the disease infringes on several aspects of their social life and relationship functioning. Further exploration around factors influencing men's illness perceptions and coping with FM may help broaden our understanding of the mechanisms underlying some of these differential outcomes.

If the psychosocial impact of FM is experienced differently by men than women, likely, their coping styles would also be different. In a review of gender differences in pain perception and coping, Bartley and Fillingim (2013) highlighted men are more likely to use problem-focused coping and behavioral distractions, while women utilize broader coping responses including more positive self-statements, emotion-focused coping, cognitive reappraisal, and social support (Fillingim et al., 2009; Keogh & Eccleston, 2006). However, some of these responses were based on experimental pain induction studies. The only study examining patients with chronic (as opposed to acute) pain in a more naturalistic setting was conducted with adolescents. Thus, it would be useful to

explore coping responses in a more diverse age group. Moreover, studies have indicated the need for further research on possible differential responses based on specific types of pain (Vaughn et al., 2014). It is possible that some pain conditions elicit a greater degree of stigma or identity threat in men than others and therefore could have a different impact on their illness perceptions and coping responses. Lastly, while generalizations have been drawn regarding gendered coping in response to pain, it is important to underscore individual differences within the population of men with FM to continue to uncover what psychosocial factors contribute to differential coping among men with FM.

### **Treatment**

While there is no cure for FM, there are many treatments to help reduce symptoms, manage the disease, and improve quality of life (QOL). Common treatment approaches include medications, lifestyle adaptations, and changes, and learning effective coping skills. Since FM is a disease involving a complex presentation of symptoms along with physical and psychological comorbidities, successful treatment should include a comprehensive bio-psycho-social approach that addresses medical, physical, mental/cognitive, emotional, and behavioral management strategies (Friedberg, Williams, Collinge, 2012). A multidisciplinary team (MDT) may be useful for patients with FM in this regard.

From a pharmacological standpoint, a handful of medications have been approved by the U.S. Food and Drug Administration (FDA) for treating FM (Kim, Landon, Solomon, 2013). The ones with the strongest evidence are anticonvulsants (e.g. pregabalin, gabapentin) and dual reuptake inhibitors such as tricyclics (e.g., amitriptyline,

cyclobenzaprine) and selective neurotransmitter reuptake inhibitors (SNRI's) (e.g., duloxetine, milnacipran), which work to regulate the various over- and under activity of neurotransmitters mentioned previously (Phillips & Clauw, 2011). However, only about 40% of FM patients report benefits from the use of medications (Kim et al., 2013). Evidence of reduced mu-opioid receptor binding in patients with FM coincides with the lack of response to opioid medications seen in this population (Harris et al., 2007). Moreover, many medications come with adverse side effects, especially for men.

Men taking medications for FM have reported associated discomforts including gastrointestinal complaints (i.e., stomach pain, cramps, nausea/vomiting, constipation, acid reflux, peptic ulcers, ileus), headaches, dizziness, drowsiness and fatigue, dry mouth, and heart palpitations (Paulson, Norberg & Danielson, 2002). There is also an association between antidepressant drugs commonly used to treat FM and erectile dysfunction (Rico-Villademoros et al., 2012). The physical and cognitive limitations from FM alone already significantly impact men's work performance, social relationships, and domestic functioning (Sallinen & Mengshoel, 2018). Thus, it is a difficult burden- when medications aimed to provide symptom relief cause men further problems. The meager benefits and potential cost of medication for treating FM only further emphasize how crucial psycho-social interventions are for the management of FM.

Psycho-social treatments focus on helping individuals adjust to living with FM and lessening the impact of symptoms on QOL. This moves away from purely medical interventions to incorporate non-pharmacological approaches including lifestyle modifications and learning ways to effectively cope with FM. Treatments such as aerobic

exercise, diet change, cognitive-behavioral therapy (CBT), and relaxation training have all been shown to generate improvements in outcome comparable to medication management (Glombiewski et al., 2010). However, since the majority of individuals diagnosed with FM are women, much of the research on FM treatments and outcomes has primarily focused on women (Prados et al., 2013). Few studies have compared group outcome differences between men and women in treatment for FM and preliminary data suggests there are indeed gender differences in response to FM treatment.

For instance, a study by Hooten et al (2007) evaluated the effects of a multidisciplinary pain rehabilitation program on psychological outcomes in FM patients. Data revealed pretreatment differences in that men reported more physical limitations and worse health perceptions, while women reported greater pain interference in life domains (i.e., physical and social functioning, emotional wellbeing, and role limitations). Moreover, men demonstrated lower post-treatment scores related to physical role limitations, health perception, and social functioning. In another study, Sanchez-Castro et al (2013) conducted a randomized control trial studying the effects of a manual therapy protocol on pain, physical function, quality of sleep, depressive symptoms, and pressure sensitivity in women and men with fibromyalgia syndrome. Results indicated greater reductions in pain and overall FM impact in women, while men exhibited greater reductions in pressure hypersensitivity and depressive symptoms (Castro-Sanchez et al., 2013). Studies examining cognitive behavioral therapy for insomnia across FM patients have also found gender differences in treatment responses in terms of sleep, pain, and related symptom variables, supporting the possibility that designing different treatment

for men and women with FM could be useful (Lami et al., 2016). Thus, it is important to gain further understanding of what factors influence the illness experience and differential treatment outcomes in men with FM. Of specific interest is how stigma and masculine gender role strain may influence men in living and coping with FM.

### **Relevant Constructs and Theoretical Frameworks**

Several theoretical models provide a framework for helping understand factors contributing to the illness experience in men living with FM. First, the Common-Sense Model of Self-Regulation, also known as the Illness Perception Model (Leventhal, Diefenbach, & Leventhal, 1992) is important to understanding cognitive processes related to general illness threat. Specific components of illness perceptions may be especially salient for men with FM. This study was particularly interested in how stigma intersected with masculinity stress and strain in men's illness perception formation. Stigma in men with FM was examined through the Stigma-Induced Identity Threat Model (Major & O'Brien, 2005). Issues related to men and masculinities impacted by living with FM were conceptualized through the lens of the Masculine Gender Role Strain Paradigm (Levant & Richmond, 2016; Pleck, 1995). For this study, the concept of masculine gender role "strain" is used interchangeably with similar terms such as masculinity "stress" or "identity threat." Overlaps and intersections between these models will be discussed in the sections to follow.

### **Illness Perceptions**

#### ***Common Sense Model of Self-regulation***



Illness perceptions are one factor purported to impact a person's illness experience and treatment outcomes. Leventhal's "common-sense model of self-regulation" (Leventhal et al., 1992) provides a framework integrating social and contextual factors with individual cognition and affect to conceptualize dynamic, multi-level processes involved in people's representations and adaptation to illness threats. This model helps provide an understanding of how individuals formulate perceptions of illness threats, navigate affective responses to the threat, and choose coping behaviors in response to threats (Leventhal et al., 1980; Leventhal et al., 2016). Moreover, the model helps demonstrate how various coping responses or styles (e.g., problem-solving, cognitive re-appraisal, emotion-focused coping, seeking social support, avoidance coping) influence health and illness outcomes (e.g., physical/psychological well-being, and social/role functioning).

According to Leventhal, Phillips, and Burns (2016), people derive an understanding of their physical and cognitive functioning when they are healthy vs. when they are ill through their individual history and past experiences with recovering from illness. Illness perceptions become activated when an individual experiences physical or cognitive symptoms or changes in functioning that deviate from their normal state of health (Leventhal et al., 2016). In turn, individuals construct cognitive representations or beliefs about their illness to help make sense of their illness experience, and the representations formed are thought to influence what actions people take to cope with illness threats.

The model explicates that cognitive illness representations are comprised of five main dimensions: cause (coherence), identity, timeline, consequences, and controllability. *Cause/Coherence* reflects a person's perceived causal antecedents of the illness (e.g., internal/external factors such as injury, genetics, infection, diet, aging, degree of personal responsibility, or other exacerbating factors). *Identity* is characterized by the disease label and its associated symptoms. *Timeline* reflect the rate of onset, expected duration, and fluctuations in the course of disease. *Consequences* involve the anticipated or experienced physical, cognitive, and/or social disruptions caused by the disease. In other words, consequences capture the negative impact of the disease on various life domains such education, work, or social relationships. Lastly, perceived *control/cure* reflects the person's expectations about the chronicity of the disease, and how much they and/or healthcare providers can control the outcome of the illness. In addition to cognitive representations, people also form emotional representation in response to illness threats that influence their selected coping strategies and subsequent illness outcomes.

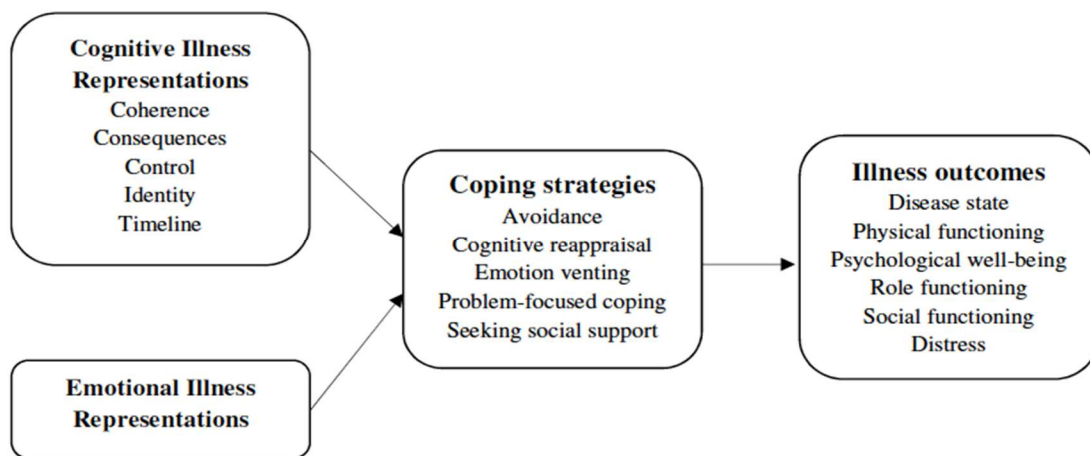


Figure 1: Common-sense model based on Leventhal et al.'s (1992) illustration, with coping strategy and illness outcome categories based on the classifications developed by Hagger and Orbell (2003).

Social and contextual factors may also influence individuals' illness perceptions. How one conceptualizes and responds to a diagnosis can vary based on intra-personal factors like personality and individual differences in one's upbringing (Leventhal et al., 1992). Additionally, individuals' perceptions of their illness and treatment may be impacted by social comparison or observing how others respond to the threat of disease (Leventhal et al., 2016). Vicarious learning (Bandura, 1998) involved in illness perception development may be especially impactful when observing someone similar, or with a similar disease process. Given that FM is more commonly diagnosed in women, it is unclear as to how men with FM relate to some aspects of illness perceptions and coping responses that have been reported by their women counterparts. Further, communications from family, friends, healthcare providers, and mass media can also inform or modify individuals' illness perceptions and coping behaviors (Leventhal et al., 2016). Since FM is a disease primarily impacting women, men may be at greater risk of receiving messages from family, friends, medical providers, or the media that are perceived as stigmatizing, elicit gender role strain, or evoke maladaptive illness perceptions. Moreover, such messages may perpetuate the stigma of being a man living with FM. Thus, understanding the illness perceptions of men with FM and the social and contextual factors that inform them are important.

### ***Fibromyalgia Illness Perceptions***

A better understanding of the illness perceptions and the social and contextual influences relevant to men with FM may help inform treatment programs and healthcare providers in ways that improve treatment outcomes. According to Levenson's Model,

illness perceptions provide the basis for communication and interventions aimed at modifying adverse outcomes. Arat and colleagues (2018) highlight the potential for improving outcomes through an indirect route by addressing and altering modifiable correlates of illness perceptions, including medication beliefs, information provision and satisfaction, quality of care, illness-related factors, and psychosocial factors. In the case of men with FM, it is unknown if messages that elicit stigma or masculine identity threat are modifiable correlates of illness perceptions (Arat et al., 2018). Moreover, modifiable correlates of illness perception may be highly person-specific (Arat et al., 2018). Thus, qualitative research can provide an in-depth and personalized understanding of how these factors may be implicated in certain illness perceptions of men with FM.

Knowing more about the illness perceptions of men with FM and possible modifiable correlates may also improve patient-provider relationships, which can also promote better health outcomes (Griffin et al., 2004; Hesse & Rauscher, 2019). Studies have found that information patients receive from healthcare professionals as well as their satisfaction with the information they receive correlate with illness perceptions (Arat et al., 2018; Hagger & Orbell, 2003). This highlights that *what* information is provided and *how* it is delivered can be influential in men's conceptualization of their FM.

Very few studies have investigated patient-provider communication between men and healthcare professionals (Olliffe & Thorne, 2007; Smith et al., 2008). Existing studies reveal that men may have somewhat different perspectives than women in terms of what constitutes "patient-centered care," and that potential masculinity concerns are likely to arise in interactions with healthcare providers. More specifically, Oliff and Thorne (2007)

highlight how men with prostate cancer often perceived masculinity threat when they interpreted interactions with healthcare providers to be subordinating. On the other hand, they experienced reduced anxiety in healthcare encounters when providers interacted in a way to reduce the patient-provider power imbalance. This is important because anxiety emerging in the context of an illness experience constitutes an emotional representation, which is the component of illness perceptions found to have the strongest relationship with quality of life (Dempster et al., 2015). The authors called for further research studies to help distinguish contexts in which masculine identity threats are most evident, as well as a need for understanding patient-provider communication strategies that will meet the needs of men while helping preserve their ego integrity.

Together, these studies suggest that healthcare professionals can play a critical role in altering illness representations in men, which may in turn improve patient outcomes. Specifically, providers can address maladaptive illness perceptions (i.e. negative self-perceptions or anticipated consequences, harmful emotional representations) that may be linked to psychological distress, poor coping, or poor engagement in treatment. Additionally, healthcare providers have opportunities to address areas of confusion, misconceptions, or gaps in FM patients' illness representations (Arat et al, 2018). Not only can addressing illness perceptions positively impact treatment but knowing which aspects of illness perception are most salient or highly influential for men with FM can also help providers avoid missteps in their interactions or better navigate rupture-repairs when they do occur. Lastly, understanding the illness perceptions of men and sociocultural factors that influence them can help

healthcare providers recognize important areas to attend to when communicating diagnosis and treating men with FM. However, we need to know more about the illness perceptions of men with FM before we can guide healthcare professionals in optimizing communication and improving treatments for men with FM.

Several studies have begun to address the illness perceptions of patients with FM. In a study investigating the illness perceptions of patients with FM and their relationship to quality of life and catastrophizing, most patients attributed their FM to external somatic causes, considered FM to be chronic with serious consequences, perceived little control over the illness, and had poor expectations for effective medical treatment (van Wilgen et al., 2008). Of note, 92% of participants in the study were women. A meta-synthesis of qualitative studies on the illness experience in FM categorized overarching themes including symptom experiences, search for a diagnosis, legitimacy, and invisibility of the condition, and coping strategies (Sim & Madden, 2008). Of the 23 studies included in the final analysis, there was a collective total of 383 participants with 360 being women and only 23 men.

Mengshoel and colleagues (2018) conducted a meta-ethnography of 18 studies to understand how individuals experience the process and consequences of receiving an FM diagnosis. Collectively, individuals spent years consulting various medical specialists trying to make sense of their symptoms and confirm the reality of their pain experience. Finally receiving a diagnosis of FM brought ephemeral relief, which diminished when therapies proved less successful than they had hoped. In the process and consequentially to the diagnosis, patients encountered significant stigma in the form of their illness being

questioned or labeled as purely psychological. Moreover, their efforts to recover were frequently questioned, which made them feel blamed for their illness and threatened their moral identity and credibility. Of note, this review included interviews with 475 informants, 450 of whom were women and 25 men.

Several studies have found stigma experiences to be related to the illness experience. A recent study by Armentor (2017) examined illness perceptions of women with FM as they related to communicating with others about their illness and managing stigma experiences. Findings highlighted how a perceived lack of understanding by friends and family led participants to avoid social interactions to hide from the stigma associated with an invisible illness. In a phenomenological exploration of the illness experiences of people with Fibromyalgia, Chronic Fatigue Syndrome (CFS), and Multiple Chemical Sensitivity, major themes depicted being stigmatized (often by healthcare providers) as being mentally ill or malingering, which had detrimental impacts on their health behaviors (Alameda et al., 2019). Unfortunately, only one male participant (who had CFS, not FM) was included in this study. While these studies begin to highlight how stigma can be embedded into one's illness perceptions and coping responses, again the participants were all women. The gender composition of all these studies continues to raise the echoing concern of whether there are nuances in the experiences of men regarding living with an FM diagnosis that are being marginalized and overshadowed by the experiences of women.

Clearly, very little research has focused on the illness perceptions of men with FM. Thus, further research is needed to understand which domains of the illness

perception model (i.e., cause, identity, timeline, consequences, control) are most salient in men with FM. More specifically, it would be useful to further understand how stigma influences illness perceptions, coping behaviors, psychosocial functioning, and health outcomes in men with FM. Illness perception and self-regulation models propose that internalized stigma can influence outcomes when people form discouraging and unhelpful representations about their pain, which in turn shape behavior (Linton & Berghom, 2011; Waugh et al., 2014). As such, this study aims to further understand the relationship between illness perception and stigma in men with FM.

### **Stigma**

Multiple definitions of stigma exist (Goffman, 1963; Jones et al., 1984; Link & Phelan, 2001; Deacon, 2006). Goffman (1963) broadly defines stigma as an attribution that largely discredits an individual and reduced them from feeling like a whole person, to a discounted or tainted one. Stigma is conceptualized as an individual psychological process, a social process, and a context-specific phenomenon (Jones et al., 1984; Major & O'Brien, 2005). Thus, stigma is viewed as manifesting at two levels – publicly or internally (Corrigan Kerr & Knudsen, 2005; Corrigan & Watson, 2002). According to Corrigan and colleagues, public stigma (also commonly referred to as ‘enacted stigma,’ ‘social stigma,’ or ‘perceived stigma’) results from majority group members’ endorsement of stereotypes and actions against a stigmatized group. Internalized stigma (i.e., self-stigma) occurs when a stigmatized individual internalizes the beliefs or stereotypes enacted on them through public stigma (Corrigan et al. 2005) or is derived



from the sense of shame that accompanies a particular deviancy and fear of enacted stigma (Scambler, 2004).

Health-related stigma is typically characterized by the social devaluation of individuals who are identified with a particular health problem (Weiss et al, 2006). Jones et al. (1984) proposed six dimensions of health conditions that can make them more or less vulnerable to stigma: concealability (the extent to which it is visible or can be hidden), course (of the disease and anticipated social consequences), disruptiveness (impact on social interaction), origin (cause or perceived blame), aesthetic qualities (how aesthetically displeasing the illness is), and peril (danger associated with the stigma) (Jones et al., 1984). As noted, FM is particularly disruptive, chronic, has detrimental physical, psychological, and social impacts. It may be concealable to unknowing onlookers when one is in a passive or low-pain state and does not require assistive mobility devices or braces. However, it may be more apparent when one is experiencing a flare-up or when engaging in physical or mental tasks. Many of the illness factors that influence stigma vulnerability parallel those involved in the illness perception model, which accentuates the convergence of health-related stigma and illness perception in individuals with FM.

### ***Chronic Pain Stigma***

Many individuals with chronic pain conditions, including FM, report experiencing health-related stigma from family (Monsivais, 2013), friends (Toye & Barker, 2010), partners (Holloway et al., 2007), and work colleagues (McGillion et al., 2011). In a review of research on stigma and chronic pain, De Ruddere and Craige (2016) present

abundant evidence that patients with chronic pain experience pervasive stigma in various aspects of life – however, they note that stigma in this population is still not well understood in regard to determinants, mechanisms, and personal impact. Moreover, the authors call attention to the need for more theory-driven research to broaden understanding of the impact of stigma on well-being and functioning in chronic pain populations.

The invisibility and lack of clear biomedical explanation for several chronic pain conditions can lead to disbelief, discounting, questioned legitimacy, and allegations of malingering (De Ruddere et al., 2012; De Ruddere et al., 2013; Frohm & Beehler, 2010; Goldberg, 2010). This is especially true for individuals with a diagnosis of FM. One qualitative study found that patients with FM experience diagnosis-related stigma in the form of skepticism and insensitivity from healthcare providers and employers due to the invisibility of their symptoms (Taylor, Adelstein, Fischer-White, Murugesan & Anderson, 2016). The gender composition of this study was 19 women and only one man, so less is known about the accounts of diagnosis-related stigma experiences in men and any nuances to men’s stigma experiences.

Moreover, patients with chronic pain often have to justify and defend their subjective experience, which can feel invalidating (Kool et al., 2010). Patients with FM reported feeling their illness is ignored or misunderstood because of not having a clear cause, prompting a sense of distrust, and attempts to hide their FM from others to avoid backlash (Sabik, 2010). Additionally, patients with FM reported feeling stigmatized by physicians telling them their symptoms were psychological or “all in their head” and

endorsed having to justify their symptoms to others, which deterred many from talking to others about their FM (Taylor et al., 2016). When there is not a clear diagnosis to explain pain, patients often question the credibility of their pain (Monsivais, 2013; Toye & Barker, 2010) which may lead to internalized stigma.

Research supports that stigma experienced by chronic pain patients is strongly associated with patient outcomes. Social withdrawal associated with the lack of empathy and understanding may contribute to greater psychological suffering among patients with FM. This was supported in studies by Kool and colleagues (2010; 2012; 2013) which found that discounting responses of others – defined as lack of understanding, denying, and/or patronizing – were associated with poorer physical well-being, psychological well-being, and social functioning in patients with rheumatoid conditions (Kool, Middendorp, Lumley, Schenk, Jacobs, Bijlsma & Geenen, 2010; Kool, van Middendorp, Lumley, Bijlsma & Geenen, 2013). Compared to patients with rheumatoid arthritis (RA), patients with FM experienced significantly more discounting and lack of understanding from their medical providers, social services, colleagues, and family members (Kool et al., 2010). Moreover, patients with FM experienced significantly more loneliness (Kool & Geenen, 2012). Again, the majority of participants in the Kool et al., (2010; 2012; 2013) studies were women (95%, 86%, and 96%, respectively), indicating the need for more studies concerning the experience of men to address the gender gap.

Stigmatizing experiences can also have a profound influence on an individual's perceptions, self-esteem, and behaviors (Holloway et al., 2007). Waugh, Byrne, and Nicholas (2014) studied stigma in individuals with chronic pain and found internalized

stigma had a negative relationship with pain self-efficacy and self-esteem, even after controlling for depression. Moreover, internalized stigma was associated with increased pain catastrophizing and reductions in the sense of personal control one had over their pain. This touches on how stigma negatively impacts the control component of illness perception. As with most studies, the majority of participants were women (76%). The study also grouped non-malignant pain conditions. The authors recommended future analysis considering how stigma may vary depending on the nature of pain and exploration of factors linked with positive coping and outcomes, such as empowerment or righteous anger (Waugh et al., 2014). A study on men with FM could help clarify if the impact of internalized stigma is more pronounced for men with particular pain conditions, and what particular factors are related to positive coping in this population.

From a social and behavioral standpoint, stigma has been found to interfere with seeking care and participating in rehabilitation (Slade et al., 2009), which is likely to hurt health outcomes. In a quantitative survey of 1,163 men with FM living on the east coast, men reported they were deterred from interacting with health-care providers for fear of stigma related to having a condition primarily affecting women, potential dismissal of symptoms, less supportive responses towards men with FM, and a lack of health education resources catered towards men (Muraleetharan et al., 2018). Moreover, the majority of men reported FM had a negative impact on their physical and mental health, quality of life, relationships, and careers. It is not clear from this study whether these negative health outcomes were allocated more to the disease itself, or the secondary impact of men's stigma experiences. Nonetheless, these findings reflect how gender-

based health-related stigma negatively influences help-seeking, and imply a possible association with psychosocial outcomes in men. However, much is left to uncover regarding how masculine ideologies interact with and/or influence the mentioned fear stigmas of men with FM. It would be useful to identify salient aspects of internalized stigma that are specific to men with FM to address any nuances of their experience that influence harmful illness perceptions that negatively impact treatment outcomes.

### ***Stigma-Induced Identity Threat***

One mechanism in which stigma affects the stigmatized is through an identity threat process (Major & O'Brien, 2005). According to Major and O'Brien (2005), stigma introduces threats to one's personal and social identity as well as their personal and collective self-esteem. Messages received within one's culture that indicates they belong to a marginalized, devalued, or lower status group can lead to social identity threat or threats to parts of the self that are based on membership in that group. The model of Stigma-Induced Identity Threat (SIIT; Major & O'Brien, 2005) was used as a guiding framework to help conceptualize how illness perceptions may be influenced by the way health-related stigma (e.g., FM) affects men's masculine identity.

Major and O'Brien (2005) conceptualized a model of Stigma-Induced Identity Threat (SIIT) to depict the constellation of social and personal factors that influence stigma experiences, identity threat, coping responses, and outcomes. The model draws from identity threat models of stigma (Crocker et al., 1998; Major et al., 2002; Steele et al., 2002) and models of stress and coping (Lazarus & Folkman, 1984; Smith, 1991). The model posits that *collective representations* of one's stigmatized status, *situational cues*,

and *personal characteristics* shape one's appraisal of stigma-relevant situations and the significance of those events for their wellbeing. Within this framework, *collective representations* are thought to be constructed based on an individual's experience with the dominant culture and understanding of cultural views regarding their stigmatized identity (i.e., FM). Cultural representations men hold related to their masculinities are likely to play a role in collective representations of FM-stigma. *Situation cues* can vary in their identity threat potential or the degree to which they indicate risk for being negatively stereotyped or devalued. Examples of situational cues for men with FM may include interacting with the medical system, in workplace settings, or with those who do not have FM. *Personal characteristics* that are thought to influence how stigma-related identity threats are perceived include stigma sensitivity (expectations for and reactions to stigma), group identification (the degree that one's stigmatized social identity is salient to their self-identity), domain identification (the degree that one identifies with domains in which their group is negatively stereotyped), and goals and motives (e.g., a motive to protect/enhance self-esteem; the motive to believe in a fair/just world) (Major & O'Brien, 2005).

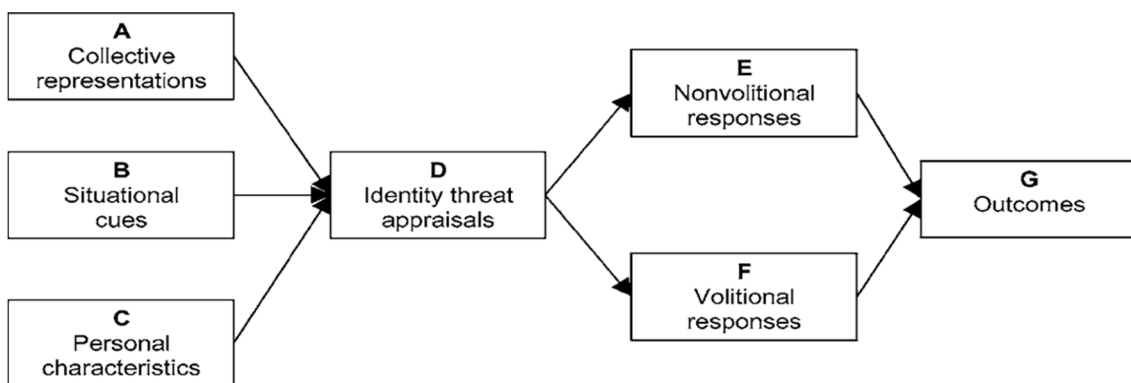


Figure 2: Stigma-Induced Identity Threat Model (Major & O'Brien, 2005)

Major and O'Brien (2005) explain that identity threat appraisals emerge when a stigma-related stressor imposes a demand that is interpreted as a harmful to one's personal or social identity, or as exceeding their resources to cope. Coping responses to identity threats are classified as either voluntary or involuntary. *Voluntary responses* convey active, conscious efforts to regulate thoughts, feelings, behaviors, physical sensations, and the environment to cope with a perceived stressor (Compas et al., 1991), such as engaging in therapy, relaxation, or utilizing social supports. *Involuntary responses* are cognitive, emotional, behavioral, or physiological responses that do not serve to assuage stress (e.g., anxiety, withdrawal, isolation, increased vigilance, and working memory load).

The Stigma-Induced Identity Threat model has several theoretical overlaps with the illness perception model. Collective representations are important social aspects that relate to the identity domain and map on with consequences in terms of anticipated fear of stigma from others. While the illness perception model may uncover how the course of FM may underscore changes in the experience of stigma over time, the Stigma-Induced Identity Threat model also taps into stigma experienced across settings or situations. Moreover, perceived control is likely to relate to personal characteristics. The identity threat appraisal element of the SIIT provides the basis for incorporating inquiry related to masculine identity threat and strain. In combination these two models provide comprehensive depth to examine various aspects of men's experiences in living with FM.

### **Masculinities**

The psychological study of men and masculinities has highlighted how gender and societal expectations of gender normative behavior significantly influences how people think, feel, and behave. Within the context of men's health and illness, it is important to consider how aspects of masculinity inform cognitive appraisals, emotions, and behavioral responses. Particularly, it is critical to consider how men's beliefs, attitudes, and level of adherence to culturally prescribed masculine norms shape their experience of stigma-induced identity threat associated with FM and FM illness perceptions.

### ***Masculine Ideology***

The term *masculine ideology* refers to belief in the importance of men adhering to a set of culturally sanctioned masculine standards of behavior (Pleck et al., 1993). David and Brannon's (1976) definition of *hegemonic masculinity* illustrates four principle ideologies or ways boys and men are traditionally socialized to think and behave in mainstream American culture that constitutes "manhood." First, men are taught to abide by the rules of "*no-sissy stuff*" by avoiding feminine behaviors or activities and refraining from showing emotions (except for anger). Second, men are taught to maintain an image of a "*sturdy-oak*" by being stoic, self-reliant, and physically strong and tough. Third, men are expected to be a "*big wheel*" by striving for achievement, success, and power. Lastly, men should embody a "*give em' hell*" attitude, by being competitive, dominant, aggressive, and risk-taking (David & Brannon, 1976).

The construct of masculine ideology emphasizes the internalized beliefs or attitudes society typically associates with men, rather than the actual degree an individual



possesses or enacts expected masculine traits (Pleck et al., 1993). As the physical, mental and psychological impacts of FM often diametrically oppose culturally sanctioned beliefs and expectations for men, there may be great potential for men with FM to experience stigma when they experience masculine identity threat or gender role strain. Masculine ideology theoretically emerged from the Gender Role Strain Paradigm (Levant & Richmond, 2016; Pleck, 1995) and is viewed as an essential part of the male gender-role strain process. It is important to acknowledge that some distinguish masculine gender role *strain* is from masculine gender role *stress* (Eisler & Skidmore, 1987), with the former being stress from violating masculine ideologies and the latter representing stress from violating masculine role norms (Thompson & Bennett, 2015). In this study, gender role strain was operationalized to include either form of gender role conflict – that is, perceived stress arising from gender-nonconformity to masculine ideologies or gender role norms.

### ***Gender Role Strain Paradigm***

Essentially, the Gender Role Strain Paradigm (GRSP; Pleck, 1995) posits how stress and strain arise when men deviate from the dominant masculine ideology (Pleck 1995). According to Pleck's original model, men's gender-role strain can take form in any of three ways: gender role trauma, gender role discrepancy, and gender role dysfunction. *Gender role trauma* involves men being socialized to develop masculinities through, particularly traumatic or painful experiences. Trauma strain is often associated with experiences in early stages of development or young adulthood, but the concept is commonly applied to groups of men who are entrenched in particularly scathing gender

role strain conditions – such as survivors of child abuse, gay and bisexual men, men of color, professional athletes, and war veterans (Silverstein et al., 2002). Considering the strong links found between trauma and chronic widespread pain (Siqueland et al., 2017), men who develop FM may have experienced traumatic gender roles socialization at some point or another. Furthermore, it is possible that traumatic gender role socialization could be associated with gender role discrepancy and dysfunction for men with FM.

Masculine *gender role discrepancy* is the psychological distress resulting from failure to conform to internalized or externalized cultural gender norms, standards, and expectations of men (Pleck, 1995). For instance, a man who holds preconceived ideas that “being a man” involves being tough and being a “breadwinner” would likely experience gender role discrepancy in the face of an illness that challenged his ideas about his manhood or his ability to carrying out those roles. This in turn may elicit psychological distress. Associated negative psychological outcomes related to gender role discrepancies include- loneliness (Blazina et al., 2007), poor self-esteem, depression, social anxiety (Yang, Lau, Wang, Ma & Lau, 2018) feelings of disconnect from other men, “internalized negative self-judgments,” and “negative social feedback” (Pleck, 1995, p. 13). The identified outcomes (especially the latter two) depict how gender role discrepancy intertwines with internalized stigma and social stigma.

*Gender role dysfunction* (Pleck, 1995) illustrates how ascribing to expected cultural norms for men can negatively impact men’s psychological and interpersonal functioning. For instance, a series of meta-analyses by Wong, Ho, Yang, and Miller (2017) found unfavorable associations between strong conformity to masculine norms

and mental health, attitudes about help-seeking, and social functioning. For example, men who adhere to masculine norms like being stoic or dominant may experience interpersonal conflict in modern-day relationships which require greater equity, open communication, and compromise.

### **Intersection of Stigma and Masculinities**

It is difficult to separate the concept of stigma and masculine identity threat/strain in relationship to FM in men. Research has linked men's masculine ideologies, conformity to traditional male roles, and gender role stress and strain with self-stigma (Booth, McDermott, Cheng, & Borgogna, 2019; Vogel & Heath, 2016). One way that FM may produce stigma-induced identity threat for men is through masculine gender role stress or strain. While there is a general stigma associated with FM, FM-related stigma may be heightened for men as the disease challenges their ability to live up to masculine ideologies/norms, which may in turn elicit expected public stigma. Men who strongly believe in the importance of adhering to certain masculine ideologies, or place high importance on certain masculine attributes or behaviors may experience significant masculinity threat and strain in the context of FM. This idea has been eluded to by several studies yet frequently cited as an area for further research. Research on men and help-seeking behaviors marks a cornerstone of empirical support that links masculine ideologies/norms and stigma to health behaviors and outcomes in men.

### ***Masculine Gender Role Strain, Stigma and Help Seeking***

The relationship between conformity to masculine ideologies/norms and help-seeking has also been largely researched. Surmounting evidence shows that conformity to

masculine norms and stigma are significantly associated with lower help-seeking in men (Seymour-Smith, Wetherell & Phoenix, 2002; Mansfield et al., 2003; O'Brien et al., 2005; Pederson & Vogel, 2007; Noone & Stephens, 2008; Springer & Mouzon, 2011; Vogel et al., 2011; Westwood & Black, 2012; Vogel et al., 2014; Himmelstein & Sanchez, 2016; Vogel & Heath, 2016; Kivari et al., 2018). Masculine ideologies have also been found to predict negative health outcomes for men by decreasing healthcare behaviors (Seymour-Smith et al., 2002; Mansfield et al., 2003; O'Brien et al., 2005; Springer & Mouzon, 2011; Himmelstein & Sanchez, 2016). Decreased health behaviors and avoidance of medical and psychological help-seeking may indirectly exacerbate physical and mental health concerns.

This phenomenon has been found in men with chronic pain. In a qualitative study of men with chronic pain, men endorsed holding off from seeking medical care and enduring prolonged pain until it reached a threshold they perceived as socially acceptable (Ahlsen, et al., 2012). Similarly, men with FM reported they postponed seeking medical attention because they concerned about being perceived as “whiners” (Paulson et al., 2002). Moreover, since everyone in a given society is susceptible to engraining socially constructed beliefs, healthcare entities may inadvertently enact biases that perpetuate masculine ideologies and stigma that deter men from interacting with the healthcare system. These findings may reflect the ways dominant masculine ideologies drive men's perceptions of what it means to have an illness, and subsequent responses to protect or retain masculine identities in the face of illness.

With numerous studies highlighting how endorsement and/or conformity to traditional masculine ideologies/norms and gender role strain is related to negative health outcomes in men (Gerdes et al., 2017; Wong et al., 2017), researchers have begun to identify adaptive dimensions of masculinity that are associated with positive health outcomes (Gerdes & Levant, 2018; Hammer & Good, 2010). For instance, some masculine norms have been associated with positive character strengths and behaviors such as autonomy, courage, endurance, and resilience (Hammer & Good, 2010), which may contribute to adaptive behaviors in the face of chronic illness. Another study found that men who perceived higher levels of gender threat demonstrated higher pain tolerance (Berke et al., 2017). In the context of pain management, this could be adaptive or maladaptive depending on the person and circumstances. Relatedly, several studies have found masculinity constructs such as gender role conflict and masculine norm conformity to be associated with both negative *and* positive health-related outcomes (Kaya et al., 2019; Levant & Wimer, 2014; Wong et al., 2012). This finding emphasizes the complexity inherent in the relationship between masculinity and health outcomes. Particularly, the notion that certain aspects of masculinity may serve as both a risk and a protective factor highlights the cultural, situational, and contexts-dependent nature of masculinity factors on health outcomes (Wester, 2008; Wong et al., 2012, 2017; Isacco, 2015; O’Neil, 2015; Gerdes & Levant, 2018). This reflects the importance of tailoring research to answer the iconic question posed by Gordon Paul (1967): What works, for whom, for what problem, and under what circumstances? Thus, while the current study

aimed to explore masculine strain in the context of FM, attention was also given to ways masculinities were adaptive to men through the process of living with FM.

### ***Masculinity and Chronic Illness***

To understand how masculinities impact men with FM, it is first important to understand how masculinities relate to men's health in general. A seminal qualitative study by Charmaz (1994) examining the identity dilemmas of men with chronic illness was one of the first to explore how gender-based conceptions of masculinity affect their identity in the context of their illness experience. Charmaz identified four processes in men's experience of chronic illness.

The first process, "awakening to death," described men being struck with an awareness of their vulnerabilities, anger, self-pity, and ongoing reminders of the chronicity of illness as their bodies changed abilities, but also with affirmations of support from family. Second, men seemed to deal with the process of "accommodating to uncertainty" either by avoiding thinking about it or by acknowledging it, leading to life reappraisals and self-reflection. Men who used "bracketing" (Husserl, 1970), or avoided thoughts of uncertainty, treated uncertainty as something separate and removed from their life, conceivably to lessen the distress associated with it and the impact it had on their social and personal identities. This allowed them to retain a sense of power by not having to face identity dilemmas. On the other hand, men who recognized and embraced uncertainty led them to reappraise, redefine, and reprioritize what was valuable for them in terms of relationships, productivity, and achievement. The third theme "defining illness and disability" captured the major ways in which men viewed their conditions: as

an enemy, an ally, an intrusion, or an opportunity. Charmaz noted how depicting illness as an enemy allowed men to externalize the illness from their social or personal identities, whereas depictions of illness as an ally was linked to the reflections and reappraisals previously discussed. Although these illness definitions were not labeled as illness perceptions, they appear to be conceptually similar. Moreover, similarly to illness perceptions, it was emphasized that illness definitions are rarely mutually exclusive or static and depend significantly on situational factors and men's personal characteristics. The last process, "preserving self," describes men's efforts to reconcile the loss, change, and identity dilemmas by maintaining valued qualities and identities of their past self that inform their self-concept. It was noted that learning new ways of preserving self is often preceded by men trying to recapture the same lives they had before their illness. This involved them looking for a medical cure or fix, which was noted to heighten identity dilemmas; only after this process were they then able to construct new self-concepts.

This study highlights several aspects of how masculine identity dilemmas shape illness perceptions and gender role strain. However, many of the men from this study had chronic illnesses that were serious and life-threatening (e.g., heart attack, Multiple Sclerosis, tumor). FM on the other hand is a condition that is not necessarily life-threatening, though it is threatening to one's quality of life. Moreover, many of the men in this study held high-status jobs (e.g., clinical psychologist, anthropologist, "competitive businessman") suggesting a sample that may not represent the voices and experiences of identity dilemmas in men of more diverse or marginalized identities. Therefore, research is needed that expands on these findings to understand the impact of

masculine identities on culturally diverse men with chronic, yet non-life-threatening illnesses.

**Masculinity and Fibromyalgia-Stigma.** Men with FM may be prone to similar types of identity dilemmas, uncertainty, illness appraisals, and reactions as other men with chronic illness. However, how different mechanisms of stigma contribute to masculinity threats, strain, and subsequent illness perceptions in men with FM is not entirely understood. Being a man with FM may elicit internalized and/or public stigma that activates the masculine gender threat. Additionally, several studies provide evidence that masculine stereotyped behavior may be enacted in an attempt to mitigate uncomfortable affect caused by gender threat (Vandello et al., 2008; Bosson et al., 2009; Weaver et al., 2010; Vandello & Bosson, 2013). For instance, Berke et al. (2017) examined how masculinity threat influenced gender role discrepancy in the context of pain tolerance and found that threats to masculinity predicted increased perceptions of gender role discrepancy, which potentiated aggression. Greater masculinity threat was also associated with higher pain tolerance, supporting the idea that masculine ideologies can exert considerable influence on men's responses to pain and attempts to preserve "manhood" in the face of pain. Men with FM may be at greater risk of experiencing stigma due to gender role strain, as the disease directly challenges their ability to live up to several notions of masculine ideology. Moreover, FM's label as a "women's disease" inherently violates the norm of avoiding anything feminine, which may subsequently evoke masculine gender strain. A few studies specifically aimed at understanding the



experiences of men with FM have begun to touch on stigma and how men's masculinities are impacted by the disease.

One study by Paxman (2019) discussed how the cultural values of hard work and independence make FM highly susceptible to societal stigma as many implicitly hold the American discourse of hard work. In reviewing 50 stories of individuals with FM, Paxman highlighted how many portrayed a 'legitimacy narrative,' set out to defend the existence of their condition against the notion that they are lazy. While participants' genders were not explicit, most narrators were noted to have women's names. Moreover, accounts marking one of the prevailing themes, "Limited ability to perform gender roles," all referenced gender role challenges as wives and mothers. Thus, even studies specifically aiming to unveil how American cultural discourse impacts gender identity in the context of FM have been limited in the inclusion of men.

In an early narrative study by Paulson et al (2002), 15 men living with FM described their experiences as a patient in the Swedish healthcare system. A major theme depicted was men's tendency to postpone seeking treatment due to fear of being seen as "whiners." Relatedly, they avoided talking about their pain experience, including the accompanying emotional components, due to fear of being viewed as troublesome. Men in this study also reflected their experience of "feeling like a guinea pig" through exposure to numerous treatments and medications with adverse side effects, all of which provided limited relief. Men expressed "feeling hopeful" about finding a cure when they were finally referred to specialty clinics, where they often felt believed and understood for the first time. Other themes included "feeling neglected" due to the long waits for

treatment, lack of continuity and follow-up, feeling disrespected or not taken seriously by medical providers, or medical staff showing disinterest when there was no clear cure for their pain. They also noted the theme of “feeling no recovery” which depicted finding temporary pain reliefs but no cure for FM.

This study helped illuminate the experiences and behaviors of men with FM. Overall, several of the themes depicted unhelpful coping responses that could be construed as associated with adherence to masculine ideologies and/or attempts to protect their masculine image from potential stigma (e.g., delayed treatment-seeking, avoiding talking about physical/emotional pain). However, further investigation is needed to infer how masculine ideologies and/or identity threats impacted their illness perceptions and responses to stigma.

Another phenomenological study by Paulson et al (2002b), interviewed 14 Swedish men with FM-type pain to understand what living with FM pain means to men. While men discussed aspects related to what it meant to them from a physical standpoint (e.g., ‘living with a reluctant body’ and living with daily pain), the overarching theme ‘becoming a different man’ is of particular interest as it relates to masculine identity. Two subthemes were identified: ‘not being the same man as before,’ and ‘not being really understood.’ Men’s narrations of the first subtheme reflected feelings of not being a “whole person.” Men cited feelings of emptiness, sadness, and anger due to being unable to perform at the same physical and mental capacity as before their diagnosis. Clearly, men with FM experienced gender role stress/strain. The authors noted that negative moods seemed to resolve as men developed a greater acceptance of themselves and their

limitations. The second theme – ‘not being really understood’ described men’s thoughts about how others (i.e., family, friends, relatives, employers) understood their pain and viewed them. Men believed that healthy people had a hard time understanding their situation. Men were especially impacted when their children could not understand why they could not fulfill common fatherly roles, such as playing sports with them. This theme highlights how perceived or actual received messages from others may trigger internalizations of gender-role discrepancies. Together, these themes imply a link between illness perceptions, masculine identity loss, and internalized stigma. However, some men with FM were able to reframe their illness perceptions and experience a sense of well-being, or at least a “tolerable existence.”

These early qualitative studies on men with FM are important in highlight men’s experiences and beginning to shed light on masculinity concerns. However, it has been nearly two decades since these studies were conducted, and it may be useful to re-examine if there have been any changes in how men experience FM across different contexts (e.g., home, work, healthcare). Additionally, given that these studies were conducted primarily with men from Eastern European regions, a study with a U.S. sample could be helpful for examining if similar meanings resonate with American men.

More recent studies have delved deeper into examining the impact of FM on different life roles for men. One study examining the work lives of men with FM found that the disease challenged their masculine identities in the context of work, and for some men, FM disrupted their career trajectories (Furgeson, 2014). Moreover, men from this study noted seeking support from other men with FM. Yet, much remains unexplored

regarding men's experience of stigma and masculinity threat/strain in a context outside of work, and how these influence their illness perceptions and coping behaviors.

A more recent narrative study on men living with FM highlighted the negative impact of the disease on men's role in the family and home, and how men express their illness experiences (Sallinen & Mengshoel, 2019). Interviews with five Finnish men revealed two different themes. The first theme, 'Adjusting life to match the illness' reflected finding balance "between health and illness and between work ability and disability" (p. 424). Namely, the men discussed how their work ability was not only limited by pain but also impacted by sleep problems that caused daytime fatigue and cognitive problems with attention and executive functioning. The psychological impact of FM (e.g., feeling depressed) was another factor men expressed as taking a toll on their daily life and work abilities. The physical pain, fatigue, and mental challenges were noted to affect their family life and social relationships, as they interfered with their ability to be the friend, husband, or father they wanted to be. They described difficulty completing household chores, disengagement from family and friends due to lack of energy and being easily irritated by others when the pain was high. They often gave up personal hobbies and leisure activities in order to sustain their ability to work, alluding to the importance of paid work roles on men's identity. Many noted having to modify work tasks, reduce working hours, or consider completely different occupations.

While the first theme reflected finding ways to live successfully with FM, another narrative captured the opposite, regarding the experience of living with FM as 'Being imprisoned by pain.' Men's experience representing this theme focused on having

complex and debilitating symptoms, unsuccessful treatments, inability to maintain vocational functioning, and subsequent feelings of hopelessness, despair, and low self-esteem. Of note, men depicting both responses to FM cited a lack of support, as most support groups they engaged with consisted mainly of women, which felt further isolating. The authors stressed the need for a more detailed study of the issues concerning the loss of masculine identity that was implied in the interviews of this study, as well as the possible benefits and limitations of men's FM support groups.

This study by Sallinen and Mengshoel (2019) helped provide understanding about how their home and work lives were impacted by their illness experience. Overall, FM infringed on both areas due to physical, cognitive, and emotional challenges associated with the disease. While this appears indicative of gender role strain, what is less clear in this study is how stigma intersects with masculine gender strain in the illness experiences discussed, and how men navigate experiences of stigma and gender role strain amidst the functional impairments of FM.

For instance, living with chronic widespread pain inevitably evokes stress and emotional turmoil. However, men are generally expected to suppress emotions. This was evident in the storytelling of 10 Norwegian men with chronic muscle pain (Ahlsen et al., 2012). The authors sought to understand how dominant norms of masculinity converge with men's subjective experiences of chronic pain. Findings demonstrated how men's narratives of chronic pain largely described objective facts related to the cause of their pain (e.g., heredity, physical injury) and the impact their pain had on their physical functioning, with sparse descriptions of their subjective experiences of distress. The authors viewed

this factual narrative quality as a display of men adhering to hegemonic masculinity norms of self-control and concealment of any emotional vulnerability that could be construed as weakness. Additionally, they discuss how men's focus on content related to biomedical factors and physical impairment may represent their attempts to establish the legitimacy of their pain, which is often invalidated. Nonetheless, subtle undertones of emotional suffering and social distress were recognized in these men's stories.

Importantly, Ahlsen et al (2012) reflected on how their cultural conformity to masculine ideologies may have inadvertently reproduced social patterns that were unsuccessful at addressing men's subjective experiences of suffering related to their pain. For instance, they noted how they may have probed to a lesser extent about the emotional lives of men. This cultural conditioning is not constrained to researchers but affects all societal members including healthcare providers, family members, and friends. Collectively, this conditioning of how we typically interact with men contributes to the lack of invitations for men with disabilities to engage in emotional storytelling (Sparks & Smith, 2002). With this in mind, it is important to ask men specifically about their emotional experiences related to chronic pain and provide a safe platform for them to challenge their internalized ideologies. More specifically, it may be helpful to explore men's emotional appraisals of, and reactions to, stigma and masculine gender role strain in the context of FM. Not only will this create an opportunity and a space for men with FM to engage in sharing their emotional accounts, but by gaining a deeper understanding of men's emotional journey's we can begin to better understand their subjective emotional experiences and interpersonal needs that allow them to retain helpful aspects of

masculinity, and relinquish or positively reconstruct other aspects of masculinity in the face of FM.

One existing study bears a close resemblance to the aims of the proposed study. Wilde et al (2019) conducted a qualitative study on men primarily in the United Kingdom with comorbid encephalomyelitis and chronic fatigue syndrome (CFS) to understand how men make sense of their identity as a man with a stigmatized chronic illness. Major themes that resonated were a loss of masculine identity, a sense of marginalization attached to their illnesses and their masculinities, and coping with masculinity threats through adjustment, understanding, and acceptance. While chronic fatigue syndrome has symptoms overlap with FM, the main complaint in CFS is fatigue whereas in FM pain is the primary symptom of dysfunction. The study by Wilde and colleagues provides a strong basis for extending the focus of this research to men with fibromyalgia in the United States to see if similar findings are replicated regarding experiences of stigma and masculinity threat across different socio-cultural contexts.

### **Research Questions**

Based on the review of the literature, FM represents a complex illness that is not well understood, making it subject to criticism from multiple sources. Existing research is primarily constrained to women's experiences of the illness, with few studies accounting for the experiences of men living with FM. Within the body of literature focused on men with FM, it is clear most men experience some degree of stigma and masculinity-related concerns. What is less clear is how these constructs interact to shape the illness perceptions of men with FM. Hence, this study aims to answer the primary research

question, “How do experiences of stigma and masculine strain influence illness appraisals, coping behaviors, and health outcomes in men with FM?” The hope is for this research to shed light on the particular needs of men with FM and provide recommendations for improving healthcare practices and treatments to be more sensitive and responsive for this population. The following sub-research questions were developed to answer the primary research question:

**1) How do men with FM experience living with an FM diagnosis? /What are the illness perception of men with FM?**

This question draws from the illness perception literature to address the dynamic, multi-level processes men engage in to conceptualize and make sense of their FM experience. Given the scarcity of research regarding the illness perceptions of men with FM, more research in this area is warranted. This question is meaningful because it taps into which domains of the illness perception model (i.e., cause, identity, timeline, consequences, control) are most salient or influential to men living and coping with FM. Moreover, there is a dearth of research on modifiable correlates of illness perceptions (Arat et al., 2018). Qualitative inquiry lacks the means to measure the correlational nature of the constructs of interest (i.e. stigma and masculinity) with illness perceptions. However, an in-depth analysis of how stigma and masculine strain experiences connect to illness perceptions may provide a foundational basis to infer the possibility of potentially modifiable correlates of illness perceptions in men with FM. Moreover, qualitative exploration could give insight into whether current quantitative measures accurately



capture the experiences of men with FM in the domains of interest (e.g., stigma, masculinity).

**2) What is the experience of stigma (induced identity threat) in men with FM?**

**3) How does FM-stigma threaten their sense of self or masculine identity?**

These two questions expand on the illness perception model (Leventhal et al., 1992) by additionally drawing from the literature on stigma-induced identity threat (Major & O'Brien, 2005) and masculine gender role strain (Levant & Richmond, 2016; Pleck, 1995) to further examine the contextual, sociocultural, and affective aspects of men's illness representations and experiences of living with FM. Specifically, these two questions collectively aim to unveil how experiences of stigma and masculine gender role strain intersect to shape men's FM illness experience. The collection of research pertaining specifically to men with FM implied a link between illness perceptions, masculinity concerns, and internalized stigma. For instance, the study by Paulson, Danielson, and Soderberg (2002) highlighted how perceived or received messages from others may trigger internalizations of gender-role discrepancies in men with FM. Yet little is known about what kind of stigmatizing gender-based messages men perceive or receive in their environments related to their FM diagnosis. It is also unclear how men navigate feelings elicited by enacted or internalized stigma.

Another study stressed the need for a more detailed examination of issues concerning the loss of masculine identity that was implied by men with FM (Sallinen & Mengshoel, 2019). These questions in the current study aimed to uncover a deeper understanding of how FM-stigma impacts men's masculine identity. These were also

posed as means to identify if there were specific aspects of stigma (e.g. sources, mechanisms) that were particularly salient to men with FM to address any nuances of their experience that influenced harmful illness perceptions and negative treatment outcomes. Additionally, these questions aimed to address men's emotional appraisals of and reactions to stigma and masculine gender role strain. Given the current lack of research explicitly focused on the intersection of stigma and masculinity as it relates to illness perceptions for men with FM, more research is warranted in this area.

#### **4. What coping strategies do men use to navigate FM, stigma and masculine identity threat/strain?**

The illness perception and stigma-induced identity threat models emphasize how both illness representations and identity threat appraisals influence coping responses (e.g., voluntary/active or involuntary/avoidant), which in turn can affect health outcomes (e.g., physical/psychological well-being, and social/role functioning). This question draws from the models to address how men cope with these threats. Given the body of literature linking conformity to masculine ideologies and norms with differential health outcomes (e.g., Himmelstein & Sanchez, 2016; Vogel & Heath, 2016), this line of inquiry intends to identify how masculine ideologies are implicated in adaptive and/or maladaptive coping and outcomes for men with FM. Additionally, Further, this question may tap into what helps men positively retain or renegotiate a positive masculine identity while adjusting to FM.

## **Chapter 2: Methods**

### **Rationale for Qualitative Research**

Qualitative approaches are fitting for exploring social and human problems or topics that have not been thoroughly researched (Creswell, 2013). The current study aims to examine the illness perceptions of men living with FM. Prevalence rates of FM indicate the phenomenon is somewhat obscure in men, thus the bulk of research has centered on women's experience of living with fibromyalgia, with much less of a focus on men. Moreover, within the current qualitative literature on men living with FM, the majority of studies were with samples of men living in European countries. Only two known dissertation studies have focused exclusively on American men with FM (Ferguson, 2014; Callier-Perry, 2017). One touched on challenges to men's masculine identity in the context of work and career and the other examined the biopsychosocial impact of FM on African American men. However, much remains unexplored regarding their experience of stigma and masculinity threat/strain, and how these influence their illness perceptions and coping behaviors.

Qualitative research is also useful for raising silenced voices (Creswell, 2013). This brings up an interesting dialectic. Idealized notions of masculinity have traditionally privileged men in society, making their voices quite dominant and largely accounted for (McIntosh, 2018; Messerschmidt, 2012). Moreover, medicine and medical practice was historically almost entirely based on men and generalized to women until the turn of the

21st century, when this approach was largely repudiated in favor of gender-specific medicine and a greater appreciation for women's health (Annandale & Hammarström, 2011; Kaufert, 1999). However, given the factors discussed regarding FM being observed and researched predominantly in women, as well as low help-seeking in men (perhaps especially for conditions that pose greater masculinity threats), the voices of men have been somewhat obscured in the context of this particular disease. Thus, a qualitative study on the lived experience of men with FM can honor men's experience and empower stories that masculine societal pressures may compel them to constrain.

An additional strength of qualitative inquiry is its capacity to uncover information that may not be fully captured by quantitative scales (Mareck, 2003). Similarly, Creswell (2013) recommends qualitative approaches for identifying "variables that cannot be easily measured" or when "a complex, detailed understanding of the issue" is needed (p. 48). The complex interrelationship and mutual entailment of factors that underly an individual's pain experience may never be fully understood, as many factors (e.g., cognition, affect, social, cultural) are subjective, contextual, and idiosyncratic, thus difficult to objectively measure. Each of the constructs this study aims to explore (i.e., illness perceptions, stigma-induced identity threat, and masculine gender role strain) are inherently complex, multifaceted, and often embedded in interactions among people. Therefore, the full depth and scope of understanding these interactions would be difficult to capture and limited by quantitative measures. In contrast, qualitative methods allow the researcher to reflect how stigma, masculinities, and illness perceptions related to FM can be dynamic and diversified depending on the context.

Qualitative research is also helpful when the goal is to “help explain the mechanisms or linkages” in existing models (Creswell, 2013, p. 48). The current study aims to do so by exploring the contexts in which men experience and address FM stigma and masculinity strain, as well as how stigma-induced identity threat and masculine gender role strain may be embedded in men’s FM illness experience. Therefore, qualitative inquiry is appropriate for exploring how these concepts apply to the lived experience of men with FM.

### **Philosophical Assumptions**

Creswell (2013) highlights that an essential step in qualitative research is for the researcher to reflect on the philosophical assumptions underlying their approach. Philosophical assumptions are based on four main paradigms, or “basic set of beliefs that guide action” (Guba, 1990, p. 17). In qualitative research, philosophical assumptions pertain to: a) understanding of reality (ontological), b) how reality comes to be known and relevance of the researcher-participant relationship (epistemological), c) how to assess and manage researcher values and biases (axiological), and d) assumptions regarding the chosen method (Creswell, 2013). More specific guiding principles for these four assumptions are embedded within various theoretical perspectives or interpretive frameworks. My research is guided by a Social Constructivist or an “Interpretivist” paradigm, which assumes relativist ontology, transactional epistemology, and interpretive (hermeneutic) methodology.

The ontological perspective of social constructivism embraces the notion that multiple realities exist, and that reality is shaped by our lived experiences and social

interactions (Creswell, 2013). In understanding the realities of men living with FM, a social constructivist interpretive framework helped shed light on the various ways that the social constructs of stigma and masculine ideologies impacted men. In line with this perspective, my research also aimed to report on differing and co-existing perspectives.

Regarding what constitutes knowledge and how knowledge claims are substantiated, transactional epistemology assumes that the “knower and the known are inextricably intertwined” (Wang, 2016, p. 364). In other words, who we are and from what we know shapes our understanding of others and the world. The assumption of the interrelationship between the researcher and their prior knowledge closely ties to this paradigm's axiological perspectives. This posture presumes that research is inherently shaped by the values and biases of the researcher (Creswell, 2013). For instance, the foundation of this dissertation was based on my interest and experiences in working with men with chronic pain. As such, it was imperative to take steps as a researcher to help account for how my values and/or biases intersected with the research process throughout the study.

Reflexivity methods such as bracketing, and writing memos are considered necessary for helping maintain a higher level of objectivity throughout the research process (Larkin & Thompson, 2011). “Bracketing,” entails the researcher to “set aside their experiences, as much as possible, to take a fresh perspective toward the phenomenon under examination” (Creswell, 2013, p. 80). One way to accomplish this is for the researcher to include an “intellectual autobiography” (Stanley & Wise, 1993) which allows the researcher to reflect on their identities, interests in the topic, or other

personal or social factors that “position them” in the research (Creswell, 2013). I have provided my intellectual autobiography later in the Methods chapter to divulge the experiences and identities I bring to this research. Keeping memos in a reflexive journal is another reflexive strategy I used to continuously examination of my values and beliefs related to the research (Shaw, 2010; Smith et al., 2009). Reflexive processes aim to prevent participant’s experiences from being undervalued, eroded, inaccurately conveyed, or misinterpreted by researcher bias.

While measures are taken to reduce the undue influence of the researcher in translating participants’ views, the social constructivist paradigm views the subjective meaning people derive from their lived experiences as being socially constructed (Creswell, 2013). In other words, it recognizes that the meaning men living with FM make about their experience is formed by their personal histories, cultures, and social interactions. Moreover, just as men’s lived experiences of FM are established through interactions with others, the meaning of their experiences would be constituted through interactions with the researcher (Giorgi & Giorgi, 2008). Thus, the researcher, participant, and interactions between us shaped interpretations and sense-making for both parties. However, men in this study were viewed as the experts of their experience, and I aimed to stay close to the data by checking in with men for confirmation during the analysis process.

This epistemological perspective is consistent with the Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009) method that will be used, which endorses several notions aligned with social constructivism. For one, it

recognizes sociocultural processes as paramount to how we experience and come to understand our lives (Eatough & Smith, 2008). By this, language and intersubjective communication are central channels for realizing our senses of self and personal meaning (Eatough & Smith, 2008). Another epistemological aspect of IPA is reflected in its concern with social cognition and discovering relationships between what people think, say, and do (Eatough & Smith, 2008). I embraced these perspectives throughout the study as I conducted interviews, asked probing questions, and clarified perceptions of meaning and significance related to participants' experiences. The social constructivist paradigm helped me approach the study with an open-minded attitude to discovery and recognize my role as a co-creator of knowledge with my participants.

### **Phenomenology**

Before discussing IPA, it is important to remark on the foundations the approach evolved from. Phenomenology is the study of the lived experience within a group of individuals regarding some shared phenomenon or concept (Creswell, 2013). The basic philosophical assumptions underlying phenomenological research are that absolute facts do not exist; thus 'knowledge' is reflected by the synthesis of a phenomenon's 'essence' (Husserl, 1962). That is, the goal of phenomenology is to capture the underlying meaning of a shared phenomenon (Creswell, 2013). The essence of an experience also entails hidden qualities or aspects of an experience that may not be observable or understood by outsiders who have not undergone a particular experience (Grbich, 2007). By looking at multiple perspectives of the same situation, researchers can start to uncover the essence of what an experience is like from the insider's perspective. This is accomplished through



an in-depth process involving inquiry and dialogue, descriptions and interpretations, and ongoing critical self-reflection (Rossman & Rallis, 2016). Phenomenology has been applied within several disciplines, especially the social and health sciences (Creswell, 2013).

There is no absolute way to conduct phenomenological research, yet some key aspects are crucial across phenomenological studies. Interviews are typically the major data source for gaining first-person inner perspectives. Data analysis usually takes an inductive and reductive approach, drawing meaning and conclusions from the interview data, and synthesizing the data into themes. However, the researcher possesses the ability to flexibly adapt the data collection method and analysis process to best answer the aims of the research (Hein & Austin, 2001). Regardless of how data is collected and analyzed, phenomenological research requires extensive and intimate involvement of the researcher in these processes, and researchers are encouraged to exercise transparency throughout each of them (Groenewald, 2004). Thus, bracketing by the researcher is a vital aspect of phenomenology. Bracketing entails the researchers attempt to separate their previous experience or knowledge related to the topic, to prevent it from interfering with the data collection and analysis process (Creswell, 2013). The purpose of bracketing is to help the researcher accurately identify and convey the participant's experience and avoid potential erosion of the data or undermining participants' experiences by imposing the researcher's perspectives. While common factors cut across several types of phenomenology, distinctions are also important to note.

Phenomenology is generally branched into two categories – transcendental and hermeneutic (Hein & Austin, 2001). Edmund Husserl's (1859-1938) transcendental phenomenology focuses on studying what was experienced through individual's consciousness, with its primary aim being to observe and describe the essence of human experience (Smith, et al., 2009). Husserl believed bracketing past knowledge (e.g., backgrounds and biases) was important for noticing others' experiences in phenomenological research (Lavery, 2003). Hermeneutic phenomenology was developed by a student of Husserl named Martin Heidegger (1889-1976). His departure from the transcendental approach was based on the arguments that bracketing personal knowledge was not entirely possible and that descriptions are already inherently ridden with interpretation because every form of human awareness is interpretive (Lavery, 2003; Kafle, 2011). Similarly, it has been asserted that capturing lived experience necessitates language, which is inevitably an interpretative process (Giorgi & Giorgi, 2008; van Manen, 1990). Hermeneutic phenomenology is attentive to how things appear and letting things speak for themselves; yet it is also an interpretive methodology (van Manen, 1990). Thus, the hermeneutic orientation diverges from being purely descriptive to employing interpretation of descriptions. It extends the focus from accounts of what was said (consciousness) to a greater focus on significance and meaning (being) (Giorgi & Giorgi, 2008). However, Heidegger still believed it was important for researchers to be aware of their backgrounds and interpretive frameworks when generating meaning about a phenomenon (Lavery, 2003). This study applied hermeneutic phenomenology through an interpretative phenomenological approach.

## **Interpretative Phenomenological Analysis (IPA)**

Interpretive phenomenological analysis (IPA; Smith, 2004) offers a structured approach to guide qualitative inquiry and analysis. IPA was originally developed within psychology and has been a widely employed method in health psychology research (Brocki & Wearden, 2006; Smith & Osborn, 2003). This approach is suitable for research aiming to explore how individuals make sense of their personal and social world, or understanding meanings that experiences hold in a particular context (Smith & Osborn, 2008). It attends to various aspects of experiences from which individuals derive understanding and meaning including memory, thought, perception, perspective, belief, emotion, as well as how these manifest through actions and behaviors (Eatough & Smith, 2008).

This approach fit with the study aim of exploring how men make sense of and perceive their lived experience of FM. Moreover, IPA has been noted to be a particularly useful approach when studying a process or complexity underlying a phenomenon, or a topic that is “dynamic, contextual and subjective... and where issues relating to identity... are important” (Smith & Osborn, 2007, p. 520). Thus, IPA is also appropriate for attempting to capture how the complex, dynamic, and subjective experiences of stigma and masculinity threats encapsulate meaning within their illness experience. A particular aspect of IPA that makes it appealing is its analysis process. IPA utilizes descriptive and interpretive processes. Moreover, it aims to illuminate the convergence of human experiences, but also attends to the variability between individuals’ experiences of a shared phenomenon (Eatough & Smith, 2008).

Three primary aspects characterize the phenomenological approach using IPA – ideography, eidetic reduction, and hermeneutics (Smith et al., 2009). Idiography is concerned with understanding the particular as opposed to universal (Eatough & Smith, 2008), or capturing the richness and texture of each particular individual being examined (Smith et al., 2009). This involves a detailed case-level analysis to derive the idiosyncratic meaning for each participant before attempting to spot across-group themes (Smith et al., 2009). The idiographic analysis was useful for mapping out salient contextual variables that provided different meanings or outcomes for different men within the shared experience of living with FM. I used idiography as my first step in the data analysis process by developing codes to identify and consolidate within-case themes (Smith et al., 2009). Idiography helped capture the broad spectrum in which men with FM experience or are impacted by stigma and masculinity threats. It also captured aspects of intersectionality that may have contributed to variations in experiences within a common experience. This process also helped validate each participant’s experience before generalizing experiences of men with FM through a collective lens.

Eidetic reduction is the process of moving beyond descriptions of the particular individual experience, to identify essential aspects and commonalities in the experience of a phenomenon (Smith et al., 2009). In other words, the idiographic process – which aimed to capture divergence across cases – was then followed by a process of identifying convergence across cases (Allan & Eatough, 2016; Pietkiewicz & Smith, 2014; Smith, 2011; Smith et al., 2009). I used this strategy in my second stage of the data analysis by identifying, coding, and synthesizing shared themes across multiple men with FM (Smith

et al., 2009). Bracketing my ideas was an important part of both the idiographic and eidetic reduction analysis to provide descriptions that accurately conveyed the understanding and meaning of stigma and masculinity threat/strain experiences of men with FM. Additionally, immersing myself in the first-person perspectives of men with FM helped ensure that the interpretive processes that took place later in the study was grounded in the descriptive data that participants provided.

The hermeneutic aspect of IPA is the interpretive process of deriving understanding and meaning from people's experiences (Smith et al., 2009). Hermeneutics views interpretation as an inherent component of a qualitative study, and the IPA researcher is seen as an active participant in a dynamic social process (Smith & Osborn, 2008). IPA is deliberate in attending to the connections between people's words, thoughts, emotions, and physical sensations, but recognizes this complexity of this task – especially given that people often struggle to express or choose not to disclose what they are thinking or feeling. (Smith & Osborn, 2008). Therefore, the interpretive activity of IPA calls for a two-stage, “double hermeneutic” process, whereby “participants are trying to make sense of their world and the researcher is trying to make sense of the participants making sense of their world” (Smith & Osborn, 2008, p. 53). While the researcher is tasked with willfully attempting to get as close as possible to the insider-perspective, it concurrently appreciates that making sense of the data is also contingent upon the researcher's thoughts and critical analysis. This dual interpretation process reflects the social constructivist stance in which IPA is grounded in (Eatough & Smith, 2008). In the current study, I engaged in my own process of making sense of participants experiences

and responses to elicit further understanding about the stigma and masculinity threats/strain experienced by men living with FM. Interpretative activity primarily took place during the data analysis phase when developing themes and solidifying the shared essence across participants (Pietkiewicz & Smith, 2014).

### **Reflexivity**

An important part of the IPA approach is embedding a cyclical process of reflexivity, reduction, and reflection throughout a study (Finlay, 2008; Smith et al., 2009). Reflexivity is a process whereby qualitative researchers “hold ourselves accountable for the assumptions we enact when we do research” (Finlay, 2002; Shaw, 2016, p. 1735). It is considered an essential process to ensure quality in qualitative research (Finlay, 2002; Pillow, 2003). Reflexivity is differentiated from a reflection in that it involves explicit self-evaluation or introspection, whereas reflection is more focused on presenting participants’ accounts accurately (Shaw, 2010). Shaw (2010) noted the two goals of reflexivity are: a) to have awareness and control over reactions when interacting with participants, and b) to facilitate the formation of novel perspectives about participants experiences. Several reflexivity strategies have been proposed that I utilized within my study.

Throughout my study I openly acknowledged my preconceptions about men with FM and consistently documented my preconceptions in an intentional manner (Larkin & Thompson, 2011). Bringing these to the surface helped me bracket what I thought I knew about stigma and masculinity in men with FM so that their true experience was not overtly hindered by my previous knowledge, values, attitudes, and beliefs when

examining the data (Creswell, 2013). As a starting point for this, I provided an intellectual autobiography in the following section. This was important because the understanding we derive about others or how things work is based on our subjective position in the world (Shaw, 2010). Therefore, I needed to stay mindful of my identities, attitudes, beliefs, and values when making sense of the experiences of men with FM. I used reflexivity to remain cognizant of how my identity as an able-bodied woman and a counseling psychology student may have impacted the data collection and data analysis processes.

I continued my reflexive process by using a reflexive journal and analytical memos during the data collection and analysis process to reflect on my decision-making process, biases, personal reactions, or other factors that may have influenced the study (Miles, Huberman, & Saldaña, 2014; Smith et al., 2009). For instance, I journaled my thoughts before and after each interview. Additionally, I met weekly with peers to discuss how the research process was going which served as another outlet for introspection about my role in shaping the research and outcomes. Moreover, during the initial phase of reading, re-reading, and free coding transcripts, I attended to and wrote memos noting my automatic responses, assumptions, and emotional reactions (Farmer & Byrd, 2015; Miller, Chan & Farmer, 2018). I also used a reflexive journal to document ideas about potential themes or ways men's lived experiences of FM connected with the illness perception, stigma, and masculinity frameworks (Oxley, 2016). Given that biases tend to operate on a subconscious level, I also followed recommendations of engaging in ongoing consultation to further facilitate reflexivity (Miller et al., 2018). My

documentation of my reflexive practices served to elevate the rigor of this study by permitting external reviewers to critically evaluate my sense-making process (Shaw, 2010; Tracy, 2010).

### ***Intellectual Autobiography***

My interest in this topic for my dissertation has been undeniably influenced by my personal experiences and interactions with men experiencing chronic pain. As I entered the world of integrated care, I instantaneously connected with the biopsychosocial model of health. As a future counseling psychologist, the appreciation for the inextricable links between the mind, body, and environment was attractive as it unified my interests in psychology and the treatment of chronic health conditions. In my work experiences, I repeatedly witnessed the vast suffering of individuals with chronic pain and the challenges healthcare providers faced in their efforts to successfully treat such a complex and subjective condition. Working with patients in various medical settings, I have also seen significant stigma and lack of compassion towards patients with chronic pain. I believe these patients are vulnerable to negative physical and mental health outcomes due to stigma, as it can lead to disengagement from family, friends, and the medical system. This drives my passion for advancements in pain psychology, and how imperative it is to continue building our understanding of the psychosocial aspects of pain.

I had the honor of working with a multidisciplinary pain team through the VA. Although pain conditions disproportionately impact women, given the gender composition of VA, men represented most patients I worked with. This unique



experience provided me the opportunity to learn about the pain experience of men in the context of a field that is hyper-masculinized. This piqued my interest in the nuanced experience of men with chronic pain, particularly their experience of stigma, how their masculinities are impacted, and how these factors shape their overall illness perceptions and coping behaviors. While the men I have worked with presented with various types of chronic pain, I choose to focus my research on men with FM to focus on a type of chronic pain that is less researched in men and is presumed to have a greater stigma and identity threat potential.

My theoretical orientation and prior clinical experience left me with some working hypotheses about themes I suspected may arise. For instance, I assumed that being diagnosed with what is thought of as “a women’s disease” can feel emasculating. Moreover, one might expect negative reactions from others; thus, for men, an FM diagnosis may represent a threat to their personal and social identity. I also expected that men who strongly ascribe to traditional masculine ideologies would engage in more avoidance coping, and this type of coping response would be strongly tied to experiences of internalized stigma, masculine-role strain, more negative illness perceptions, and poorer health outcomes. Moreover, I believed that men who endorse significant masculinity threat and strain and use avoidance strategies would experience significant mood dysfunction (e.g., depression), emotional and behavioral dysregulation (e.g., lowered distress tolerance threshold, substance use, pushing their body despite pain and thereby perpetuating the cycle of pain and disability) and interpersonal problems (e.g., withdrawal and isolation, lashing out). From my observations of men with other types of

chronic pain, those who strongly ascribed to masculine ideologies (e.g., “man up,” “suck it up”), and norms often pushed themselves physically to the point of over-doing it. In turn, the resulting pain exacerbation and prolonged incapacitation tended to perpetuate internalized stigma and gender-role strain.

My intention was to provide transparency by disclosing these assumptions, as well as remain accountable to their influence throughout the research process. I strived to continuously keep these preconceptions in check when interacting with men in the study by making sure that my questions and responses did not lead them to these ideas, and rather that any of the emerging themes were expressed by participants without inordinate provocation. Additionally, I remained open-minded to men’s accounts that refuted these ideas, such as positive masculinity paradigms.

It was also important to recognize how my own salient identities as an able-bodied woman and psychologist in training, may impact the research. I kept in mind that while some men may feel more comfortable talking to a woman, this may not be the case for all. Furthermore, I considered how being a counseling psychology student studying men with FM may elicit concern that my perception of their FM is that it is psychologically based. Thus, I made my biopsychosocial perspective of pain explicit in the pre-interview script that I followed at the beginning of each interview.

I recognized that some men may question my potential as a woman to understand their experiences as men. I was aware that being an able-bodied woman who does not have fibromyalgia could have elicited scrutiny in my positionality as a researcher on this topic. While I lacked the exact identities and experiences I sought to explore, drawing

from similar personal experience and my clinical work with veterans with chronic pain helped bridge my understanding. For instance, as a woman growing up in the U.S., I have been socialized to internalize many of the gender-stereotypical notions of what men and women “should” be like, and often experienced criticism when exercising more androgenous or gender-nonconforming roles or expectations. Additionally, as an athlete, I endured several injuries, some of which never fully healed and cause chronic but tolerable pain and physical limitations. I acknowledge these examples are not completely parallel experiences, so while they provided an innuendo of understanding, it was also important to bracket these at times to truly enthrall myself in the essence of what it is like to be a man with FM.

I stived to get as close as possible to the participants experiences through curiosity, humility, and openness. I viewed the participants as experts and bracketed what I thought I knew about their experience. In addition to the reflexivity strategies discussed, I took steps to include men’s perspectives in formulating the interview questions. I piloted my interview questions with two men (one with chronic pain) prior to interviewing participants to garner feedback. I also collaborated with participants in the analysis process by gathering any member reflections to help ensure the data accurately conveyed men’s experiences. Additionally, I used my clinical skills, consultation, and training in research to guide my decision making, interactions with participants, and to produce a credible scholarly work.

## **Data Collection**

### **Participants and Sampling**

The projected sample this study aimed to recruit is a total of 6-10 middle-aged American men living with FM. Eligibility criteria for participants included: identifying as a man, having a confirmed medical diagnosis of fibromyalgia (based on either the ARC 1999, 2010, or 2016 criteria), being between the ages of 45-65, residing in the U.S., and able to speak and read English. As noted, few studies on men with FM included American men in their samples. Middle-age and older-adulthood is when FM diagnoses have been found to peak (Chen & Mackenzie-Brown, 2015). While older adult men have been vastly understudied in masculinity research (Gerdes et al., 2018; Springer & Mouzon, 2019), men over 65 were excluded from this study because older adulthood itself poses stigma and masculinity threats that could have been difficult to tease apart from those implicated within the context of FM. Given fibromyalgia has high comorbidity with other chronic health and pain conditions (Fitzcharles et al., 2018), men with comorbid health conditions were permitted to participate. However, consideration was given to including participants who identify fibromyalgia as their primary pain condition, or the pain condition that most significantly impacts their functioning. Lastly, inclusion was based on gender identity, not biological sex. Other practical aspects for participants in the study included access to a computer and broadband capabilities to complete virtual interviews via Zoom.

Purposeful sampling was utilized to specifically select a homogenous sample of men living with FM. Small samples (6-8 participants) are ideal for IPA to appreciate the nuances of each participant's experience and enable the time consuming and detailed case-level analysis (Pietkiewicz & Smith, 2014). A fairly homogenous sample is also

recommended in IPA in order to distill meaningful information about the phenomenon (Smith et al., 2009). As mentioned, given that masculinity can change across the lifespan, narrowing the age group served to promote a more homogenous sample to allocate more meaning to the context of FM (not age). While homogeneity is ideal, demographic variance can illuminate important intersectional experiences as well as idiographic accounts – a key feature of IPA. While racial and ethnic variation was a hopeful aim of this study, no racial minority men applied to participate in the study. Snowball sampling efforts were made by utilizing the relationships and social networks of active participants (Creswell, 2013) to attempt to recruit racial minority men. However, this did not result in any additional participants.

Saturation is not typically an aim of phenomenology or IPA given that meaning can be inexhaustible, especially when considering that the analytical focus of IPA is not solely to capture shared experiences but also individualized accounts of a phenomena (Hale Treharne & Kitas, 2008; Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, & Jinks, 2018; van Manan, Higgins, & van der Riet, 2016). Moreover, According to Smith, Flowers, and Larkin (2009), a small sample size is acceptable because “IPA is an idiographic approach, concerned with understanding particular phenomena in particular contexts” (p. 49). Thus, data saturation was not a primary concern in decisions of when to discontinue recruitment. Instead, in accordance with recommendations by Elliott, Fischer and Rennie (1999), it was determined an adequate sample was met when there was sufficient data to achieve a thorough understanding of the lives of men with FM and reflect the collective and nuanced experiences.

## Recruitment

Potential participants were recruited through multiple methods, including local and national agencies, organizations, and social networks. Outreach to local hospitals and healthcare clinics that offered rehabilitative or chronic pain management services was conducted. Additionally, participants were recruited from websites that provide information and support specifically to men with FM and other FM specific online sources including support groups, forums, and social media pages (e.g., [www.menwithfibro.com](http://www.menwithfibro.com), [www.fibroguys.com](http://www.fibroguys.com), Men with Fibro Facebook group). Additionally, I attempted to contact support group leaders and/or facilitators of local meet-up groups catered to individuals with chronic pain/FM. A recruitment flyer (see Appendix B) was created informing prospective participants about the purpose of the study, inclusion criteria for participation, what participants would be asked to do, and contact information for the researcher so that potential eligible participants can express interest or make inquiries. The flyer informed potential participants that the study would involve virtual or phone interviews to understand their experiences of being a man living with FM, sharing a memento that depicts their experience of being a man with FM, and reviewing transcripts and the data analysis for accuracy. They were also informed that they would receive a \$30 Amazon gift card for their participation in the study.

The recruitment flyer was distributed through email and postings while abiding by recruitment stipulations outlined or communicated by contact points. The call for participant flyer included a Qualtrics link directing them to the informed consent agreement and demographic questionnaire (see Appendix C and E). The survey also

asked for information about their FM (e.g., length of time from diagnosis, average daily pain rating). The informed consent agreement (see Appendix C) reiterated the purpose of the study, described the procedures, and discussed confidentiality, potential risks/benefits, and the voluntary nature of the study. The researcher also followed-up with potential participants by phone/email to verify that they met the inclusion criteria and to arrange interviews. Of note, there were 131 responses to the Qualtrics survey but unfortunately the majority of these responses were presumably bots as the forms were left incomplete (e.g., did not provide name or contact info). Additionally, there were multiple individuals from outside the U.S. that attempted to feign as viable participants who were ultimately screened out. Only seven individuals met the inclusion criteria. Of those individuals one was unable to participate due to inability to schedule after multiple attempts. Participants who met the criteria and signed the informed consent agreement were contacted by phone and/or via email with an invitation to the study as adapted from Moustakas (1994) (see Appendix E). Informed consent documents and the interview guide (Appendix F) were approved by the IRB at the University of Denver before data collection.

## **Interviews**

Interviews are one of the most common data collection methods in qualitative research (Hays & Wood, 2011) and were the central tool of phenomenological inquiry used in this study. Interviews were semi-structured, based on a 12-question interview guide (see Appendix F). All interviews were conducted via Zoom (audio only) or phone. The decision to utilize phone/audio only and exclude video was for the purpose of

minimizing the potential visual impact of gender differences from negatively impacting men's comfort during the interview. This seemed to help create a space for greater authenticity and vulnerability in participants person disclosures. Semi-structured interviews were desirable because they provided the opportunity for rapport building with participants and encouraged sharing and meaningful reflection (Rubel & Okech, 2017). Interview questions that were developed were guided by the three theoretical frameworks discussed (Illness Perception, Stigma Induced Identity Threat, and the Masculine Gender Role Strain Paradigm) to address gaps in the literature regarding the stigma and masculinity threat experiences of men with FM. Interview questions were reviewed with input from experienced qualitative researchers, men with chronic pain, and pain psychologists before conducting initial interviews. Participants were offered the opportunity to receive a copy of the interview protocol prior to the interview. Interviews were projected to last approximately 60-90 minutes in length, though they ranged from 90-120 minutes. Additionally, there was a brief (20 minute) follow-up interview with one participant to clarify questions regarding the information they provided in the first interview. Other participants answered clarifying questions via email. Each interview was audio recorded for later transcription.

The goal of the interviews was to obtain detailed, specific accounts of participants' experiences (Smith, et al., 2009). Therefore, the interview questions were used to draw out men's thoughts, feelings, and reactions to their experiences of stigma and masculinity threats in the context of their FM illness experience. The semi-structured interview format was designed to provide a blend of structure and flexibility for



cultivating a working relationship with participants, eliciting meaningful dialogue, and allowing enough time and space for sense-making to occur (Smith et al., 2009). The information derived from the interview provided enough breadth and depth to execute a comprehensive analysis of the stigma and masculinity threat experiences of men with FM.

Before initiating the interview, a pre-interview script (see Appendix G) was used to introduce myself and the goal of the study. The researcher additionally reviewed the consent form and encourage the importance of sharing meaningful information. Participants were also encouraged to bring up any questions or concerns regarding the study at any time. Moreover, it was reiterated that there are no “right and wrong” answers and reminded them of their right to decline to answer any question and to take pauses to collect their thoughts or reactions (Warren & Karner, 2010). Finally, participants permission to audio record was obtained prior to starting the interview. Per recommendations by Warren and Karner (2010), two recording devices were used to ensure sharpened retrieval of information for transcription, and to prevent the possibility of data loss if one recording device failed.

During the interview, I worked to establish trust and build rapport by expressing my genuine interest in their experience. I accomplished this by allowing them the initial uninterrupted and unprompted space to discuss their general experience of being a man living with FM before moving to a more specific inquiry. This ‘funneling technique’ of moving from general to specific is recommended in IPA because more broad unprompted responses are thought to help the researcher get as close as possible to the participant

view as possible (Smith & Osborn, 2008). Moreover, this helps begin to reveal salient experiences or meanings that helped direct the rest of the interview in a way that helped me continue to enter the personal and social world of the participant, as opposed to forcing them to enter mine (Smith & Osborn, 2008). Thus, funneling served a quality function in that it helped promote rich open dialogue and protect against researcher bias. More explicit prompts were used when the participant indicated difficulty in understanding the question or gave a generic response.

Given that IPA requires the dual aim of comprehending the first-hand experience of participants through their sense-making as well as interpret meaning, it is standard practice to tailor the interview according to any important observations (Smith & Osborn, 2008). This flexibility allowed for a wide scope of coverage. For instance, depending on participants' responses or my reactions I either continued with the protocol as planned, modified questions, sought clarification, or probed novel, important, or interesting areas that arose, (Pietkiewicz & Smith, 2014; Smith & Osborn, 2008). It was important for me to attend to participants' displays of avoidance and emotionality during the interviews, and respond sensitively (Pietkiewicz & Smith, 2014). My clinical training and intuition helped guide me in carrying out the interview in a productive way and gathering rich data.

### ***Mementos***

Mementos are visualization representations of personally relevant data for the purpose of reminiscing, reflecting on, or sharing life experiences (Thudt et al., 2015). Mementos are a type of tangible artifact that carries personal symbolic meaning of an

experience (Thudt et al., 2015). When participants were contacted to arrange the interview, I encouraged them to bring any significant items that hold meaning to their experience as a man living with FM to share during the interview. I provided examples of mementos such as an object, photograph of themselves or others, piece of art, fibromyalgia-related healthcare materials, or other media (websites they visit, ads, etc.), or anything else that depicts their experience. I asked them not to use any moments that include private health information to best protect their privacy. Participants were asked to pick their memento(s) before the interview so there would be time to review the memento(s) together in the interview. Four of the six men chose to share a memento. One participant shared a photograph he took of a broken down power plant with a picture he drew of his eye hyperimposed over the photograph. Another man shared a quote/meme that resonated with him. One participant shared a book that helped him learn how to anticipate and control his FM symptoms. Similarly, another participant nominated Wikipedia as his memento because of how much he relied on his own research to understand and treat his FM. These mementos will be discussed further within the results section.

### ***Debriefing***

Debriefing is a cardinal process when completing an interview with a research participant (Warren & Karner, 2010). Given the concentration of the interview was likely to spur difficult memories, thoughts, and/or emotions, it was important to check in with participants before concluding the interview and direct them to additional resources or support as needed (APA, 2002; Warren & Karner, 2010). At the end of the interview, I

provided time for participants to share anything else they believed to be important, make clarifications, and I answered any questions they had regarding the interview, data collection, analysis process, or other aspects of the study. I also utilized a personal debriefing process after each interview. This involved documenting notes about the interview, procedural reminders, and reflexive memos including my thoughts, feelings, insights, actions, and reactions that occurred during the interviews.

## **Data Analysis**

### **Transcription**

To carry out analysis of the data, the interactions were documented via verbatim transcription as recommended (Oxley, 2016; Smith et al., 2009). Each recorded interview was transcribed verbatim. While IPA does not require detailed accounts of all prosodic or non-verbal aspects of the recording to be transcribed, it has been recommended that significant pauses, hesitations, and notable non-verbal utterances (e.g., laughs) be noted using brackets (Smith et al., 2009). Complete transcripts served to guide the analysis process with fidelity and transparency in extracting themes and conclusions that were supported by the data in the text (Braun & Clarke, 2006). Annotations, memos and analytical comments were documented concurrently throughout the initial coding and recoding processes (Smith et al., 2009). After completing the transcript for each interview, I sought “member reflections” (Tracy, 2010) by emailing participants a copy of the transcript to review, providing them the opportunity to add, omit, or clarify information, or expand on information they shared in the interview. Member reflections helped verify that participants were able to accurately communicate their experience and

provided space for further data, reflection, and complexity to unfold (Tracy, 2010). Any additional comments or edits offered by participants was included in the final transcripts.

### **Data Analysis Process**

There are two main levels of analysis in IPA – first-order and second-order analysis (Finlay, 2011). In the first-order phase, the goal is to curate descriptive accounts of the experienced phenomenon from the participant perspective (Miller et al., 2018). That is, concrete details of important events, relationships, values, or nuances that hone into what matters to them are documented (Larkin & Thompson, 2011). Second-order analysis involves the interpretive component, focusing on a deeper exploration of the underlying meaning participants assign to their experiences (Larkin & Thompson, 2011). In this phase, the researcher expanded their view to interpret participants’ descriptions of their experiences through social and cultural contexts or theoretical frameworks (Miller et al., 2018). Thus, the general analytical focus of all IPA studies involves describing participants’ convergent and divergent experiences, explaining the meaning participants make of their experience, and applying an interpretive lens to convey the meaning within socio-cultural and theoretical contexts (Larkin & Thompson, 2011; Miller et al., 2018).

Smith et al (2009) offer guidelines for the analytical stages of IPA that can be adapted flexibly and creatively by the researcher pursuant to their research objectives. The IPA framework is time consuming, complex, and requires deep immersion with the data to accomplish the aims of substantiating both the participant’s and the researcher’s sense-making of a phenomenon (Pietkiewicz & Smith, 2014). This was realized through close engagement with the data that included ongoing memos, coding, and thematic

development. My data analysis process was guided by a six-step process outlined by Smith, Flowers, and Larkin (2009). Throughout each stage of engagement with the data, I documented thoughts and feelings in my reflexive journal (Smith, et al., 2009) or analytical memos. Reflexive journaling and memos are recommended due to the repetition of reviewing the data, the significance of interpretation, and the need for bracketing any hindering biases, values, or attitudes (Smith, et al., 2009).

After completing written transcripts, the first two steps of analysis involved “reading and re-reading” of the transcript and “initial notes” (Smith et al., 2009, p.82-83). The purpose of step one was to gain close familiarity with the respondents’ accounts from a holistic perspective, and to provide space to generate new insights upon each transcript review (Smith & Osborn, 2008). I reviewed one transcript at a time in detail before moving on to examine others to facilitate the idiographic approach (Smith & Osborn, 2008). After familiarizing myself with the verbal and non-verbal exchanges in the transcript, I began to annotate the transcript, noting interesting or significant statements (Smith & Osborn, 2008) that helped me begin identifying how men with FM were talking and thinking about their experiences of stigma and masculinity threat/strain.

No rules dictated what to comment on initially, though the aim at this stage was to document descriptive comments of men’s experience that mattered to them (e.g., values, events, places, processes, relationships, etc.) and the meaning those held for them (Smith et al., 2009). Types of comments that were considered included descriptive (the content of what was being discussed), linguistic (language use such as metaphors, repetitions, pauses), and conceptual comments (initial interpretations) (Smith et al., 2009). Other

recommendations for this phase included noting emotional responses, distinctive phrases, significant observations and thoughts about the interview, or personal reflexivity (Pietkiewicz & Smith, 2014).

The third step, “developing emerging themes,” entailed going through my exploratory comments within a given case-level transcript and identifying patterns, connections, and interrelationships (Smith et al., 2009, p. 93). The goal of this step was to reduce the amount of detail by extracting conceptual, higher-level themes that depicted the psychological essence of the phenomenon in question (Osborn & Smith, 2008). N-vivo (2019) software was used to organizing significant statements, identify themes or units of meaning, and facilitate pulling direct quotes to support themes. As encouraged by Smith et al (2009) I utilized a synergistic process of descriptive and interpretive analysis for deriving themes.

Smith et al (2009) also encouraged an analysis process that starts with hermeneutic empathy and then moves towards her hermeneutic suspicion. The former took form through accepting statements as they are, using a descriptive and empathic stance to summarize participants’ perspectives. The latter involved engaging in a more critical reflection of participant’s sense-making and probing for meanings that are less explicitly stated, but still supported by the data (Etough & Smith, 2008). For instance, by analyzing participants use of metaphors, temporal referents, or underlying meaning through the lens of a theoretical framework (Miller et al., 2018; Smith et al., 2009). Smith and Osborn (2008) posed that in IPA analysis, researchers can reflect on critical questions such as: “What is the person trying to achieve here? Is something leaking out here that

wasn't intended? Do I have a sense of something going on here that maybe the participants themselves are less aware of?" This last question was especially fruitful for beginning to make sense of that data through my chosen conceptual frameworks. By continuously checking my interpretations against the data, I engaged in a dual descriptive-interpretative process as I attempted to develop themes that captured the experiences and meanings of stigma and masculinity threat in men with FM.

After developing emerging themes for individual cases, the fourth phase of analysis involved "searching for connections across emergent themes" (Smith, et al., 2009, p. 94-). During this step, I distinguished standalone themes and themes that clustered together to represent superordinate concepts (Smith, et al., 2009). Smith et al (2009) outline various strategies for organizing observed patterns in themes including abstraction (grouping like themes and creating a superordinate name for the cluster), subsumption (elevating an overarching theme to superordinate status), polarization (identifying contrasting themes), contextualization (attending to cultural, temporal or situational information), numeration (frequency) and function (how the statement serves the participant).

Similar to the previous step, a dual process of analysis that is both descriptive and interpretive was used to make sense of the connections across themes (Etough & Smith, 2008). Again, any clusters of themes derived from my own sense-making process were checked against the transcript to make sure that they connected to the participants' actual words (Smith & Osborn, 2008). To document this process, I organized a table of



participants' exemplary statements that supported identified themes as suggested by Smith and Osborn, (2008) (see Appendix I)

In the fifth step, "moving to the next case," (Smith, et al., 2009) I continued the analysis process with the other cases/transcripts using the same steps described above. During this process, I used themes from the first case to orient my analysis for subsequent cases. An important part of this step that Smith and Osborn (2008) asserted was to be diligent in discerning new emerging themes as well as recognizing repeating patterns. This is consonant with the IPA aim of paying respect to the convergence and divergence across participants' accounts. This process also initiated the final stage of "looking for patterns across cases" (Smith, et al., 2009, p. 101). This step moved the analysis to a more theoretical level (Smith et al., 2009). In this stage, I established themes that cut across multiple participants (Pietkiewicz & Smith, 2014). I eliminated or modified themes based on their importance, relevance, prevalence, and vividness found in participants' expressions (Pietkiewicz & Smith, 2014). As noted, I also arranged themes in a master table showing superordinate themes, subordinate themes, and specific examples of participant statements reflecting the themes (see Appendix I).

Once my data analysis was concluded, I completed a narrative illustrating the themes that give essential meaning to men's experience of living with FM. My goal was for the results and discussion of findings to provide readers with a clear understanding of men with FM's shared lived experience from their first-hand perspective, descriptive information, and interpretive data.

Each theme will be described in the following results chapter and exemplified by supporting data (e.g., excerpts, quotes, mementos). Finally, the findings will be discussed from an analytic perspective (Pietkiewicz & Smith, 2014) with the final narrative demonstrating multiple levels of interpretation (Pietkiewicz & Smith, 2014; Smith & Osborn, 2008). In the following chapters, I present an emic perspective to honor participants voices by using direct quotes or metaphors, rich descriptions, and specific details to describing “what” they experience as a man with FM. Additionally, I attempted to illustrate “how” they experience being a man with FM (e.g., meanings, special significance, effects, thoughts, emotions, beliefs, behaviors) through their own words as well as my interpretive sense-making. Incorporating my guiding frameworks (i.e., illness perception, stigma-induced identity threat, and masculine gender role strain paradigm) helped me make sense of the data and make interpretations to a deeper, more conceptual or theoretical level (Finlay, 2011).

### **Meeting Criteria for Quality Qualitative Research**

To assess quality and rigor in the current study, I utilized guidelines set forth by Tracy (2010) for high-quality qualitative research as well as an IPA-specific Quality Evaluation Guide for assessing an IPA study’s trustworthiness (Smith, 2011). Tracy (2010) details eight key components to assess the quality of qualitative research: a worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence. As discussed in Chapter One, this topic is relevant given the underrepresentation of men in the fibromyalgia literature, and recommendations for further study that explicitly focuses on masculinity concerns (e.g., Dempster et al., 2015;

Sallinen & Mengshoel, 2019). To attain rich rigor, my study is framed by appropriate theoretical constructs; a clearly defined sample; and extensive time and effort in the data collection and analysis processes.

Sincerity pertains to the use of self-reflexivity and transparency (Tracy, 2010). My intellectual autobiography, reflexivity journal, and keeping analytical memos throughout the research process served as platforms to examine how my social position, biases, subjective values, or inclinations may impact the research (Pietkiewicz & Smith, 2014; Tracy, 2010). My study aimed for transparency by using memos throughout the data collection and analysis to document my methodological decisions, as well as decision-making regarding the development of themes, and accounting for how my values and biases are intersecting with the research process.

I have attempted to meet the standard for credibility by using thick descriptions, multivocality, triangulation, and member reflections in my data analysis process (Tracy, 2010). Providing thick descriptions involved my use of concrete details and speaking to culturally situated meanings that account for specific circumstances (Geertz, 1973; Tracy, 2010). IPA's dedication to idiographic phenomenology helped accomplish multivocality by including multiple and varied voices (Tracy, 2010). Triangulation was achieved by using multiple data sources (interviews and mementos) (Creswell, 2013), as well as by using multiple theoretical frameworks to triangulate my conclusions (Shaw, 2010). I also used member checking as a collaborative process that enhanced credibility by allowing participants the chance to review the transcripts to provide edits or further information (Creswell, 2013; Tracy, 2010). Lastly, sharing my reflexive memos alongside my

analytical conclusions with an external reviewer served as an audit trail that allowed the rigor and logical sequence of the study to be evaluated and/or replicated (Creswell, 2013; Cacary, 2009).

I aimed for the standard of resonance by composing an artistic, engaging, and evocative narrative (Tracy, 2010) as I discuss the prevailing themes. Other aspects of resonance include transferability and naturalistic generalizations (Tracy, 2010). While generalization is not typically an aim of initial qualitative inquiry regarding a phenomenon, the findings accentuate how the experiences of men living with FM in the study may be (to some extent) generalizable to other similar contexts (e.g., other medically unexplained illnesses, situations, or populations). Further, this study provided significant contributions by expanding on the small amount of research related to men with FM. Moreover, findings helped reflect ways that individuals, helping professionals, and healthcare systems can improve the care and health outcomes for men with FM.

In terms of ethical standards, I complied with all ethical guidelines outlined by the Institutional Review Board and the American Psychological Association (APA) Ethical Principles and Codes (APA, 2017) regarding human subjects. My informed consent form (see Appendix C) included the description and purpose of the study, how it would be completed, voluntary participation and the right to withdrawal, potential risks and benefits, and how the researcher would protect participant's confidentiality (APA, 2002). In line with APA ethics code 8.03 (Informed Consent for Recording Voices and Images in Research) I also secured participant's permission for audio recorded interviews. Confidentiality was protected by omitting identifying information and using pseudonyms

when presenting findings (Rossman & Rollis, 2010). I also took measures to protect confidentiality through my data storage and management by using password protection with technologies and documents related to the study, and locking up physical data (Rossman & Rollis, 2010).

Relational ethics (Tracy, 2010) refers to the genuine regard and care a researcher shows for participant's well-being. I built rapport with my participants and treated them with respect and dignity in my interactions with them. When instances arose during the interviews where participants were exhibiting negative reactions to questions, or experiencing distress, I attempted to comfort them, showed empathy, offered for them to take a break, and provided resources to mental health services as needed (Rossman & Rollis, 2010; Pietkiewicz & Smith, 2014). Participants were also reminded they could answer in whatever capacity they were comfortable with. Lastly, Tracy (2010) discusses exiting ethics, which refers to how the collected data is represented and used. As mentioned, I included participant reflections to work collaboratively with them during the analysis phase to optimize the integrity of the findings. I provide implications of the findings, such as ways my participants' stories can inform improved societal treatment, healthcare practices, and experiences for men with FM.

Finally, the eighth criterion of meaningful coherence is characterized by the study meeting three objectives: achieving the study's stated purpose, use of methods/procedures that fit the goal, and developing meaningful connections between the literature, research questions, and results. I clearly stated my rationale for my methods at the beginning of this chapter. Moreover, I developed my research questions based on

identified gaps in the literature, framed questions based on relevant conceptual frameworks, and framed my overarching research question in the IPA format (Larkin & Thompson, 2011; Smith et al., 2009). I established meaningful coherence by tying the results back to the literature, theoretical frameworks, and overall research aims.

In addition to the quality standards stipulated by Tracy (2010), Smith (2011) created an IPA Quality Evaluation Guide to assess trustworthiness. Several standards coincide with those put forth by Tracy (2010), however, some of the benchmarks are particular to IPA studies. First and foremost, IPA studies must cohere to the “theoretical principles of phenomenology, hermeneutics, and idiography” (Smith, 2011, p.17). High-quality IPA studies must also have a sufficient sample of participants who can elaborately describe the phenomenon in question to allow for a detailed, nuanced analysis at a descriptive and interpretative level (Smith et al., 2009; Smith, 2011). Another important quality measure for IPA research is providing dense evidence to qualify and support themes (Smith, 2011). Smith (2011) outlines specific guidelines for exemplifying themes depending on the sample size, but the general standard is to have sufficient extracts from close to half the participants to substantiate a theme (if less than half, should have extracts from at least three participants and use a prevalence measure). These guidelines were utilized in decisions about qualifying themes.

## **Chapter 3: Results**

### **Demographics**

Six cisgender, white men were included in this study. Three men were from the Midwest; two were from the Northeast, and one was from the Western region of the United States. The participants ranged in age from 46-63 years. Three participants were married, one was in a long-term relationship, and two were divorced. Three participants reported they were currently on disability, one was unable to work, one was unemployed but looking for work, and one was employed full time. Household income ranged from \$10,000-\$19,000 annually to over \$150,000. The age in which fibromyalgia first started affecting participants varied. Two participants started noticing symptoms as early as their teens, two men were first affected between the ages of 25-45, and two did not start to experience FM symptoms until after age 50. The age when FM started to significantly interfere with functioning also varied, with most men reporting between the ages of 36-51, and one participant noted being impacted around age 60. Participants reported average level of physical pain on a 0-10 scale ranged from 4-8, with the median being a “7.” Participants reported an average level of emotional pain, or pain related distress, ranging from 1-8, with the median being a “6.” Five out of six participants endorsed comorbid chronic health conditions, but noted FM most significantly interfered with their functioning.

Table 2  
*Participant Demographic Information*

Name	Age	Race	SES	Employment Status	Relationship Status	Sexual Orientation	Spiritual Orientation	Other Identities
Trevor	45-50	White	\$60 - \$70k	Unable to work	Married	Hetero	Atheist or agnostic	N/A
Stan	45-50	White	\$10 - 20k	On disability	Divorced	Hetero	Druid	N/A
Jim	61-65	White	\$50 - \$60k	On disability	Married	Hetero	Catholic	Meditator
94 Gregory	51-55	White	More than \$150k	Unable to work	Married	Gay	Open-minded, non-practicing	Globalist; Thinker
Fred	51-55	White	More than \$150k	Employed FT	Divorced	Hetero	N/A	Father
Matthew	56-60	White	\$10 - 20k	On disability	Long term relationship	Hetero	Catholic, non-practicing	Veteran



Table 3  
*Participant Fibromyalgia History*

Participant	Age FM Symptoms Started	Age FM Started Interfering w/ Functioning	Years to Diagnosis After Onset	Date Diagnosed	Avg. Physical Pain	Avg. Emotional Pain
Gregory	51	51	1	2019	8	6
Stan	Before 18	26-35	--	1996	7	N/A
Matthew	26-35	36-45	18	2011	7	8
Jim	56-65	56-65	--	2018	7	8
Trevor	Before 18	36-45	20+	2018	4	1
Fred	36-45	36-45	--	2009	4	4

## Results

Results of this study were primarily derived from the interviews, corresponding transcripts, and reference to the mementos that participants identified. Additionally, feedback, comments, and any additional information or changes noted by participants after reviewing the interview transcript was incorporated into the data collection process. Both descriptive and interpretative thematic analyses were derived from the interview transcripts with each participant (Pietkiewicz & Smith, 2014). Themes were initially formulated from a within-case review and then subsequently across-cases to arrive at the shared experiences of the men with fibromyalgia. The codes represent the sense making process and the meaningful essence of what it means to be a man with fibromyalgia. The analysis aimed to address the studies primary research question - How does health-related stigma and masculine gender role strain relate to illness appraisals, coping behaviors, and health outcomes in men with FM?

## Themes

Participants were asked to talk widely about their experiences of being a man with fibromyalgia, including experiences of stigma, any impact FM has had on their identity as men, and how they cope with these experiences. After in-depth review of the transcripts using within-case and cross-case analyses, participant accounts clustered around 9 superordinate themes: *Precipitating Events; Fibro Experience; Psychosocial Stressors; Emotional Impact; Impact on Identity; Social Impact; Adjusting to Physical Aspects of Fibromyalgia; Coping with Psychosocial Aspects of FM; and Coping with*

*Stigma and Masculine Identity Threats.* Superordinate themes were grouped across three over-arching categories: Pre-diagnosis & Early Diagnosis Processing, Post-diagnosis Living- Psychosocial Pain, and Post-diagnosis Living- Coping. Themes were developed in accordance with the recommendations by Smith et al., (2009), where prevalence of the theme reflects the shared experiences across the participants and also served as an indicator of validity. However, it should be noted that while some themes were endorsed by all participants, a wide range of responses and experiences were captured to represent each superordinate themes. Therefore, subordinate themes were created to provide additional understanding of the data. A Summary of Themes Table (see Appendix I) can be used as a reference guide to review the constellation of themes covered in the remainder of this section.

### **Pre-diagnosis and Early Diagnosis Processing**

#### ***Precipitating Events***

All of the participants shared factors in their lives that preceded the onset of their fibromyalgia. These included biological predispositions/family history of FM, illnesses and/or injuries, a stressful life event (e.g., loss of a loved one), accumulative stress, or a history of trauma (physical, emotional or sexual childhood abuse, medical, military related). Each participant acknowledged how such antecedent event may have served as a partial etiological trigger or contributor to their FM onset, yet all of them also indicated having no clear understanding of the exact cause(s) of their FM.

Stress/trauma and injury/illness were the most prevalent precipitating events to FM. For example, Trevor, a 46-year-old hetero-man who was diagnosed with FM in

2018, described a major medical event a few years prior to being diagnosed. “I had an internal bleeding, and I almost bled out to the point where I died. I was actually in the ICU for like a week.” The majority of participants experienced a combination of physical and emotional hardship shortly before their FM symptoms significantly manifested. For instance, Gregory, a 52-year-old, gay man who was also recently diagnosed with FM in 2019, indicated how the lingering impact of not being able to properly mourn his father’s death while he was in college, coupled with more recent physical and financial stressors precipitated his FM:

“I can't change that horrific bereavement that I had when I was still in school. But I've got through life this far to my 50s. And ... I had a bad reaction to a cholesterol medication 18 months ago, and I lost \$60,000 on a bad pension investment. So, I had to sue my IFA. So, this was what I had about 18 months ago, which I felt that was the last straw for my body to contend with.”

Similarly, Matthew, a 57-year-old hetero man who was diagnosed in 2011, attributed a multitude of factors as potential causes of FM, stating, “When I had those injuries on top of each other, and then going through the emotional deal I was with my [marriage] separation, I think that just brought everything to this point that it just BOOM!” Another example of this was offered by Jim, a 63-year-old hetero man who was diagnosed with FM in 2018:

“I think it's three things. I think the fall and going from doing a more physical job. That definitely helped bring it on... In 2017 my mom passed away. So, it was

right as everything was ramping up... the conditions under which she died was - it was an accident. So maybe it impacted things a slight bit.”

Both Jim and Matthew also endorsed growing up in abusive households and saw this as another contributing cause, or an exacerbator to the impact of FM. Several men (Matthew, Gregory, Jim) also endorsed either working a highly stressful job, or a very physically demanding job as a factor they believed triggered a drastic uptick in their FM symptomology. Lastly, some participants indicated a family history associated with their FM. For instance, Stan, a 47-year-old hetero man noted, “I got officially diagnosed by my doctor, who diagnosed my mom with fibromyalgia, when I was 22.” Similarly, Fred, a 53-year-old hetero man who has been diagnosed since 2009, expressed, “Now that I look at how many people in my family have been diagnosed with it, I would be willing to go out on a pretty firm limb that there could be a genetic component to it.”

### ***Fibro Experience***

This superordinate theme captures the constellation of sensations and symptoms men with FM experience and how they experience them. The primary subordinate themes were described as *Physical Pain Descriptions and Progression*, *Cognitive Limitations*, *Loss of Physical Control*, *Physical and Emotional Pain Linked*.

**Physical Pain Descriptions and Progression.** All six participants provided qualitative descriptions of what their pain sensations feel like day-to-day as well as during pain flare-ups. Participants commonly described “good days” and “bad days” to differentiate pain levels and perceived control in their ability to cope with pain. The majority of men described a progressive worsening of pain over time (and progressively

worse functioning). Men described FM pain as constant, and widespread, endorsing pain that is “all-encompassing,” “coursing throughout your body” and “everything hurts all the time,” or “always in pain.” Matthew shared the following account of his daily pain experience:

“Everything you do from the time you wake up to the time you go to sleep something is causing a pain sensation to flow through this part of your body, to that part of your body in an increasing wave. I go through every day; I would say at a 7 on a 0-10 pain scale.”

Fred discussed his experience of seeking out medical attention and describing to his doctor, “EVERYTHING hurts. Like I'm never not in pain... From my hair to my toenails, hurts. And I don't know why, and it doesn't feel right.” While some men knew the pain they were feeling was out of ordinary, others had grown so accustomed to pervasive pain that they perceived it as normal. One participant, Trevor, shared how his FM functions, “I feel myself in sort of this weird balance between both extremely high and extremely low pain thresholds. There are some things that hurt me that probably wouldn't hurt a fly.” Contrarily, he shared other times he notices bruises, cuts, or gashes on his body with no idea how he got them because he did not feel it. He summarized, “it's this weird dichotomy” between high and low pain tolerance. While describing their pain, men in the study used language to emphasize the severity of their pain such as describing their pain as “extreme,” “incredible,” “really hurt”, and “so much pain.” In the following excerpt, Stan depicts the suffering of constant pain, and how even in moments of relief there is still pain and suffering.

Stan: *“I hurt so bad whenever I got home and finally relaxed at the end of the day, just 'ahhh.' It felt good to sit down and just, suffer.”*

Interviewer: *“And suffer?”*

Stan: *“Yeah.”*

Interviewer: *“It was like lesser suffering than when you were at work or..?”*

Participant: *“Eh yeah, probably because I didn't have to move around and be quick at my job... But at home, I can just sit there and kind of relax, and my legs would spasm and hurt.”*

In line with participants sentiments that FM affects everybody differently, there were a multitude of pain descriptors including: hurting, exploding, burning, dull, aggravating, vibrating, spasms, stabbing, pressure, stiff, pins and needles, numb, buzzing, constant warmth, arthritic pain, and taser feelings. Burning sensations were most commonly reported by the men in this study. For instance, Jim described feeling, “like my skin is on fire,” while Gregory described feeling “like someone microwaving my nervous system... and my joints were just burning, and numb, and I would lose circulation in my body.”

**Physical Limitations and Loss of Physical Control.** It's no surprise that all the men described physical limitations as part of their FM experience. These included a loss of control of their physical capabilities (e.g., walking, dexterity), and not being able to participate in physical activities in the same way they used to before FM (e.g., sports, exercise, traveling, activities with family, hobbies like playing music, and instrumental activities of daily living). For instance, Trevor shared an account of when he lost his

ability to grip (which was commonly reported among participants). “I got a tremor, and I lost control of my hands, which happens from time to time. And I dropped the cup. It shattered on the floor, coffee everywhere.” Similarly, Matthew shared how he is “constantly dropping stuff,” and Stan stated, “I can't really grip good today.” Gregory echoed this phenomenon, stating “I physically have to drop things because I get these stabbing taser feelings.” Jim also shared how limitations in his hands in arms interfere with his ability to play guitar.

All the men described changes in their ability to walk. For instance, Jim discussed how FM has impacted his ability to walk, which has disrupted his ability to work, go on daily walks with his wife, and enjoy travel and site seeing in the same way that he used to. “I really was having issues just walking.... I can't walk. And the only way that I can get around and live my life, and actually see things, and go places, is on my scooter! You know, that's the only way. I can't walk. I can walk a block one way, and a block the other way. That's it. My legs won't take it.” Stan also noted how pain limits him from engaging in activities he used to enjoy, stating, “You can't go hiking through the woods and have fun and go fishing in a bass boat. Because that would hurt really bad. I'd be down for days. I can't hike that far in the woods anymore. I can't go fishing very long.”

Gregory, Matthew and Stan each described feeling as though their body is “broken.” Matthew depicted this is describing his memento that held meaning to his experience of being a man living with FM - a photo he took of a run-down power plant:

“Whenever you see anything about [location redact], and how it's been destroyed, that's usually the picture shown is the old [redacted] Plant. It's been like that for



over 40 something years... If you see those bullets through windows and destroyed nature of the landscape. And then, if you see the Photoshopped eyes, that's a drawing that I did - my eyes. [It represents] being imprisoned in a [pause] broken down body, I guess. So, that's where that came from. So, it holds a lot of meaning.”



*Figure 3: Matthew's memento*

Physical limitations were often linked to feelings of embarrassment, loss of independence and/or identity and grieving of their past abilities. This was especially amplified in men who held physically laborious jobs or who held identities/social roles linked with physical fitness (athletes, veterans). Physical limitations disrupted their functional abilities to carry out important family, work, and social roles, as well as their ability to enjoy personal hobbies and experience a sense of engagement. With physical limitations, men also described the onset of the cycle of pain and disability (where they

decreased mobility due to pain and the muscle atrophy hastened pain, and at the same time fed into emotional pain).

**Cognitive Symptoms and Limitations.** All six of the men with FM in the study noted *Cognitive Symptoms and Limitations* of FM. This subordinate theme depicts the fatigue, apathy and “fibro-fog” described by men. Such symptoms were displayed throughout several of the interviews when men would have difficulty with word finding, remembering timelines, losing their train of thought, or forgetting the question at hand. When these moments occurred, men would readily identify and name the process happening, and it was typically accompanied by frustration. For instance, Stan made the statement at one point in the interview, “I can't remember the proper terminology for it. But that's part of my FM acting up today, because of my pain.” Jim had a similar moment of forgetting, and commented, “see there it is again, it just goes out of my brain. God damnit, what was I going to say? I tell you, this is the way my brain is. I have the worst case of fibro fog in the world! [laughs].” Another participant began, “And I was at the beginning of.... Yeah, I just drew a blank what I was trying to say... it was umm... Shit, I forget what I used to call it...” He went on to share the timeline of different factors leading toward a “downward slope” with his pain and mood, and within this same excerpt stated, “I forget where I was going with this... Apparently, I'm in a bit of a fog today.”

Matthew noted how his FM experience involves significant difficulty concentrating because of how much of his cognitive resources are focused on his pain:

“It does cause problems, because I'm not paying attention to anything other than that [pain]. Conversations get started. I don't hear em'. I get told about that often

because I'm trying to concentrate on getting through this pain that's so overwhelming that it's shutting down my thought process basically. I think they call that fibro fog.”

He also noted how his inability to concentrate and retain information has led him to give up on activities that used to give him joy such as playing guitar and reading.

“I've donated a whole library to a base station, probably 500-600 books... I don't read anymore because I can't really retain anything I read. I'll read a paragraph and then I have to go back and re-read what I read because I forgot it halfway through the first sentence of the next paragraph.”

Difficulty focusing on things because of being bombarded by pain, as well as using significant mental energy in attempts to cope with pain, in turn appeared to play a significant role in experiencing fatigue and apathy. Matthew stated, “I space out a lot. So, it's hard to retain info. Which interferes with starting projects, work.” He went on to state, “One condition that this fibromyalgia does bring about is a lot of apathy towards s\*\*t... I've been working on that for the last few years trying to get past this apathy towards getting back into mainstream life.” Similarly, Gregory noted, “I spotted that fatigue is a strong part of the male Fibro experience.” Trevor agreed, stating “the biggest thing I associated with [FM] is, well, the biggest things are pain and fatigue.... The fatigue issues are very real. And for a while there I was just hopeless. I was just burning myself out left and right.” Jim also described a sense of hopelessness when it comes to fatigue, “The fatigue part, that's the symptom that feels like you just don't really have much control over it. And when that comes on, you just have to lay down, there's not

really a way to fight through it.” Moreover, he shared how his constant state of fatigue interferes with his quality time with his wife, “when it's three or four days in a row of this heavy, heavy malaise, and multiple naps in the day, it gets disheartening. Because I don't get to spend as much time with my wife.”

**Physical and Emotional Pain Linked.** This theme represents the mind-body connection inherent in the pain experience of men with FM, where men described a bidirectional relationship between their pain and their moods. For instance, at the beginning of Stan’s interview, he noted how the cold weather was exacerbating his pain, and stated, “I apologize just in case I get a little snippy today.” Matthew discussed how his diminished mental capacity impacts him emotionally as well, “It's affected my mental wellbeing big time. My emotional health.” He elaborated, “That's where I am now with the therapist. We're trying to figure out ways I can fight this overwhelming pain that just puts me in this negative space.” In describing how this affects his day-to-day functioning, he further connected how the relationship between his pain and mood is mediated by the depletion of his mental resources. “I guess I break down more often over silly stuff, just because you're using a lot of your mental capacity to stave off the pain sensations that your constantly feeling.” Other participants echoed this as they described a negative feedback pattern or vicious cycle between unpleasant emotional states and worsening pain. For instance, Gregory shared his meaning making process of the early onset of his FM, “In my head I was panicking, I was starting to panic. And what I didn't deduce at the time was that the panicking, and anxiety, and depression, and stress, manifests as pain within the body.” He added, “If I'm mentally over-exerted by obsessing about something

or being anxious about something, that would have the same results that would trigger me to have flares.” Fred additionally acknowledged the emotional impact living with FM has had on him over time, when he stated:

“Living in pain every day re-wires your brain. I'm much more negative and cynical than I used to be. And I would at least partially attribute that to living in constant pain. You know, [laughing] it's hard to be upbeat and positive when everything hurts!”

### ***Psychosocial Stressors***

All of the men with FM encountered psychosocial stressors during the early onset of their FM and throughout the process of seeking out a diagnosis. While psychosocial stressors related to living with FM were ever-present for participants, two particularly salient stressors in the early phases of their FM progression included *Frustrations with Healthcare Experiences* and *Uncertainty of Not Knowing*.

**Frustration with Healthcare Experience.** Five out of six participants experienced frustration during healthcare encounters, including feeling their healthcare providers did not understand, believe them, or were dismissive of their pain, as well as feeling their medical providers failed to treat them with empathy, failed to adequately address the mental health side of delivering a diagnosis of FM or the psychological impact of FM, and did not sufficiently prepare them for what to expect or how to treat FM. Additionally, men described a significant course of self-directed treatment and trial and error process of navigating medication regimens and activities when their medical

providers advise or recommendations were not working, or when they felt judged or criticized.

Men with FM commonly experienced feeling that healthcare providers could not understand, believe them, were dismissive, and un-empathetic of their pain experience. Matthew described his experience over the span of more than a decade when trying to arrive at a diagnosis. He noted one provider diagnosed him with Tension Myalgia Syndrome, yet he received ongoing invalidation from subsequent providers, stating, “every doctor that I mentioned it to afterwards for probably 10 years just said it was some made up diagnosis... They just called it f\*\*\*ing B.S.” He described that it was not until he suffered a severe injury, where he fractured multiple bones in his hand and told the team of doctors caring for him, “it doesn't even compare to what I go through every day,” that they began to take his widespread pain complaints seriously. Prior to that, he shared frustration with feeling like his pain was dismissed by medical professionals, “I was so disgusted the doctors would just say ‘oh, that's just normal that you're in pain like that.’ But I was like, um?” Fred shared an account of feeling misunderstood when he tried to explain his experience:

“The physician that I had at the time did not understand at all what I meant when I said, “everything hurts all the time.” She asked me why I'd come in for the visit. And I said, “everything hurts all the time.” She's like, “I don't understand.” I'm like, “EVERYTHING hurts. Like I'm never not in pain.” And she just could not wrap your head around it... And she had nothing for me.”

Matthew echoed this account, noting how providers inability to fully understand his pain experience is what leads to the skepticism and disbelief he experienced for so many years. He also shared his sense making process of the skepticism and disbelief from doctors being related to FM being an “invisible illness,” especially given his outward appearance as healthy guy. He experienced additional feelings of invalidation and stigma in healthcare encounters where he felt compelled to reassure providers that he was not drug seeking. He expressed:

“With some of the medical professionals that I've dealt with, I don't believe that they fully understand what pain does to you. What long term chronic pain does. It seems as though they disbelieve you for your word, first off. That, 'Nah, he looks healthy. He can't be like this.' So it's kind of denigrating that you think that I'm lying about this. Like with the VA and stuff. I told them I didn't want no painkillers at all for this stuff. I wasn't there because of painkillers. I was there to get help.”

Jim shared how he has witnessed similar accounts:

“I've heard people say that their doctors didn't believe them, in the men's [online support] group. Especially if you're young, if you're 23 when you have what I have... They don't believe you. And at 23, you have to go like nine times to just keep getting more and more documentation, seeing more doctors. You need a thick file before they'll give it to you [fibromyalgia diagnosis] as a young man. And a lot of mis-diagnosis with men. You know, 'Oh, no, it's not that.' ... And then it takes them years to get a diagnosis.”

While Gregory did not experience being dismissed or disbelieved while seeking a diagnosis, he shared how he experienced low empathy and understanding from his medical team when they delivered his FM diagnosis as though it were “fantastic news.”

He accounted:

“I remember very vividly being so desperate and her [the doctor] bouncing around and being very upbeat. And she had three female student doctors with her. So, I saw this panel of female faces as judge and jury over my fate. And the expert being fully delighted, says, “I've got such fantastic news for you. You're fine.” And I went, ‘No, no, no, no, no, this isn't. You've not said the right thing. I'm not getting any comfort from this.’ And, I said, 'What's going on?' 'I've killed myself-- I've suffered the pain to walk an hour to get here today because you've told me that I need to do a lot of exercise.' She says, "You do." I said, 'Well, I feel like death. I feel like I should be in a wheelchair.' And there's this panel of very young female heads. Super bright people. But I felt concerned that they were not treating me as a human and a very distressed case. They were looking at it from a medicinal challenge and a textbook case. No one was taking on the mental aspect of what state of mind I was in. So, I remember feeling a little bit angry at the time. And I wasn't expecting that to come out. I think there was just a frustration point.”

Gregory expressed feeling very dehumanized by the medical providers in this encounter, as their jovial manner of delivering the news of a life-long condition was



made him feel like they saw him as a collection of medical tests that helped them deduce a diagnosis, rather than a person whose life was drastically changing.

Men with FM also expressed frustration related to lack of guidance, and collaboration in treatment planning with their healthcare providers. For instance, Gregory described his less than satisfying experience after receiving his FM diagnosis, “I was shocked with how little information they gave me. They just printed out an updated medicine sheet and pushed me back out the door... She thought that was going to be sufficient to send me on my way.” He continued, “You might have gone through the medicine handling. But I'm leaving here completely bamboozle and borderline angry. And I don't feel that's enough for me to handle the next phase very well.” He concluded,

“I think what happens with the doctors, they just they don't manage your expectations... they do nothing to manage your mental health, or how to manage possible expectations of your own recovery, or situation.” He noted feeling “desperate for useful health advice on what to expect, how to manage yourself, and not to give up.”

Moreover, men expressed feeling frustrated when their healthcare providers did not seem to know how to help them or seemed unwilling to. For instance, Stan noted, “what I've come to terms with is, the doctors don't know what's causing it, so you have to make the best of it until then.” Gregory expressed similar sentiments, highlighting how skepticism about the legitimacy of FM by some of the medical community can influence the inconsistency in guidance that people with FM receive. Matthew and Jim noted having a difficult time convincing their providers to help them file disability paperwork.

Matthew noted, “She had been saying that it's hard to fill out this paperwork. And then when she'd seen my hand (a severe injury he complained less about than his FM), she filled the paperwork out.” Jim similarly noted:

“To get to this [disability], you have to go through like 700 doctors. I went to two neurologists; I went through cardiologists. Every kind of doctor you can think of.... just trying to get doctors so that they can support my position so that I can get my disability.”

Gregory shared his experience of self-experimenting with his medications and doses to find what worked best for him, and his surprise that his positive results were not realized with the help of his prescriber:

“I started my own medical regime; I went back to an old 50 milligrams daily dose, and it took away the worst of my day to day burning feelings and the arthritis feelings had stopped. And I went - this is a genuine miracle! And a doctor didn't tell me this. I stopped doing what the doctor told me and I was self-medicating. And it just gave me such a lift.”

Stan shared a similar experience, and yet when he shared his results in an attempt to team with his provider, he felt dismissed and unsupported:

“I did my own research and started taking herbal medications. And I found the proper combination for me, because everyone's different. For me, it works just as good as Lyrica. And I told my doctor about it and now she doesn't treat me the same. She was all, 'Oh, you're taking herbal stuff, so then you can treat yourself.’”

While this theme largely conveyed negative experiences in healthcare encounters, one participant did not have anything negative to say about his experience within the healthcare system. He attributed this to having an interdisciplinary team of pain specialists including a doctor, physical therapist, and psychologist. A couple of other participants referenced at least one neutral-positive experience within a healthcare encounter, but their negative experiences significantly overshadowed these.

**Uncertainty of Not Knowing.** Another psychological stressor men with FM experienced was uncertainty. This included uncertainty about what was happening to them when they started experiencing FM symptoms (before having a diagnosis or name for their experience), uncertainty about the cause of their FM, and uncertainty about how to treat or cope with it. The feeling of uncertainty was highly linked with feelings of frustration. It should be noted that feelings of uncertainty were also experienced by men post-diagnosis – specifically men noted the unpredictability of pain and constant uncertainty about what to expect in terms of pain levels or functional ability each day. They also noted the subjectivity of FM and how it affects everyone differently, therefore making it difficult to rely on any uniform recommendations.

During the initial onset of FM, men expressed being quite bewildered by the experience of pain. For example, Fred shared, how he started experiencing pain in little things like chores around the house, “like turning a screwdriver the six or seven times that it took to take a screw out, my arm would burn with pain. And I didn't understand why.” As his pain became more widespread and pervasive, so did his uncertainty, “Everything hurt all the time and I never knew why. I didn't know what was wrong. I

didn't know what to do.” Trevor expressed the difficulty of coping with the unknowns involved in the early onset of FM. “It's very frustrating. I mean, it's frustrating to not know what's causing things. It's frustrating and not know how to treat it.” Participants shared how not having a name for their experience added to the sense of uncertainty and what the future would hold. For instance, Trevor shared, “Before we had a diagnosis, before we knew about what was going on, the fatigue issues are very real. And for a while there I was just hopeless.” Gregory shared similar worries, stating, “I started to have started to doubt myself and what the future would hold and could no longer be of assistance on doing such a natural thing, like having a yard sale, carrying light things out.” Moreover, he expressed, “I didn't have a diagnosis, I didn't have a reason to say why I couldn't help.”

Men experienced receiving a diagnosis as empowering moment because it opened more hope for a direction to pursue for practical solutions and support. For instance, Trevor expressed, “Having a name let me research, look into what others are going through. It means I wasn't alone – others share the experience, to a degree.” Yet, even with a diagnosis to help point men towards resources and support, men were clear that there is still some uncertainty inherent in FM because “it is different for everyone.” For instance, Stan shared how newly diagnosed men will join the Men with Fibromyalgia Facebook group and ask about what to expect, “and you really can't tell them what to expect because it's different for every person.” Trevor commented on how this results in, “so much trial and error and so much never knowing.” Gregory added, “some things work for some people and not for others. And some people have very layered, additional

health problems on top of it. And they're juggling mental health erosion at the same time." While these psychosocial stressors were heightened in the pre-diagnosis and early onset of FM, several men continued to experience frustrations during healthcare encounters and feelings of uncertainty beyond that point.

### **Post-Diagnosis Living: Psychosocial Pains**

As men adjusted to living with FM, they encountered numerous changes that caused distress and pain in several domains of their life. The following sections will focus on the psychosocial impact of FM on life after receiving the diagnosis. Themes that will be covered in this section will include, *Emotional Impact*, *Impact on Identity*, and the *Social Impact* of FM.

#### ***Emotional Impact***

The superordinate theme of *Emotional Impact* explored men's emotional responses to FM illness threats after receiving their FM diagnosis. Additionally, this theme represents the emotional responses to FM-related stigma and masculinity threats they have experienced in the context of living with FM. The primary subordinate themes were described as, *Anger and Frustration*, *Depression and Anxiety*, *Feeling Alone* and *Guilt and Shame*.

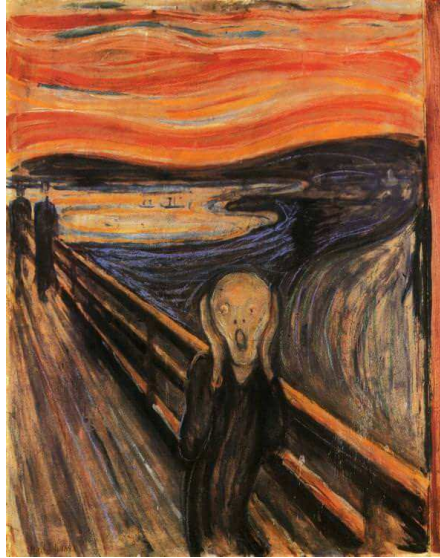
**Anger and Frustration.** As noted earlier, men with FM experience significant frustration occurred in the context of healthcare encounters and the early onset of FM when they were experiencing changes in their physical functioning but had no clear answers of why. For instance, while Gregory was recalling the memory of being diagnosed with FM, he stated, "I remember at the end of my tether, being so confused,

and frustrated, and sort of aggravated in that scenario.” In addition to feeling the team of doctors were being insensitive while delivering his FM diagnosis, his anger arose in the context of a young resident reprimanding him for his medication regimen. He recalled responding:

“How dare you? You're 22 and telling me what I should and shouldn't be doing, and what I'm feeling. And that was enough to kind of make me snap and say, 'You don't understand what I'm physically feeling or have felt in the past.’”

Men also expressed feeling angry and frustrated with the symptoms and life-limiting aspects of FM. Jim shared, “I'd say the most frustrating thing about being a man with fibromyalgia are the trials and frustrations of exercise.” He described, “any initial gains through physical therapy cause more pain as treatment continues.” He noted how the increased intensity of pain and small improvement “derails me.” Stan stated how, “living with it for 30 years. I'm tired of it.” Earlier it was also touched on how living with constant pain can negatively impact one’s mood. Matthew noted, “I have a lot of angry thoughts throughout the day.” He went on to describe this feeling of irritability that comes with pain through a metaphor:

“It's like trying not to let the inner being scream out, almost like that Edvard Munch painting - The Scream. That's what it feels like. For many people that are going through this, if they could just shed their skin and tear it right off. It's just basically every inch of your body there's some sort of pushback on. It gets to be irritating trying to deal with that.”



*Figure 4: Edvard Munch "The Scream" (Courtesy of WikiArt.org)*

Moreover, participants noted significant frustration with the lack of understanding and empathy they experience from others. For instance, Stan noted, "It's frustrating, angry, sadness for me. I just could not wrap my head around why they cannot understand it. Or why they don't understand it. Which would just make me angry."

**Depression and Anxiety.** Men with FM endorsed various symptoms related to feeling depressed or anxious including: depression, sadness, apathy, loneliness, hopelessness, anxiety, fear, feeling overwhelmed, and past bouts of suicidal ideation in response to living with FM. For instance, Fred noted, "on bad days it can be very, very depressing." Moreover, Stan stated, "There's always low times with this."

Men's experiences of anxiety and depression were very intertwined. Men experienced a chronic sense of hopelessness early in their FM journey that paralleled the chronicity of their pain experience. For instance, Gregory shared, "I was quite desperate. I remember being very desperate for some very hard news, some facts, because I'd made

up this worst-case scenario in my head.” Trevor expressed a similar mixture of feelings shortly after his FM onset when he stated, “My brain was just full, it was just full, it couldn't process any more, any day. I was just in some kind of state of over being overwhelmed. For a while there I was just hopeless.” Men described early attempts to make sense of what was happening that often lead to a negative spiral of ruminating on questions of – why? They described these feelings as being more frequent and more difficult to cope with in the earlier stages of FM. For instance, Trevor stated, “there were definitely times I felt like, what's wrong with me? What am I doing? Why am I like this?” Jim additionally reported, “At the beginning it was very bad. I had serious depression, and you get the "why me?," and, "why is this happening to me? and all that.” He went on to note the impact FM had on his daily mood:

For a while, I woke up and I was a grumpy son of a bitch. And in my mind, every day was cloudy. It was always raining. Like, why does it always rain on me, right? There's a song from a long time ago - 'Why Does It Always Rain On Me?' And that's how I felt. Like, why, why, why? Why do I always feel this way?

Stan expressed a similar ruminative processing style that he has become aware of and attempts to catch it before it takes a hard grip on his mood. For Stan, high pain days coupled with feelings of loneliness tend to lead to this unraveling:

“There's some days in the house, and it's quiet, and there's no one around. Nobody messages you on Facebook. Not even family. It's like, "What can I do? There's nothing to do." And especially on your bad days. And then you start to mull on it - What am I doing wrong? Why don't people talk to me?”



Men's depressive symptoms occurred in the context of the loss of their physical functioning abilities and their ability to maintain important social roles – particularly changes related to work and relationships. Matthew and Jim identified their inability to work as the most significant contributor to feeling depressed. For instance, Jim stated, “I was definitely very depressed. And I really didn't want to deal with it because I really liked the job I used to do.” Moreover, he noted how cultural messages from his upbringing that placed high importance on men working amplified a sense of identity loss and despair associated with work forfeiture. Relatedly, Matthew described having a strong work ethic and how he envisioned himself working into his 70's. “Yeah, you feel good and then you feel depressed because [work] stopped way too soon.” Men also noted the very life limiting impact of pain and fatigue and the emotional toll this takes on them as it reduces their quality of life and engagement in activities/social roles. Gregory shared his experience of this during the earlier phases of living with FM:

“I was anxious and depressed, and not sleeping very well, because I was concerned about the behavior of my body recently. And instead of just going away after a physical exercise, it just enveloped me. It really took over. And then I was starting to experience fatigue that I didn't even want to stand up. I went outside and I thought - my quality of my experience was really deteriorating.” Jim also noted how fatigue factors disrupt his life, which tears down his mood: “You know, when I get into serious malaise like over the past week... I've been crashing. I've been sleeping like 14 hours a day. That, to me is really crazy. It hasn't been this bad in a while. So, it affects me in a way that I feel sad because I

want to be able to be up and about, and at least to spend time with my wife, or spend time on my computer... So, I get sad, but I wouldn't say that I get depressed. I call it down in the dumps. You just feel really crappy.”

At the most severe points, men expressed having thoughts about suicide. Gregory noted a time in his life when, “I was publishing some very black and bleak images on social media.” I try not to have my dirty laundry in the public, and not whine and be an attention seeker. But I went to some dark places.” He went on to share:

“That's when I'd had a serious conversation with myself saying, 'You can't just be living a life of being tasered every 30 minutes.' You know, I made a deal with myself that, I could probably cope. I probably had the mental energy for years of coping with that, but if there was nothing to move the needle, then I made a rational decision to stop my life.”

Matthew similarly noted, “A lot of people would f\*\*\*ing kill themselves feeling like this day in day out. I'm not gonna say that hasn't crossed my mind throughout the years.” He also shared, “There's blog I'm on I've watched plenty of people that have dropped off, then finding out that they took their own life because of the unending burden.” While Fred did not experience this firsthand, he also noted witnessing other men express this on various FM support websites, stating, “I've seen a lot of guys that sound like they're contemplating suicide.”

**Feeling Alone.** Men with FM experienced a heightened sense of loneliness in the early stages of FM when they were unsure what was happening to them. Gregory described this feeling before receiving a diagnosis. He recalled how alone he felt, “not

knowing, not having the control, and not having anyone to talk to about it.” He continued, “I was having this physical breakdown, and mental breakdown, to be honest, with nobody around.” Trevor echoed this experience during the early onset of FM, stating, “I was feeling very lost and alone.” Men also experienced loneliness in context of losing friends when they had to stop working or spend more of time at home due to their pain. For instance, Fred described, “my health failed to the point that I had to punch out of work. So, I was alone a lot.” He added, “And that sucks when you're meta-cognizant, because you spend a lot of time thinking, and that's really hard [laughs]. So, when you're down, and alone, that makes that stuff really, really, difficult.” Stan similarly shared, “I do miss going to work, and seeing other people.” He echoed the impact of loneliness on mood that Fred mentioned, stating, “there's always low times with this. There are some days in the house, and it's quiet, and there's no one around. Nobody messages you on Facebook. Not even family. And then you start to mull on it.” He acknowledged feeling lonely, followed by stating, “But after a while you kind of get used to it. A person really shouldn't get used to it but...” Additionally, men reported feeling alone because of the lack of understanding and empathy they receive from others who don't what it is like to experience FM. Men also noted that they have few (if any) friends with FM in real life.

**Guilt and Shame.** Feelings of guilt and shame were also predominant amongst men with FM. These feelings were often experienced in the context of adjusting to the intra/interpersonal consequences of FM surrounding their physical limitations, needing help, intimacy challenges, or being unable to fulfill personal or social roles that they used

to. Moreover, guilt and shame occurred in response to situations that seemingly called their masculinity into question.

For instance, Trevor and Jim noted guilt and shame related to intimacy challenges. They both shared how the pain and fatigue associated with FM as well as the side effects from medications have negatively affected their sex drive. Trevor shared, “There's a lot of different moving parts here that any one of them could put a damper on the sexual side of things and put it all together and it could be a real challenge.” He noted feeling rather comfortable about having open conversations with his wife about this, but is somewhat less comfortable discussing the topic with his doctor.

Jim initially expressed feeling “pissed off” when his wife had purchased a vibrator. In further discussion, he reflected more underlying feelings of guilt and shame, “that I'm not able to do that, you know, not able to please her. It's a basic thing.” He additionally reflected on the cognitive aspects that can additionally interfere with sexual functioning, “I struggle with thoughts about impotence... I get too much in my own head about it.” While Gregory and Fred did not personally endorse intimacy challenges, they shared that this tends to be a common phenomenon for men they have interacted with on the Men With Fibro support group. For instance, Gregory commented, “they have a lot of sexual issues. And some of the meds we take are very strong, and they feel very emasculated. And I try to help decouple that from their experiences.” Jim and Trevor noted how while difficult at times, being able to decouple these challenges from their sense of masculinity helps them maintain their esteem, yet the guilt for the impact this has on their relationship often remained to some degree.

Men also described feelings of guilt and shame when their physical limitation prevented them from getting as much done as they wanted or from being able to help others with tasks. For instance, Trevor expressed feeling guilty about not keeping up with house projects. He stated, "I try my best, but there's always some residual guilt. When I have this laundry list of things I wanted to get done, and it's just growing instead of shrinking." Gregory noted feeling embarrassed when he was unable to help prepare for a yard sale. He shared:

"I did feel ashamed when my friends were here joking at my expense - going 'why is Gregory sat down watching us lift this old dusty furniture out onto the front yard?' They were joking at me, and actually, deep down I hated that. I didn't have a diagnosis, I didn't have a reason to say why I couldn't help."

Of note, men noted how younger men with FM may be prone to feeling more guilt associated with the disruptive impact of FM, and how guilt is often a driver of ineffective pain management. For instance, Gregory who mentors several younger men with FM shared:

"They feel totally obligated, if they have a good day, to immediately go out and do something with a family and the kids, or take their wife shopping, or do something. All the families seem to be waiting for the male to have a good day, and have more credits in their bank, which they then blast through and do a big job. And then they have several days afterwards of being in a lot of pain and triggering a flare but felt like they owed their spouses this kind of credit day. So,

they feel like they're in some awful psychological anguish, that they feel embarrassed and ashamed about.”

While the emerging themes depicted in this section reflect many of the more difficult emotional experiences, it is important to note that men expressed several other positive, neutral and more nuanced mixtures of emotions as well. Their more positive emotional experiences are featured in the proceeding “Coping” section. The constellation of emotions men experienced across time and situations in their FM experience helps highlight the dynamic way that physical and social factors can impact mood, and vice versa. These feelings were closely intertwined with masculine gender strain, loss of identity and self-esteem, and internalized stigma resulting from FM.

### ***Impact on Identity***

This superordinate theme represents the impact of FM on men’s identity and sense of self. Subordinate themes included *Masculine Gender Strain Influenced by Cultural Pressures and Expectations for Men*, and *Identity Loss*.

**Masculine Gender Strain Influenced by Cultural Pressures and Expectations for Men.** This theme represents men with FM’s experiences of threats to their identity as a man and strain on important masculine gender roles. Masculine gender strain was highly intertwined with pressures and expectations men held themselves or believed others expected of them. Such cultural expectations and pressures to conform to traditional masculine gender norms or roles often complicated their illness adjustment process. For many men, these social pressures contributed to difficulty adjusting to physical limitations from an emotional standpoint because of how these messages were

often internalized and impacted how they viewed themselves. Men often described challenges with acceptance of their new realities, especially when changes they endured because of FM impacted their masculine identities. Some of the expectations that were widely mentioned and internalized included expectations for men to be physically healthy, emotionally strong, and to work and contribute financially as the breadwinners. For instance, Stan noted, “it's the stereotype of a man, you're supposed to be healthy, and the breadwinner, take care of everyone. It's hard to give that up.” *Self-Reliance and Stoicism* and *Work Challenges and Financial Strain's Negative Impact on Self as a Provider* emerged as the predominant cultural pressures men with FM faced and which were experienced as major adjustment challenges related to identity and self-worth.

***Self-Reliance and Stoicism.*** Almost all of the men endorsed ways that FM presented masculinity challenges related to adjusting to the loss of independence, as well as accepting limitations and needing help in the form of either physical or emotional support. For instance, Fred shared that it is difficult asking his kids for help because it provokes, “processing that I can't be the dad that I want to be.” Trevor expressed challenges mentally adjusting to using assistive devices, stating, “the cane itself is actually kind of convenient to have, but at the same time, I hate that I have to rely on it.” He expressed greater disdain for having to rely on his wife to physically assist him on “bad days”:

“I feel almost helpless sometimes. Sometimes it's a struggle to walk across the room, and my wife has to actually physically help me. And it's hard not to feel a

little infantile, when that happens. I'm a grown-ass man, I should be able to walk across the room without fearing that something bad is going to happen.”

Gregory recalled feeling like an “invalid” and seeing himself as disabled when his FM pain prohibited him from helping with a yard sale. He recalled, “I couldn't lift anything... He got his friends and the neighbors to come over to help him carry stuff down. And this included a lot of women. And they were doing things that I could no longer do.” Similarly, Matthew shared how loss of his physical abilities and independence translated to loss of confidence:

“You lose self-confidence after this wearing down and beating on your system for so many years. Am I doing this right, or do I need to go get help? And then it falls into the trap that somebody has to help me. They're doing what I need to be doing. You know, so it's a wicked trap that we get caught in mentally when it comes to confidence and ability.”

Gregory, Matthew and Stan shared about masculine ideologies they were brought up with that make it difficult for them to express their feelings or depend on others. Gregory noted how even at his bleakest moments when contemplating suicide, he was reluctant to share how he was feeling. “It made me realize that mental health is a significant factor in fibromyalgia, and it's just not cool or macho to talk about such things,” he stated. Matthew shared, “the mental outlook that a man has is that you're just on your own when it comes to trying to figure out how to deal with this. The only person that's going to be able to help is ourselves.” He further expressed:

“It's difficult because something that you once were able to do, now you have to



sometimes depend on others. And that kinda takes away from the masculinity portion. You're supposed to be a strong, silent type. My outlook on masculinity may be different than others. That's probably something that I was brought up with - don't complain.”

Stan shared how he was brought up to internalize a similar “suck it up” mentality, noting, “It's definitely harder for guys to talk about their emotions on the [Men with Fibromyalgia] board.” He shared the following sense making process:

“I think it all stems back to the man stereotype - you're not supposed to show emotion. That was the way I was raised. If I hurt myself and I ran into the house crying my dad would yell at me, 'Shut up, suck it up and go on. You're a man, you're not supposed to cry. Suck it up.' And that's just kind of drilled into us as we're growing up and it just stays with us.”

Self-reliance also manifested in men's expressions of not wanting to feel like a burden on others by showing pain/discomfort or complaining about pain. For instance, Fred noted, “I try not to let people know that it's bothering me if I can help it.” Similarly, Jim said, “I really try not to talk about it too much because then it's always about me. I really try not to make it all about me, but sometimes it is. I try and bite my tongue, not complain too much.” Jim noted adopting a “Don't Ask, Don't Tell” approach to choosing how much to share about his FM with his children.

Fred discussed a similar dilemma in choosing how much to tell others about his FM. He shared, “Something that you struggle with, with fibromyalgia is, when people greet you and they ask you, ‘Hey, how you doing?,’ it's not always easy to tell if they

really want to hear the answer or not. He continued by sharing a solution he's come up with that guides him in how much to appropriately share with others:

“I developed a couple of phrases I would share that allowed me to express how I felt, honestly... And help the person that asked me. Like, if they didn't care, they could walk away without a care in the world. And if they did care, they could scratch the surface and dig a little deeper. So, if somebody asks me how I'm doing, I'll say, "I'm in good shape for the shape I'm in. The other phrase is, "I've been better, I've been worse." And it allows me to express how I'm feeling. So, I get to be honest to myself with a short phrase, without burdening somebody unnecessarily. If they don't understand, well they can ask, ‘what does that mean?’, if they care enough. And if they were just saying that as a way of saying hello, it's no skin off their nose and I still get to express myself.”

***Work Challenges.*** All of the men with FM described work related challenges, disruptions, and adjustments they had to make in response to FM, including having to cut back on hours, change jobs or job roles, or file for disability. Trevor, Fred and Gregory all had to cut back on hours, change positions, or go on short-term disability, but have been able to get back to (or are in the processes of searching for) part-time work. For instance, Trevor stated, “When I hit 40, specifically is really when it took a sharp downwards turn. And it was getting to the point where I was really having a lot of struggles doing my day job.” He continued, “I was an IT Consultant at the time, I'm sort of pseudo-retired from that, at this point... I've sort of changed careers to something that is extremely part time.” Gregory described taking a prolonged leave from work while

figuring out how to manage FM and is now eagerly in search for a part-time job. Fred shared the following account as he recalled the day he decided to take time off work:

“I went in one day for a meeting, and I had a breakdown in my boss's office. And I told him, "I don't know when I'm coming back, but I ain't coming back to the office tomorrow. I'm gonna take a medical leave." I had to stop working. And I literally just walked out of the office... I spent most of the year on unpaid medical leave. And I had exhausted my FMLA protection. So, while I was gone they wrote, my job out of existence and laid me off when I was ready to come back to work.”

Fortunately, he was able to secure a new position and advocate for his needs prior to starting. “I explained the situation told him that working flexibly a couple days a week was very, very helpful. And he was willing to sign off on reasonable accommodation paperwork, which brought up the quality of life.” Of note, Fred, Trevor and Greg each worked in white collar type jobs, and while they had to make significant changes and adjustments to work (changing jobs, only working part time, reasonable accommodations), they have been able to find their way back to work in some capacity.

For Jim, Matt and Stan – who all worked in blue collar jobs that required physical labor, maintaining work has been more difficult, and they are currently on disability as their only source of income. For instance, Stan stated, “Stan: I can't go out and work. There's no way I could hold down even a part time job.” Like the other men, Matthew noted, “When I was getting sick, I had to back off on the hours... because of my physical ability, I just wasn't able to perform my job duties anymore as I could.” Additionally, he

described how FM fatigue and concentration symptoms interfered with his work performance at his manufacturing job- “I was finding myself making mistakes that could have been catastrophic.” Jim too noted how he struggled to keep up with the demands of his job:

“My job was the kind of job where you gotta move because we had so many customers. It was a very, very demanding job. So I went on disability and from there on, month, by month, by month, everything just kept getting worse. More pain, less mobility.”

***Financial Strain's Negative Impact on Self as a Provider.*** Several men experienced financial loss and worries about finances due to FM’s impact on their ability to work. For instance, Jim described his concerning thought, “as my symptoms got worse and worse, and my disability was running out, I said, what are we gonna do?” Trevor reflected on the hardship of FM taking its toll on him amidst relocating for a new job, then having make a career change. “It's tough to go from making a good salary to making almost nothing.” Moreover, his accounts reflected the additional financial burden of living with a chronic disease:

“We were struggling for a while, but we're back on our feet now. That was a real-world concern. How are we going to pay the bills? How are we going to pay the mortgage, the rent? Medical bills, piling up, all of a sudden, out of nowhere. I have thousands of dollars of medical expenses a year.”

Not only was the financial impact of FM stressful, it represented a threat to their role as a provider. Many men’s comments supported the notion of masculine strain from

the culturally engrained pressures for men to be “the breadwinner,” which cut across men in both hetero and same sex relationships. For instance, Gregory noted how his spouse jokes “half in jest and half seriously” saying things like, “I married this guy, hoping that I could retire early, and he was going to make a whole lot of money, and then he goes on sick on me.” Trevor noted a difficult identity struggle adapting to bringing in less money than before his FM affected his ability to work full time:

“I guess more from the man's side of things, there is some cultural stress that the man should be the bread winner/earner, that kind of thing. I feel I was making a good salary back when I was working in IT regularly, and now I'm bringing in a pittance. That is somewhat tolling on me. There's some [mental] adjustment there that has to happen.”

Stan, Matthew and Gregory both spoke about how changes in their work status outside the home also translated to changes in their roles within the home, where they began taking on more domestic work. Stan noted how this changed his self-view, stating:

“Well, I don't see myself as the hard working, difficult guy. It's went from going out and working 40 hours a week to staying home and doing something little around the house every day to keep the entire house clean. I pick something to do every day, so that way, the house stays clean. And I went from pretty much the man's role to a woman's role. If you think about it, old school.”

However, Stan noted how over time this adjustment has had less of an impact and having worked in housekeeping roles historically helped ease this transition. On the other

hand, Gregory who historically has been less involved with domestic roles described having a more difficult time adjusting to this:

“Right now, in the absence of work, I do the housework... And [my spouse] is the breadwinner right now, and I badly want to get back up to join him. Because my brain--I'm thoroughly bored about it. And I have a Groundhog's Day of deciding what to cook for lunch, for dinner. And I clean out the cats, and do a bit of housework, wash some clothes, but this is so dull. It's not satisfying me mentally... And he's kind of viewing me in this Cinderella housekeeper role now and I'm absolutely fighting just to spite him to get back up as a breadwinner, too. So, we're playing with these gender norms, and most days it's good natured.”

Jim and Gregory reflected on the difficulty of adjusting to changes in their abilities to carry out work roles that previously shaped their identities. For instance, Gregory reflected, “My ego is not prepared to sit down and accept my housekeeper role right now. And I'm so happy about that. Because it means I'm not done. I have this pride that screaming to get back up there.” Similarly, Jim stated:

“It [my sense of self] did [change] in the beginning, only because like I said, my family's hardy stock, and I couldn't work. And my job is to take care of my family, and I've been taking care of my family. Supporting them financially and everything. You know, that's my job - to take care of my family, and I can't do that. So, yeah, that in the beginning, that was a hard pill to swallow.”

Men with FM also spoke about the joy, sense of accomplishment, and/or meaning they experienced from their work roles. For instance, when talking about work, Jim

stated, “I really loved, well I didn't really *love* the job I was doing last. I really liked the job I used to do!” Additionally, Matthew shared about the sense of accomplishment his various work roles provided him:

“I worked on some cool stuff as a machinist. I put stuff up in outer space. The first replacement knee that they came out with, I worked on a prototype of that. Worked on racing engine stuff for racing. Automotive, medical, aerospace. And now washing dishes or cutting grass is the extent of my ability to be productive. That has a lot to do with tearing down your own self-worth. Being unsure of your abilities... When you have that blank spot of accomplishment that's just there in front of you...”

He went on to express how the inability to work negatively impacts his sense of self-worth because “I just don't feel like I'm productive. My sense of worth has been destroyed because of the inability to perform.” Stan spoke of feeling more disconnected since stopping working, stating, “I do miss going to work, and seeing other people.” He also expressed regret for the limited time he had, and wishing he had found his passion sooner in life given that his ability to work was cut short because of FM:

“I love to work. The last job I had, was working at a cabinet manufacturing place and I built the cabinet doors. I really enjoyed that job. And it's weird because after working so many different jobs- I estimated over 40 jobs when I was able to work from age 18 to 35- that cabinet manufacturing place was the best job I've ever had. I loved it. I was only able to work there, I think maybe a year. It was probably a little bit less. I just really enjoyed working with wood, and I should

have done that right off the bat.”

**Identity Loss.** This theme denotes changes men experienced in their identity, sense of self, or self-worth resulting from FM. The following subthemes (*Internalized Stigma* and *Grieving One's Past and Future Self*) help to further illuminate the essence of FM's impact on men's identities. Each subtheme was highly intertwined with occupational loss and role strain men experienced, as these factors provided a strong sense of identity, purpose and esteem for men in this study.

***Internalized Stigma.*** This subtheme depicts the internalization of social stigma (beliefs or stereotypes), where men with FM felt a sense of shame or about his FM symptoms and their consequences. This was depicted in men's expressions of how FM has impacted their self-concept in negative ways. Men used words in phrases to describe themselves such as, “failure,” “lazy,” “broken,” “defective,” “invalid,” “infantile,” “disabled,” “less of a person/man,” and “not a whole human.” Men with FM's internalized stigma predominantly manifested in expressions of low self-worth and/or inadequacy.

As mentioned, self-stigma arose primarily in the context of social role dysfunction, such as not being able to perform or fulfill responsibilities at home or work in the same way. For instance, Trevor said he felt “infantile” and called his manhood into question when needing help from his wife at home. Matthew also talked about feeling “babied” when people in his life over-help, how this inadvertently communicated negative message he internalized, and took away opportunities for him to maintain a sense of dignity through personal mastery:



“There has been instances that I'm like, 'No I'll take care of that.' Or I can do it but maybe not in the same fashion I used to, but I could still do it. Those are the times that get me kind of in the condition, [thinking to self-] 'Now, okay, well, you're just saying that I'm not useful anymore when you try to take that portion away from me.'”

Fred expressed feeling like less of a person because of not being able to be the dad he envisioned himself to be. Matthew discussed the negative impact on his sense of self from the change of being a highly productive worker in a very masculine industry to “the extent of my ability to be productive” being chores and yardwork. He noted, “that has a lot to do with tearing down your own self-worth. this lack of being able to do what you want, it just kind of makes you feel like half the man that you used to be.” Stan endorsed the sense of being “broken,” “in a way because I can't go out and work,” noting how it's changed his view of himself as a hardworking guy. Gregory shared, “I fell from the dizzy heights of Director of Project Management to learning how to live again, and I so badly wanted to get back to that sense of self.” Similarly, Jim noted, “extreme pain rules me and I feel worthless not working. A fading feeling of self-worth.” When Jim was asked about how FM impacts his life, he shared “I come from a family of a very hardy stock. My father was an animal. He was so strong.” He went on to say, “Here I am a weakling now. What's wrong with me? Why am I so defective? You know, you point everything at you. What's wrong with ME?” He attributed his tendency towards negative self-references as being strongly related to his upbringing that emphasized hard work,

strength and stoicism. This connection between masculine ideologies, work, and self-worth is further illuminated by Matthew in the following:

Interviewer: *“If you had to describe what being a man with fibromyalgia means to you, what would you say?”*

Matthew: *“What it means to me? ...Almost like I'm a failure. Because I succumb to all these pain sensations going throughout my body. That I'm a wimp. Why can't I just go to work or have a normal day that I'm not hurting... So yeah, I don't think too highly of Fibro. Yeah, it has a very negative effect on my thoughts in relation to me being affected by Fibro.”*

Interviewer: *“Like your sense of self or?”*

Matthew: *“Exactly my sense of self is destroyed from it.”*

Matthew further reflected on how working in an industrial labor role influenced some of the messages he internalized about masculinity, and how this intertwined with his sense of his self-worth being destroyed when he stated, “working in a very masculine-type industry [laughing] all of a sudden go from being some badass to a pussy overnight type deal.” He additionally noted, “It puts a lot on you throughout time. Now I'm sure I'll get used to it more and more, but I'm still fighting that feeling of inadequacy because of it.” Clearly, men experience difficulty reconciling a positive concept when they are no longer able to work.

***Grieving Past One's Past and Future Self.*** Men with FM experienced a sense of grief over the loss of their physical abilities, social status, and their ability to engage in hobbies and social roles in the way they would like to. Additionally, this subtheme

captures the shattered assumptions and mourning of the lives they envisioned for themselves. Many men with FM expressed a yearning for their previous life and/or abilities. Trevor described the vexing experience of coming to terms with loss when he stated, “It's like sort of an alternate reality almost. It's hard to get your head around. Just why is this me? What happened? Where did my life go?” Matthew and Jim expressed understanding and acceptance with some of their physical limitations, but voiced frustration and difficulty coming to terms with some of the more nuanced or less expected physical limitations and challenges brought on by FM (e.g., household chores, playing guitar). For instance, Jim stated:

“If I could just do some of the things I used to do, it would be great. I know I can't play volleyball anymore. I can't body surf. That stuff I understand, and I can live with. But I can't play my guitar. My muscles in my hands. Now, this is part of my body that I really would like back... If I could just play my guitar, I would be happy, but I can't even do the simplest things.”

Some men described ways they have navigated loss of their ability to be father's in the ways they would have liked. For instance, Stan, who started experiencing FM symptoms as early as age 17 and witnessed its impact on loved ones was somewhat prepared for this loss before it happened. He shared:

“I had a child early on. So that way I could, you know, get down on the floor and play with her, and go to games, or whatever she wanted to do in life. You know, her school activities... Because I knew from seeing my mom and my aunt that later on in life I won't be able to do them as efficiently as I want to.”

Similarly, Fred shared, “I'd like to be like most dads, you know, feeling like super dad- can do anything, anytime, all the time. And that's just not realistic.” He described ways he had to adjust to this and other limitations, and the consequential struggle of trying not to let changes in his abilities define him or his worth. This complex process of “mourning one’s past self,” and adjusting to a “new normal” while maintaining self-esteem is captured by Fred in the following:

“There's a certain amount of mourning the person that you used to be, and no longer are. There's a certain amount of mourning for, I'm less of a person than I used to be and that's hard to reconcile. I'm not less of a person, I just can't do some of the things I used to do. And therein lies the struggle. What is it that defines me? Is it doing five things in a weekend? Or is it accomplishing in the weekend that which I originally planned? So that I can still be a full and whole person if I did what I plan to do, even if that's less than what it would have been 10 years ago.”

This constant ebb and flow and struggle of reconciling one’s self-worth while grieving one’s past life and abilities was further illuminated by Matthew as he described his difficulty maintaining his self-esteem in the face of his lost abilities:

“You're just stuck in this middle ground that, 'okay, I'm worthless,' then 'oh, no, I got this,' and then, 'I'm worthless.' So, it's an ongoing, never-ending situation. I don't see anything other than if I was to get back into my old life, to get over it. I don't think anything will change my mind, no matter how much therapy I go through. That the loss of being able to do stuff and then losing your confidence

because of that.”

In a similar vein to Stan’s early mentioned disappointment of not finding his passion in carpentry sooner (see Work Challenges), Matthew expressed disappointment and sadness that his ability to work ended to soon, stating:

“Having to retire early. The lost sense of income, the lost sense of what could I have done in these last 10 years or next eight years if I was to work to retirement in my life... That shouldn't have stopped naturally like that. It's not the natural order of what life is, per se, or how we've been brought up to view it as.”

He continued, “I probably would work til' my 70’s if it came down to it. But yeah, when you lose all that, it puts a twinge on accepting everything that has to do with Fibromyalgia.” Additionally, some participants emphasized how the feeling of identity loss and grief may be more severe for younger men because FM disrupts their lives at a time they expected (and are expected) to be in their physical prime and able to work. One participant captured this when he said, “guy's younger than me may have even a greater hit on their egos from that because it takes a while to get used to the fact that this is all I'm going to be able to do physically, mentally...”

### ***Social Impact***

Men with FM described a variety of ways FM impacted them on a social level. The social consequences of FM ranged from negative to positive in various social relationships (with friends, family, co-workers, healthcare providers, strangers). All of the men with FM referenced positive social supports in their lives, however, these will be discussed further in the Coping section. The following subordinate themes help to further

depict men's experiences and sense making process in this domain: *Social Stigma, Invalidating Responses, Relationship Strain and Loss.*

**Social Stigma.** This section includes men's experience of FM health-related stigma including real and/or perceived social stigma they've experienced from others including strangers, friends, family, partners, and healthcare providers. Some of the ways men experienced social stigma were by perceptions of others that they were broken/damaged, being treated differently, viewed as having a women's disease, being viewed as lazy, being ridiculed or devalued through statements or jokes, and being dismissed. For instance, Stan noted, "it seems like every lady that I've come across, they want somebody healthy. They want somebody that has a job and makes a lot of money. And they don't want somebody, as my ex put it, 'broken.'" The rejection Stan experienced in romantic relationships was also experienced more broadly when he was no longer able to work. He shared how after he got his disability, he felt like, "I wasn't even a part of society. It's like I got kicked out. Shunned." Similarly, Matthew noted, "it has taken its toll just because of the loss of being part of society." Matthew and Stan both reflected how social stigma is entwined with the experience of identity loss and strain.

Men also shared about actual and anticipated stigmatizing views from others related to having FM. For instance, Jim shared how strangers viewed him negatively when he would use assistive devices to help him get around. He noted, "People stare me down. Like what? Why the hell do you have a cane? Why are you riding in a scooter?" He noted the way this impacted him, stating, "How I felt the beginning- judged, disrespected. Only because it was not something I experienced before." Matthew and

Trevor shared their sense making process about the stigmatizing view and misperception that men with FM are “lazy.” For instance, Matthew reflected on how internalizing stigmatizing views of others impacts him, stating, “I think it does affect a man's sense of well-being, of self. That they're, they're told, 'oh, you're lazy.’” Trevor shared:

“Society's view of men being the breadwinner is still predominant, even if it's less true today, it's still culturally the view of things. So, when you see someone like myself, who's no longer holding a 9-5 job, it's like, what are you doing? Why aren't you out there working? You're in your 40s, you're much too young to retire. So, I think someone who kind of looked at my situation but didn't know any better might accuse me of being lazy, or a bum I guess, or just not holding up my end of society's contract.”

Men’s actual experience of enacted stigma by others varied quite a bit. While some of the men referenced actions by others that explicitly represented societal stigma towards men with FM, others experienced it more indirectly by observing the experiences of other men with FM. Additionally, some men identified factors that served to protect them from experiencing stigma. For instance, Gregory’s FM began impacting him at the start of the pandemic and due to social distancing ordinances, he was less in the public sphere for his symptoms or life adjustments to be noticed. He shared, “I've read the horror stories of other guys. And I'm relatively fortunate to have been in isolation when this changed everything.” Similarly, Trevor noted how the pandemic as well as relocating lessened the public display of FM impacting him.

**Factors that Influence FM Social Stigma.** Men with FM identified several

factors which they believe contribute to why they experience stigma. Two of the predominate factors discussed were FM being an invisible illness and the lack of representation of men with FM.

*Invisible Illness.* Almost all of the participants made sense of other's negative views towards them as resulting from the concealability of their illness. There are no obvious outward markers of having FM or being in constant pain. As Stan noted, "we look normal. That's the bad part about it. We look healthy." Matthew echoed this, "Yeah, I look fine. I look perfectly healthy. I stand up, look like I'm a healthy guy... I've got a decent build. I've kept myself in shape." He noted how this leads people's disbelief and faulty assumption such as, "Oh he can't be like that... Why are you so lazy?" Similarly, Trevor stated, "You don't look like you're living in constant pain... when I'm out with a cane, that's kind of a giveaway that something's going on. But it's not always as obvious what I deal with." Trevor noted a particular experience when he asked a stranger at a coffee shop to stop kicking him and the person replied, "I'm lightly tapping you... It couldn't possibly hurt." He reasoned, "that's one way you could say, I dealt with a session of intolerance. But they didn't even know to be tolerant. I was sitting down, they didn't see the cane under the table or know anything about me."

Even in instances when men with FM did show outward displays of their condition, such as using assistive devices, or disclosing their pain or FM to others, it was often responded to with contempt, disbelief, or minimization. Matthew shared how people have looked at him "with disdain" in the past when he's verbalized about his pain



because it's hard for people to believe or understand how someone who looks like him could be in so much pain. He further shared:

“From the years previous where doctors didn't even give it a thought, that it was just some bull\*\*\*\*- it's gotten better now but there's still a stigma as far as, 'You look healthy guy, you can't be in that much pain.’”

Trevor eloquently summarized how the invisibility of FM contributes to stigma:

“I think that it's very easy to fall into the trap of seeing someone, not knowing what's going on in their life, and saying, they're lazy, or they're a bum or, why are they working? Why aren't they doing this? Why are they doing that? I think that these kind of invisible diseases in general, man or woman, contribute to that.”

***Lack of Representation of Men with FM.*** All the men shared how the lack of representation, including the lack of information/resources specific to men with FM influenced stigma. Not only was this noted to contribute to social stigma, but it also contributed to internalized stigma of having “a women's disease” and exacerbated difficulties with understanding and adjusting to living with FM. Trevor, Stan, Matthew, Fred and Gregory acknowledged there is a lack of discussion, research, and understanding of men with FM or how to treat men with FM effectively. Trevor asserted, “there's not enough information about what causes this because there aren't enough studies. I'm actually on one medication of which there was like one study.” Stan similarly stated, “it seems like they still don't do the research on guys, on men. It's mainly focused on the women and helping them.” Matthew stated, “I know there's a lot more known towards the effects on woman more so than men because of the higher percentage of

woman that tend to have this condition.” Fred noted, “I don't know that I've ever seen anything in mass media about Fibromyalgia that included guys... What drug ads I've seen that target Fibromyalgia tend to have women in them.”

Gregory shared he could not identify with the majority of FM information he found as it was all tailored to women:

“I was googling stuff, all of the body charts, the images that are used in all of the reports and the blogs, it was showing women's bodies. It wasn't showing any men's [bodies]. And you know what, I'll use a phrase without guilt, but it made me feel, I have got women's disorder... And I was given no help, no resources by the specialists, so I was having to find my own. And the ones I was seeing, I couldn't identify with because they were showing you will get breast sensitivity, and you'll have urinary tract pain, and they were putting all these hotspots on these women's bodies and talking about women's issues. And physically I don't identify myself here. I've got very different behaviors in my body. And it just made me think there's a huge lack of male testimonies.”

Participants noted several consequences of the lack of representation of men with FM and FM being characterized as a “women’s disease.” As noted above by Gregory, it caused confusion and made it difficult for men to find helpful resources to better understand their condition or how to treat it. Jim and Gregory shared how they struggled to find support even within the FM community. Gregory noted the first Fibromyalgia Facebook group he joined provided little help because of how much it centered on women’s issues. He stated, “I felt fraudulent, and awkward, and I felt emasculated.

Because I couldn't find any resources to show that men had a legitimate, different experience.” Jim shared that he felt unwelcomed in an FM online support groups because he was a man. He shared, “in the beginning there was only women's groups, so I joined, and they were giving me flack, so I got out of it... They definitely didn't appreciate us [men] being in their group.” This relates to another consequence several men noted - receiving more skepticism. For instance, Jim stated, “I think we're less believed than women. I think that for a lot of women, just-- it's a woman's disease, and that's how it's seen a lot of time.” Matthew voiced agreement, stating, “I believe [men get] 100% more skepticism. There's no doubt in my mind about that, especially in relation to medical care.” Additionally, Matthew shared his belief that medical providers may also be skeptical because of his rugged appearance, thus further reflecting the notion that the invisibility of FM can contribute to being treated indifferently, lack of empathy and disbelief, and this may be even more pervasive for men who activate socially constructed biases/masculine gender ideologies in others by their outward appearance.

Another consequence of the lack of men with FM being exemplified in healthcare materials and research that participants described was internalizing stigma and concern for further social stigma. For instance, Gregory recalled:

“I knew, due to whatever internal sexism that my brothers, or husband, would see me sharing diagrams of women, and there's me saying, I match to this. And I was just really upset to be to not see myself out there in on the internet, as being a candidate to have this. And now I can't even use any resources to educate people,

my nearest and dearest. And I felt embarrassed even more if I couldn't see any evidence of it being a guy thing.”

As Fred was discussing the dearth of research on men with FM he reflected, “I think perpetuates that stereotype that it's a woman's disease.” He went on to share a powerful statement reflecting how gender bias in medicine, masculinity concerns, and stigma may interact and contribute to compromised care for men with FM:

“There are doctors out there that don't think men get it. So, if they don't think men can have this condition, then they're not going to look for it. And if they don't look for it, then they're not going to be able to diagnose it. And if they DO know that men get this, so they are looking for it, then men should also be comfortable with seeking a doctor saying, I think this is what I have. Or should be comfortable being told by a doctor, "this is what I think you have." Because of the whole "toxic masculinity" and this kind of thing being seen as a weakness maybe, I think there are more men that suffer from this than either know it, or are willing to admit it, or both.”

Fred shared how the lack of men represented with FM was a motivating factor for him to serve on panel at a medical University conference, “I wanted there to be at least one guy on the stage that wasn't there as a support person for his significant other.” He emphasized, “I wanted the medical doctors to see at least one guy that's affected by this directly.”

**Invalidating Responses from Others.** Men with FM also described regularly experiencing invalidating responses from others. Many of the invalidating responses from

healthcare providers are described in the earlier theme, *Frustration with Healthcare Experience*. However, men also noted invalidating responses from others at home, in the workplace, and in public settings. These were experienced in the form of others discounting their pain, not being believed, being questioned or confronted by others, others offering overly simplified advice/solutions, or making hurtful, misinformed, or unhelpful remarks.

For instance, Gregory shared how his husband and brothers “will tease me about, ‘Oh, still not working, eh?’” While he assured the jokes and teasing are in good fun, he also expressed some annoyance with these comments as he stated, “I would like to earn a bit of money so that my husband can shut up and stop playing that jokey card, which has worn very thin.” Trevor noted similar annoyance with the oversimplified advice from people asking, “Have you tried yoga?” He commented, “this is some of the lack of support [people with FM] get from their associates or family. It's almost a running joke at this point on some of the fibro forums - [the question] have you tried yoga?” Matthew noted how his friends, family, and/or girlfriends would often respond to his pain complaints by talking about their own pain. While their intention may have been to forge connection over a shared experience, the impact was the opposite. For Matthew, this style of responding felt like others were discounting and diminishing his pain experience because their acute, isolated pain was being inappropriately compared to his chronic, widespread pain. He noted how this sort of “comparison shopping” response has become a reason he is less open about outwardly expressing his pain:

“As much as I talk to family and friends, they still don't understand what Fibromyalgia, or chronic pain, or chronic fatigue actually is. When you get, "Oh yeah, I did this and it does this," and trying to have competition on it, it tends to shut you up from wanting to say stuff, like talk to others.”

Other forms of invalidating responses men with FM experienced were not being believed, being questioned, or being confronted by others. For instance, Matthew expressed, “‘It's all in your head buddy.’ That's what it is. ‘It's all in your head.’ That's how I see society views it [FM].” He also shared frustration over feeling like his condition was questioned by people close to him, stating, “how can you question me on something like that? You know what type of person I am. That's with personal people I knew. Even places I worked at.” Fred similarly shared feeling challenged by his assertion of having FM by a work colleague:

“When I first got diagnosed, somebody... I forget how it came about, but somebody challenged me. I said you know that I wasn't feeling well, I have fibromyalgia and his response was, "Well, I thought that was a woman's problem." And it was the first time somebody confronted me like that.”

***People Don't Try to Understand.*** Another invalidating response men with FM experienced was a general lack of understanding and empathy from others. Men conveyed feelings of frustration, sadness, and feeling alone in response to these experiences. As noted throughout by Gregory, he experienced this in his medical encounter when being given his FM diagnosis, yet feeling he was not being treated as a human. Matthew also experienced low empathy from healthcare providers. Fred shared

hope that increased attention is being given to training medical professionals on showing empathy, and he is involved in a program conducting this training. Jim expressed feeling hurt by the negative looks he has gotten from people. He shared, “It's like you see little people, you know, and people stare at them. I watch Little People Big World and people call them "midgets" and stuff like that. It's so disrespectful. And it's kind of like that situation, you know?”

Fred, Matthew, Jim and Stan conveyed how lack of empathy on a societal level, or personal level in their relationships is connected to masculine ideologies and influences the stigmatizing messages they have received. For instance, Matthew noted, “For years, it's like your lost in a different world because of the lack of understanding.” Stan expressed:

“It's just frustrating that people won't understand it or can't understand it. And most of the time, it's won't, because they don't want to believe that something like that can happen to a guy. Especially if it's another guy. Or like, one guy said to me, "That must be like stripping away your manhood.”

Men with FM articulated that they just want to be treated normal, with respect and understanding. Trevor made mention of how people with long COVID are showing lingering symptoms that individuals with FM experience and stated, “I'm hoping that one of the positive outcomes of this pandemic might be a little more sympathy in the in society.”

**Relationship Strain and Social Loss.** The majority of participants shared about relationship strain and/or losses as they became less able to engage in social activities or

roles at work/home because of their FM, or when relationships deteriorated due to the burden FM placed on it. For example, Matthew noted, “I read about all the divorces going on all the time with these people on these blogs that I’m on. How much it has destroyed their inter-relationships with others because of the lack of understanding.” Stan shared, “it really affected a marriage. It puts a lot of strain on a marriage. Four years ago, I got divorced because of that. She just walked out and said, ‘I want somebody healthy’.” Fred also shared the most significant change in how he was treated because of having FM was his ex-wife leaving:

“She punched out right at the beginning of a medical crisis. And I honestly believe that, among other reasons for divorcing, part of it was living with a guy with fibromyalgia. It’s that she didn’t want to have to take care of somebody. So that’s the single and most extreme [example of] being treated differently by somebody is that she was okay when I first figured out what it was and got it under control, but when it started to slide, I think that was just one of many straws that broke the camel’s back. And she peaced out.”

The other three men (Trevor, Gregory and Jim) shared that while they’re spouses have stuck with them and supported them, FM did add stress to the relationship. As noted previously, this was typically surrounding finances and/or intimacy challenges. However, men also shared how their FM symptoms and life adjustments they had to make were frustrating for their partners at times. For instance, Gregory noted, “on good days he’s supportive. Some days, he’s like, ‘Oh, God, why can’t you just come and help me?’ So, he does get frustrated in his own ways.” Jim also shared, “I understand my wife is at a point



where she can't help herself, and I don't blame her, but she'll say something like, 'Oh, well I hope this doesn't interfere with your nap.'" Trevor shared how when him and his wife were first dating, he would come home at the end of the work week, "and Saturday and Sunday I'd be like a zombie. I would just sit there and have no energy, and could not do anything, and it was very frustrating for her." He continued, "it was very frustrating for her because she doesn't want to live her life like that, and I don't blame her. Where I'm either at work, or I'm at home but not here."

Fred and Stan also experienced changes in their friendships. For instance, Fred shared, "when I quit working, I fell off the radar. Nobody called, nobody checked up on me. I basically fell into a deep hole. Like literally I disappeared from the office. And nobody called to check up on me, nobody." Stan similarly recalled, "I had friends on Facebook that I worked with. And then, I posted I was disabled, and POOF, they're gone." He added, "once somebody finds out that you do have [FM] and they know what it is, they don't really talk to you again. It's really strange." He recalled the following story to further illustrate this:

"A couple summers ago, I was out fishing. And I was having a good day, so I didn't have my cane with me. And I bend down and a little twinge of pain in my legs and he [another man fishing] said, 'What's wrong with you?' And so we started talking, and after I informed him what Fibromyalgia was, he just packed up everything and left. He didn't say bye to me or anything. He just reeled it in, packed it up, and left. Like, he was afraid he was going to catch it. And I told him

it's genetic, it's not contagious. He just kept walking. So, it's just really hard for me to make any friends... And we need friends too.”

Based on men’s descriptions, stigma from others surrounding being a man with FM, or being on disability due to FM resulted in various social losses.

### **Post-Diagnosis Living: Coping**

Men with FM adopted several coping strategies to help them navigate living with FM. The various strategies are organized by strategies they used for *Adjusting to Physical Aspects of FM*, *Coping with Psychosocial Aspects of FM* and *Coping with Stigma and Masculinity Threats*. It is important to note however the interconnected bidirectional relationship between adaptive strategies for coping with the physical and psychosocial aspects of FM. While stigma and masculinity threats are indeed a psychosocial aspect of FM, special attention was given to the ways men with FM cope with these experiences as they were a central focus of this study.

#### ***Adjusting to Physical Aspects of FM***

Men responded to the physical symptoms and limitations imposed by FM in a multitude of ways. Moreover, men described how their coping strategies have changed over time or fluctuated depending on other internal and external factors (e.g., how they are feeling physically or emotionally, weather). Subordinate themes that inform this superordinate theme include: *Navigating Physical Activity* and *Gaining Understanding and Control*.

**Navigating Physical Activity.** Men exhibited three primary ways of responding to pain from a physical standpoint. They either avoided movement, pushed through pain,

or used activity pacing. Part of adapting to FM for men involved changes in these responses over time and across contexts.

***Avoiding Movement.*** Several of the men noted that when they had no control over their pain, they coped by avoiding movement entirely. For instance, Gregory described how early in his FM journey before he learned how to use his “credit system” method, he noted, “I felt the only control I had that was non-toxic was to just lie down.” He makes sense of this looking back on his experience, noting:

“I felt I was becoming a prisoner. And you know, very, very cautious. Just didn't dare do anything. Didn't dare go out for the day to see a park or any of [the city's] beautiful things. I was becoming housebound through choice and nervousness.”

For Gregory this has changed over time as he has found ways to pace his activity and disrupt the pattern of fear-avoidance. Stan shared how the weather vastly dictates his sense of control regarding pain and activity. He stated, “Pretty much on bad days I just sit on the couch. Likewise, Trevor identified avoiding much physical activity on “bad days.” He shared, “You know, even little things like my wife, she's constantly serving me dinner and bringing it to me, so I don't have to move.” Jim also expressed anticipation of increased pain causes concern he will not be able to follow through with physical therapy. Jim stated, “I'm rehabbing my upper body, the gym is the next step, I fear that the pain will become excruciating, and I'll have to stop.”

***Pushing Through Pain.*** On the opposite end of the spectrum, some men also noted times when they coped by pushing through pain. This behavior was described as a

helpful strength in some situations. For instance, Matthew viewed pushing through his pain as a positive asset engrained in him from his military experience. He stated:

That's probably the biggest thing that has helped me is going back on those lessons I learned from all the physical aspects of what I did in the military - to push on, drive on no matter how much it hurt. And the pain, I can do it, it's just mind over matter.”

Other men, like Stan and Fred also described pushing through pain, but recognized negative effects of over-exerting themselves. For instance, Fred stated, “I can pretty much throw myself at something if I have to,” while noting the consequence of then needing an extended rest and recovery period. Similarly, Stan expressed:

Well, being a guy, you want to push through the pain. You want to work for your family, and provide for them, and do the lawn mowing, and the house maintenance, and the car maintenance. You just push and push until it finally catches up to you and pushes back.

Several factors influenced men to push through pain. For some men it was hard for them to make initial adjustments to slow down and do less than they previously could. As discussed previously, this is complicated by the notion that men struggle to separate their self-worth from what they can contribute/provide – physically, financially, or otherwise. This was felt by men as both an internal pressure they placed on themselves and an external pressure from others.

***Activity Pacing.*** As men learned to navigate these two extremes, they were able to find more balance between complete avoidance of movement and over-exerting themselves. For instance, Stan noted how when he first got his disability, “I'd always fight it and try to push through the pain, and try to do things, and it seemed like the

harder I tried, the worse it got.” When he learned to slow down and pace himself, he was able to adapt better. “Once you accept it and learn how, I guess you could say dance with it, you don't get your feet stepped on, and it flows more easily.” Similarly, Matthew noted that when he is more inactive, he experiences worsening pain. Gregory and Matthew adopted the understanding that their nervous system was sending them “false alarm” pain signals, which helped them overcome the fear of movement.

Jim expressed a similar philosophy when he stated, “Exercise - if it's possible for the patient - is the only way in which fibromyalgia patients see any movement towards normal levels.” However, he noted how difficult it is to maintain regular exercise because of the strong increase in pain intensity, while experiencing minimal improvements overall. This indicates that it can take a lot of time, patience, and trial and error to experience success with activity pacing.

Fred, Gregory and Matthew shared ways they have come to understand the way regular moderate activity benefits them and learning ways to accommodate for their individual needs. Fred and Gregory both did extensive self-studies where they tracked their symptoms, medication usage, activity levels and other factors. This helped them learn about their FM patterns and develop routines that worked for them to stay active without causing significant flare-ups, as well as scheduling in rest and recovery time. Fred noted, “I would track my activity level and I could see that if I really exerted myself hard for a day or two, it costs me a couple of days after.” Gregory shared his conceptualization of a “credit system” to guide how much activity he can safely perform each day:

“It's a feeling of, you've got x credits per day, if you're not flaring. If your body's in a flare it's in a punishment cycle, and you have none. So, you've got to find this line, your own line to stay underneath. And I really started to believe, and I supported this theory that you have a credit system within the central nervous system, once it's blown a fuse. The behavior has two patterns, if you stay under-exerted, then you've got this credit system in place, I figured out. But if you exceed it, if you ignore the warning signs in your knees, or you do something which really compromises your body, you can really burn through those credits.”

Several of the men echoed Gregory's sentiments about recognizing warning signs and “listening to your body.”

Similar to Fred, Matthew also noted having to factor post-recovery time, stating, “If I go out like to be among friends, like a normal party on a Friday night that takes me days to recover from. Because of just being active.” Fred noted how men with FM can vary in their pacing needs:

“Some folks [with FM] have to build in a couple of days *before* they want to do something, to prepare themselves, to be able to go and do something. I don't have kind of the pre-build, I have more of the post-recovery that I have to cope with.”

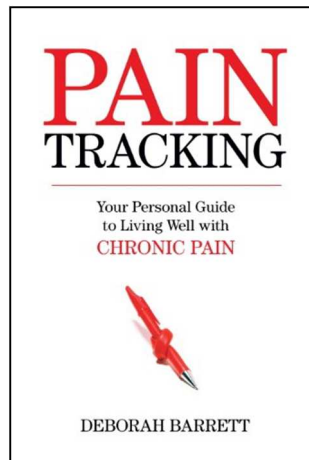
Men also noted ways they have adjusted activities to accommodate their physical limitations. For instance, when Matthew goes to play music with friends, he will take multiple trips to carry his equipment. Similarly, Fred noted, “I got to take a small chunk of four hours out of the day and do what can I do in that four hours.”

Successful pacing of activities required men to let go of ways they had been traditionally socialized to push through pain, overcome barriers of setting limits, and learning to saying no or accepting help at times. While difficult, when men were able to pace themselves, they experienced the benefit of not overdoing it and regained a sense of control over their physical bodies.

**Gaining Understanding and Control Through Trial and Error.** In addition to activity pacing, men noted several other ways they gained understanding of how FM functioned for them and learned strategies to help “tame it,” minimize pain flare-ups, and enhance their sense of control over the impact of FM on their lives. As mentioned, some men gained understanding through symptom tracking, self-studies, and online research to make ongoing trial and error adjustments to their medication and activity regimens. Fred and Gregory identified this journey towards understanding and control of their symptoms as particularly meaningful in their experiences of being men with FM, and they both shared mementos associated with this. Fred shared:

“The memento is I came across a book called "Pain Tracking: Your Personal Guide to Living Well With Chronic Pain," by Deborah Barrett. And it had a companion website that does not appear to be functioning any longer. In the book, what it tells you is all these different things that you can track and how you might track them. Joint pain, muscle pain. You can basically create your own custom survey for how you're feeling day to day. The website provided a place for you to build this survey and then take it every day. So that's what I did. I tracked my pain levels and my doctor and I work together on my blood chemistry, and after we

chipped away at a couple of things, she basically said, ‘You have fibromyalgia.’ So, she diagnosed it, relatively speaking, right out of the gate.”



*Figure 5: Fred's Memento (book cover found on Amazon.com)*

Similar to Fred’s research and self-study process that helped him arrive at a diagnosis, Gregory relied on a similar process to help him glean understanding:

“You asked me to think of something which I kind of symbolize in my fight and my journey with fibro. And it was quite clear, there was only one thing to me, which I lent on all the way throughout my very fortunate amount of time of me being my own experiment. So, I felt I owed it to myself and other people because I didn't really have any other advocates, and I couldn't get to see a doctor regularly because of COVID. So, in my self-diagnosis, I would lean on Wikipedia, I would be on Wikipedia almost every day, reading up on medications and what they're intended to do. So, I nominate Wikipedia as my crutch, my token, my support. And I triangulate that with Web MD, and NIH, and the [redacted] med systems, all the ones I trust. But Wikipedia was my... there's a



certain structure to it and I was able to contrast descriptions of things side by side, and I used that as my amateur detective doctor in me.”

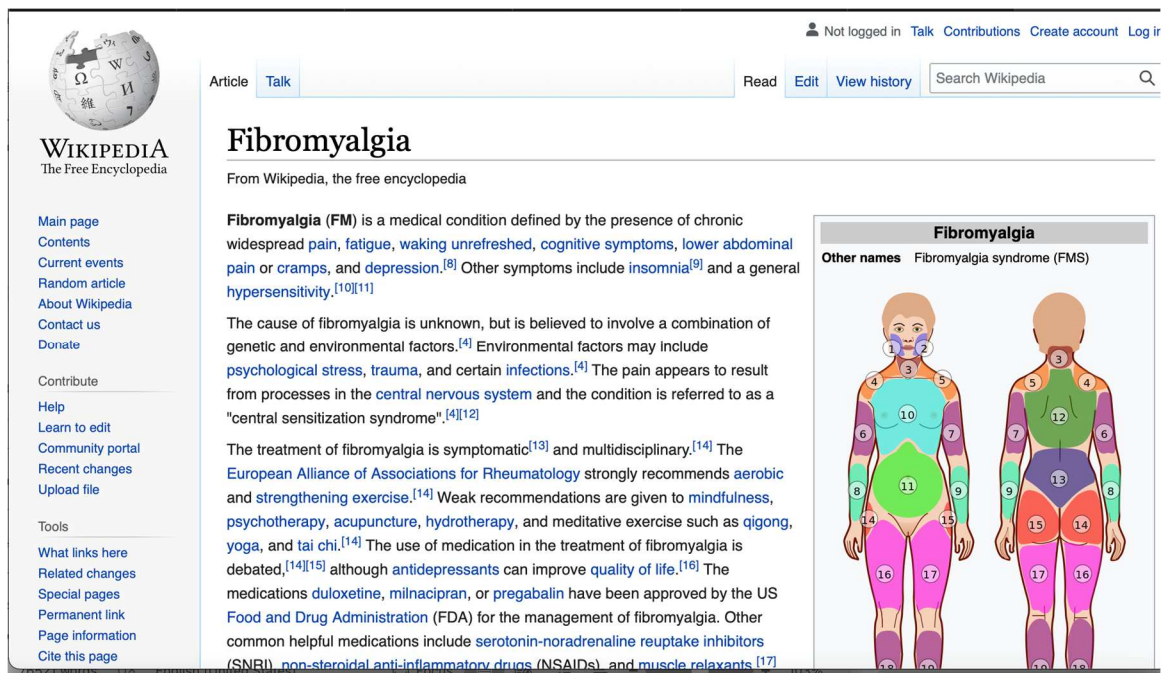


Figure 6:Gregory's Memento – Wikipedia

It should be noted that participant's sense of control over their FM varied, where some expressed feeling they had no control and others felt a manageable amount of control. All participants recognized FM as a complex, multi-faceted condition that could never be cured, thus no participant endorsed absolute control over FM's symptoms and impact. This illness perception allowed men to gain realistic expectations and hope around management of their pain and functioning. Additionally, some men's sense of control changed over time. The common course was initially feeling they had no control, yet as they learned more about FM their sense of control grew. All the men endorsed that since there is only so much they can control with the pain and physical aspects of FM, they have gained a sense of control by focusing their coping efforts on their emotional

wellbeing. This will be further discussed in subsequent sections, though noted here to highlight the importance of the mind-body connection when it comes to men with FM experiencing a sense of control. Some of the factors that helped them learn to manage the physical effects of FM included, medications, learning to recognize triggers, and planning (yet maintaining flexibility). Men described gaining understanding and control as an ongoing process of research and trial and error.

***Medications.*** One prominent trial and error process men with FM faced was figuring out a medication regiment that worked for them. Trevor described the process as, “Pure trial and error. We'll throw darts at a dartboard and see what sticks. There's no rhyme or reason.” He went on to say, “I've tried four or five different medications. I'm still on three or four. One of them wasn't working as well. So I tried something different. And we've threatened to try yet another different one. It's just a never-ending battle.”

While some men have found fairly successful medication regiments, others noted very minimal effects from medications. For instance, Jim shared, “They tried everything, just so you know. Every Fibromyalgia drug that's available doesn't work. So, then they say go for pain management. They tried me on every type of oxy. All it actually does is put me to sleep.” Conversely, Gregory stated, “My medical regimen and my fibro is so responding to my protocols, my best practices.” He explained how finding the right medication(s) is a frustrating trial and error process. “You probably won't get the first medicine to be right,” he noted. Yet once he found the right combination “it was like hitting oil – it felt as though I had control back.” Another factor men commonly experienced was negative side effects from the various medications they take, including

fatigue, sexual dysfunction, and at the extreme end negative drug interactions that resulted in hospitalization. Trevor provided a description of the challenging cost-benefit analysis that men with FM have to weigh when considering various pharmacotherapies: It's a frightening prospect, what medication could do to you, and I hate that I take so many meds. I really do. It interacts with me in so many different ways that I do not like, but at the same time, I think I'm better with it, that without it. So, it's a sort of a Faustian bargain here, where you really just can't help but, you just have to make the best of what you have and deal with the evils that come with it. Like there's one medication I'm on that basically makes me nauseous all the time, and I've lost my appetite. And I don't eat much anymore. But at the same time, what can I do? It's better than either getting worse, or dying, or dealing with pain. Depending on which medication we're talking about, and for what purpose, sometimes the side effects, as bad as they are, are better than dealing with the raw symptoms.

Because of the risk of side effects and limited effectiveness of many prescribed medications for FM, the majority of participants sought out alternative medicines to help with their pain. Stan for example shared, “I did my own research and started taking herbal medications. And I found the proper combination for me, because everyone's different.” Jim, Trevor, and Matthew also noted benefits of cannabis and/or CBD. Jim stated, “Medical Marijuana helps like 20 percent.” Trevor and Mathew both made a point to share they were purely using CBD/marijuana to cope with pain. Likewise, Trevor expressed:

“I don't do it at all to get high. That's not even remotely a thing for me. I've never, ever in my life would have imagined I was doing this kind of stuff. But here I am. I do it for medicinal reasons, and my doctors and so forth are supportive of that. They totally get it and they say - if it helps, do it.”

***Identifying Triggers.*** Learning about their individual FM triggers also helped men gain a sense of control. For example, Matthew noted that his work with his therapist has helped him discover triggers that impact his pain and his mood. Several participants referenced the effects of weather or temperature changes on their pain, however as noted by many “it affects everyone differently.” Some men’s pain was intensified by the cold, rain, or wind, while others pain was more sensitive to heat. Fred and Stan both shared how the rain negatively impacts their pain and how tracking the weather allows them to better plan for when they will be able to do more. Fred shared:

“I actually tracked barometric pressure and discovered that it's a factor in my pain levels. And it's usually a pressure drop, it's usually when the storm comes it has an effect on me. So I learned to keep an eye on the weather, and see what the weather is looking like three days out five days out, you know, so I can kind of plan for - okay, the weather looks like it's gonna go south, that may be a bad day.”

Trevor shared, “Heat heals me. So I love being in the heat. I don't mind being in Vegas in July. I'm out in the sun, and I feel wonderful!” Conversely, heat has the opposite effect on Jim:

“For me it's like a fire. Literally, it feels like my skin is on fire. So, I gotta watch with the sun now, because I can't expose my skin to the sun. I bought long sleeve

UV resistant shirts that I can wear to the beach. Because if I got a sunburn on top of this - Oowww. Yeah, it would be bad.”

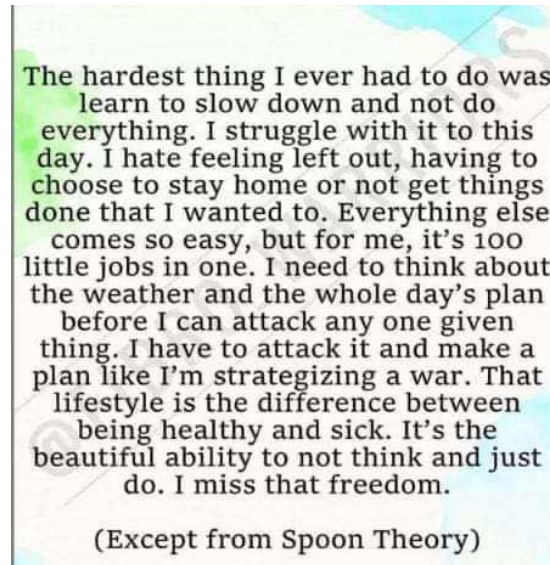
***Making Plans and Preparing to Break Plans.*** Planning was cited as a necessity for living successfully by all of the participants. As described earlier, men used methods of tracking their symptoms, identifying triggers, and scheduling daily activities in ways to avoid flare ups to help them structure their lives. For example, Matthew stated, “it's just a non-stop day of ... almost like a schedule that you're on. That okay, if I don't do this by this time, I'm going to be like this.” Adjusting to their limitations and planning accordingly was very much linked to an activity pacing approach.

While planning affords men with FM some degree of control, having to diligently plan was described as an inconvenience that many of them resented. For instance, Stan stated, “it's like a battle, you have to plan ahead. You got to think, 'Okay, what's the weather forecast? I can do things on these days.' So that's really the only control that you have over it is the planning.” However, men noted the importance of having flexibility and being prepared to have their plans change at any moment due to how they were feeling. For instance, Trevor stated, “plan some things but be prepared to cancel if you have to. And be flexible with your approach to things.” Fred echoed this, stating, “My life is constant contingency planning.” This was a shared experience for Jim as well, who emphasized the lack of freedom that comes with having to make or break plans:

“I'm not free to do whatever I want any single day. I mean, you plan a day to go somewhere and if I have a huge wave of fibromyalgia where three or four times a day I'm napping, then I just have to say - no, I can't do that today, sorry. And it

doesn't happen that frequently that I have to cancel plans, but it's always there in the background that I could.”

This is further depicted by Stan’s memento – which was a meme that resonated with him to summarize what it means for him to be a man with fibromyalgia. The quote he shared read:



*Figure 7: Stan’s Memento*

In sum, recognizing their pain triggers provided some ability to plan for potential flare-ups and for active time vs. rest time. However, having to operate daily with such strategery was paralleled to preparing for a war. Moreover, it was a war they did not enlist for, which made them resentful of the task. Moreover, men had to be ready to let go of plans at any time. Thus, recognizing the confines of managing their life around their FM was experienced as having limited freedom.

### ***Coping with Psychosocial Aspects of FM***

This superordinate theme captures the various coping responses men with FM used to adjust to pain related distress. That is, the personal, emotional, and social impact of FM (e.g., adjusting to changes in identity, relationships, work status, mental health symptoms, stigma, etc.). Strategies included *Perspective Taking*, *Acceptance*, *Focusing Externally*, *Meditation and Spirituality*, and *Social Support*.

**Perspective Taking.** One way that men with FM found helped them cope with the impact of various changes in their lives imposed by FM and the pain related distress was through perspective taking. This included finding ways to change their attitudes and/or mental outlook about living with FM, recognizing the positive life changes that have come from having FM, using humor, practicing gratitude, and learning to live more mindfully in the present. Men with FM emphasized the importance of making the best effort they can to have a positive attitude. For instance, Trevor noted, “you gotta keep a positive outlook on things.” Similarly, Jim reflected, “my practice in life is just being positive every day, as much as I can... I can wallow and just feel bad for myself or just move on and try and do the best I can.” Trevor and Jim also both noted how humor helps them have a better attitude. For instance, Jim stated, “I try and find some lightness. It's not easy. I'm telling you. It's not easy. But I find myself now able to laugh more.”

Another thing that helped give men with FM perspective and allow them to have a better attitude was recognizing their blessings. For instance, Jim shared, “there's always somebody worse off.” At least I can have some mobility, I can walk around. I can't run a marathon. I can't walk five miles. But you know, you got to look at the glass half full.” Likewise, Gregory noted, “there are people in much worse situations than myself. So,

that's put a cap on the amount of self-pity that I would normally permit myself.” Matthew shared how watching his nephew with quadriplegia go through life has reminded him to be grateful for the abilities he does still have when he stated, “So when I get in those moments of being really down in the dumps, I realized that - okay, my nephew was in much worse shape.” Trevor also noted, “I count my blessings. I definitely hear about the struggles of others.”

Another way men demonstrated perspective taking was by recognizing the positives that have come from living with FM. For instance, Jim and Gregory both referred to the way dealing with FM has allowed them to “be in the moment” and “live in the now.” Gregory and Stan described how in some ways FM has helped them improve themselves and their quality of life. For instance, Gregory noted, “I'm a better person I feel... I feel as though my understanding of life and the priorities has been permanently improved.” He continued:

“Maybe in some twisted way, this is a blessing. And it's a time for me to reevaluate my life. And to take better care of myself, not just taking on these big crazy, stressful deadline projects, stop jumping around, and actually enjoy your quality of life, of stability, and put some roots down and settle.”

Similarly, Stan noted:

“It just changes your outlook on life... I've slowed down quite a bit. And it's amazing how fast you move, and how much you miss. You miss your kid growing up. You miss all the beauty and nature. You miss the sunsets and sunrises. And now that I slowed down, it's like, wow, they are really nice!”



**Working Towards Acceptance.** All of the men with FM described the process of acceptance as an important coping mechanism. This included moving towards acceptance of the chronicity of FM, the changes in their physical and cognitive functioning, and the changes in their social and occupational functioning. All the men noted how acceptance was a difficult and ongoing process that constantly fluctuated. For example, when Fred was asked about how he copes with the realization that he must make “trade-offs” he stated, “On good days well, on bad days, not so well [laughs]. Yeah, I mean, that comes and goes, like other things. I've generally come to accept it. On good days it's not a problem.” Trevor reflected his grappling with acceptance when he stated, “It's almost like a cognitive dissonance, where I know that I have to compartmentalize and understand that there are days like this, but at the same time, I should be able to do all this stuff, what's the problem?” Matthew noted challenges with accepting the way FM has impacted his self-confidence when he said, “It tears a lot from you and it's kind of hard to come face to face, to accept that. Since I've had this condition, I've had a hard time accepting it, that this is my life.” However, at other times in the interview he made comments indicating he has come to terms with the physical impact of FM when he stated, “I wish I had a day that, hell, my body is kind of like normal again! But I don't expect that to ever happen. And that's alright.”

Trevor described his ability to accept his condition and the changes that come with it has improved over time yet can still present as more challenging at times. He noted this in his reaction to his doctor completing paperwork for him to get a handicap placard. He expressed, “that really took me a while to come around to accepting that.

That really upset me. Very, very much when I first got it. It's even still a little hard for me to swallow these days.”

Men also shared about the difficult process of accepting how their life was versus how they imagined it. For instance, Trevor stated, “it's not what I envisioned life to be, and it's not really what I want it to be.” He continued, “But at the same time, I understand that it is what it is, and I need to accept it, and kind of do my best.” Jim echoed Trevor’s sentiment, stating, “you just have to say, "it is what it is." That's my mother's saying - it is what it is. You can't change it, so just roll with it.” He also noted, “It kind of goes along with, it's out of my control. You have to let it go. You embrace it.” Stan noted what helps him embrace acceptance is thinking about his FM as “my sloppy lousy roommate.” He stated, “We need to accept we got that lousy roommate that we can't get rid of. Instead of fighting it, we need to work with it.”

Another way men demonstrated acceptance was through their understanding of FM as a chronic condition. “This is something that can be treated and improved, but never cured. So, you have to come to terms with adjusting your life appropriately,” Trevor noted. Jim added, “I think that's the number one mistake that people make is that they think there's going to be a pill, there's going to be something that's going to save the day. There isn't.” All the other participants were unified in this perception of FM, which allowed them to focus on ways of learning to live better with FM rather than trying to cure it.

**Meditation and Spirituality.** Another frequently mentioned behavior men with FM used that helped them cope with pain and help them find acceptance was practicing

meditation, mindfulness, or other spiritual practices. Matthew, Stan, and Jim each talked about using meditation to help them cope with pain and pain related distress. For instance, Jim reflected how meditation helps him to “just open up and just say - this is the way it is, I can't change it. I can't change it.” Matthew shared, “I do a lot of meditation. I meditate multiple times a day. I try to zone out... I have a lot of angry thoughts throughout the day, and that's where I have to go into that meditative state.” He also shared that using meditation has helped him self-reflect, have self-awareness, and engage in self-care, which have helped him cope with internalized stigma. Trevor and Matthew both noted they also practice Tai Chi. Trevor and Jim also have found benefits from yoga. Jim expressed sadness that he is no longer able to engage in the physical aspects of yoga, but continues to utilize the psychological aspects of listening to yoga tapes to guide him in his meditative practice. He noted, “meditation helps a lot. Just to clear your mind, and just breathe.” Similarly, Gregory has found gardening serves as his meditative practice. He shared:

“It was my kind of yoga. I was doing gentle activity in the garden. And it really suited me. So, it was kind of like a holistic discovery. And that was when I was really decided that mindfulness and wellness is something that has to be a permanent part of my life.”

In addition to meditation, Stan shared how he also has incorporated the spiritual practice of Druidry and having a connection with nature as a new “way of life” that has helped him cope with his circumstances:

“A couple of years ago a lot of things just hit rock bottom for me emotionally. So, you start doing a lot of searching possible church groups, and this and that, try to do something be interactive, and you want a religion that fits your way of thinking best. And I came across Druidry. The way that they think, and they react to things I really, really connected with. So, I took that up. And it's helped me out quite a bit too.”

**Focusing Externally.** Participants shared how engaging in activities that provided them a sense of meaning and purpose helped them cope with FM by improving their mood and by giving them something to focus on other than their pain. Some of the ways they did this was by finding new hobbies or work pursuits, spending time socializing, or focusing on helping others. Men found distraction from their pain by engaging in enjoyable activities. For instance, Stan noted, “I'll surf the internet on days like this to keep my mind off the pain. And look for recipes for the crock pot. Oh, I love the crock pot!” As mentioned, Gregory started a vegetable garden and noted, “I'm on this wonderful loop inside my head when there's something external to do.” Additionally, he shared how during the holiday season, “Christmas became my project. I've been so busy with it. And just having this as an external project, there were times where I'd I forget that I have fibromyalgia.” Furthermore, he described his pain as being less noticeable when his spouse was in the hospital and his focus was less on his own pain and more on helping his spouse recover. Jim noted a similar effect from “being in the moment.” He shared, “I try when I'm in a group with a group of people, like we went away with a couple, and we're all just having conversations and we're all laughing.” These statements

help demonstrate the power of mindfulness in managing their FM.

**Giving and Receiving Support.** Each of the men with FM in this study noted the importance of giving and receiving social support. Several men reported providing support to other men with FM helped them in their own adjustments and served as an additional way to focus on something external. Thus, giving support to others overlapped heavily with the previous theme. There were several ways men engaged to support other men with FM. Fred for instance shared that he has been highly active in work to educate the medical community about how to treat men with FM. Additionally, he finds fulfillment from being involved with FM advocacy. “I’ve also had an opportunity to go to the Hill to lobby for more funding for fibromyalgia research and education.” On a more personal level, Fred shared that he interacts with other men with FM through online social media support groups. Similarly, Gregory shared, “I help counsel and I mentor some people in the group that are new to the Fibro experience.” He also expressed:

“I’ve had a whole year wallowing in my own issues. I got a health breakthrough, which I feel proud about finding myself accidentally, and I want to do something again, I so badly want to manage a project, pass on my expertise and things that I’ve learned within the fibro community.”

In terms of receiving support, men in this study primarily experienced support from family, friends, and online support groups. However, the types and range of support men received varied across participants. Most men indicated they felt supported by their family, close friends, and current partners. For instance, Trevor stated, “My individual situation, among my circle of friends and family, is pretty good. I actually do get a lot of

support personally.” While Gregory noted times when his family or spouse have joked with him about his condition, he assured that his loved ones have shown him deep concern and have been very supportive of him. Family and friends sometimes provided men with instrumental support (e.g., helping them carry things), however, the importance of emotional support that made men with FM feel accepted and understood was emphasized. For instance, Jim shared:

“You know, your partner, or whoever you have, a parent, a partner, whoever, they're very important. They're very important as far as holding you up and saying, 'Oh, I understand. I understand you're going through this. I'm really sorry.' You know, but you got to give them a break, too.”

Similarly, Matthew expressed:

“I have a group of friends that are great about it. They don't sit there, 'Aw you're just you just hurt because of this.' They understand my background. My family is the same. My brothers said stuff at first and then they realized, 'Well God I grew up with this guy. He never complained when he was a kid when he was getting his ass whipped all the time so why would he complain about aches and pains unless it's something more.' So my family, my sisters, my girlfriend, they've given me a lot of support.”

Fred, Jim and Stan all discussed feeling supported by their children, though all of them mentioned feeling a sense of inner turmoil associated with their children having to support them as it at times elicited inner thoughts about being burdensome or their disappointment of not being able to father in ways they wished. Stan spoke of his

daughter, stating, “she's more accepting of people that have fibromyalgia than anyone I know.” While most men in this study have felt generally supported by loved ones, Fred and Stan both experienced their wives leaving when their FM worsened. As noted in previous sections, Matthew also noted times when his girlfriend or others would minimize his pain complaints through “comparison shopping.” Additionally, Stan noted that he lost several friends since having FM. Thus, the range of social support FM experienced from close others not only varied across participants but also across time.

Another predominant source of support men with FM referenced was being part of an online FM support group. Support groups served not only as a space to receive support but also to give support to other men with FM. Men found these support groups helped them cope with both the physical and psychosocial aspects of FM by providing a platform for exchanging information, problem solving, experiencing a sense of common humanity that they are not alone, and for giving and receiving emotional support. For instance, while Stan noted difficulty establishing friendships, he said he does feel a sense of support from being part of the Men with Fibromyalgia Facebook group. Gregory noted towards the end of our interview:

“I'm fine. And it's probably because of being with these fibro groups... No one's hiding behind anything, because we're all suffering the same thing. And we all want to help each other. So, there's nothing off limits. Everything is in the open for us in in a trusted space.”

Fred also noted that he provides others support by sharing information or helping them through similar emotional struggles he has experienced by providing a sense of

hope. The participants also all noted their ability to impart information to help other men with FM was a large motivator for their participation in this study.

### ***Coping with Stigma and Masculine Identity Threats***

This superordinate theme depicts the various ways men with FM coped with the experiences of stigma and threats to their masculine identity resulting from FM. This included *Coming out of Hiding*, *Communicating Challenges and Needs*, *Therapy*, *Regaining a Sense of Self Through Purpose and Acceptance*, and *Challenging Traditional Masculine Ideologies*. It should be noted that many of the coping themes depicted in the prior section assisted men in coping with stigma and masculine identity threats and/or strain in addition to more general psychosocial adjustments. Similarly, many of the coping strategies highlighted in this section were also helpful in coping with adjustments outside of stigma and masculinity concerns. While heavy overlap exists among these sections, they were separated to help account for which strategies were most used or helpful for men with FM in navigating the specific phenomena of interest pertaining to this study.

**Coming out of Hiding.** All the men with FM took measures to conceal their FM at one point or another as a form of social protection. Men shared several motivators to conceal their FM including that it was hard for them as men to talk about their emotions, to “avoid some of the misguided, but well intended sympathies” or other invalidating responses, and to avoid potential stigma. As noted previously, men with FM were often reluctant to disclose about their FM at work because of experiences of it being dismissed



or stigmatized. Several participants also hid their FM in other social settings. For instance, Trevor shared:

“One of the things you learn is just to be able to hide it. I mean, just socializing... Except maybe particularly on your very bad days, when it's beyond the level or you can hide it. But, when I'm out in public, I don't express nearly as much as I do in private, with just my wife around. So, I know that's sort of a mask that we all wear.”

Stan shared his beliefs about what compels him and other men to hide their FM: Guys don't want to lose their friends, their past life. So, they hide the FM no matter the consequences... The way that I have been viewed by other people once they find out I have FM is not kind. I am viewed as broken, damaged, no fun, afraid they will hurt me if I'm touched. So, I'm left alone.

Although the majority of the participants felt more comfortable being open with their family about their FM, this was still a challenge at times, primarily because of the ways men have been socialized to not show vulnerability and conceal their emotions.

Gregory depicted this as he shared about the beginning of his FM experience:

“I didn't talk openly to [my husband] or anybody else about it. I was just in this very meek, hibernating, spiral and it, but it made me realize that mental health is a significant factor in fibromyalgia, and it's just not cool or macho to talk about such things.”

Over time, men with FM noted how they have grown more comfortable sharing openly about their FM. For instance, Matthew shared how he has experienced a shift over

the years, stating, “When I first had it, I didn't tell anybody I had it. I tried like hell to cover up that it was bothering me. But in the last years, I've been more open about it with everybody.” Trevor and Jim expressed being comfortable with family knowing about their FM but feeling less comfortable showing it or letting it be known outside the home. Gregory shared, “I've gotten used to that transparency with people like you, who are stakeholders, who have a good, vested interest in advancement of all these areas. I wouldn't dare talk about that with just random people.” Other men echoed that they are selective with who they feel comfortable sharing about or discussing FM with. Participants seemed to feel most comfortable discussing their experience with other men with FM or with therapists.

***Communicating Challenges and Needs.*** Part of men's process of coming out of hiding was learning how to communicate with family, friends, partners and employers about their challenges (physical and emotional), limitations, and needs related to FM. This included communicating with employers about reasonable accommodations and being able to ask for help. Trevor, Gregory and Fred all talked about the process it has been to accept their limitations and communicate boundaries with how much they can do. “There are times where I just have to say- I can't do something today,” Trevor noted. Fred shared how as his kids have aged and understand more about his FM it has been easier to communicate with them about it, yet still finds it a challenge to balance how much he shares or asks of them when he stated, “I try not to lean on them, but I do in some cases. I want them to be kids, but there are sometimes where I really need to ask them to step up and I need their help.” As noted previously, other men were hesitant with

how much and how often they shared with their family and kids or asked for help because they did not want to be perceived as a burden or feel dependent.

As mentioned, several men pushed themselves through their pain in order to maintain employment, and it was a difficult transition for them to have to slow down at work or go on disability. It was also difficult for men to navigate how much to disclose to employers about their FM. Stan shared how negative responses he received in one job setting made him reluctant to reveal his condition to future employers. He recalled his bosses who “were all male, they just blew it off like I was just making it up. Even though I did have the medical papers to back it up.” Men in blue collar jobs (Matthew, Stan and Jim) experienced greater difficulty with this, as there were greater physical expectations of them in their positions. Moreover, these were noted to be more hypermasculine industries, which further challenged their security around sharing about their FM or requesting accommodations.

Fred shared that the way his pain and “fogginess” affected him and “it would sometimes be misinterpreted as me being angry or hostile to my co-workers.” He shared: “One pivotal time that comes to mind is that I was in a lot of pain, and I was struggling to speak, and my chief engineer misinterpreted my body language. He started going down a path of like, “Look, I can tell you're angry, I can see you're upset.” And I'm like, “No I'm not angry, I'm not upset. I'm struggling with trying to decide how much information to share with you without sharing too much information.” And he's looking at me puzzled, I'm like, “Okay, I have a condition. I live with chronic pain. I am in a shit ton of pain today. I am having a hard time

forming sentences. And that's what's affecting this conversation that we're having. I'm not upset about anything, I'm not angry with anybody. I'm just struggling, physically and emotionally, in this particular situation."

Some men have found that as they have opened up and shared more about their FM it has been helpful to them in many ways, including improving their mental health, quality of life, interpersonal experiences, and regaining a positive sense of self as a man living with FM. For instance, Stan noted, "I look at it as education. If you inform somebody else how it affects you, in turn, they know how to treat you... Because most people they don't know about fibromyalgia. They don't know how it affects people." Matthew shared, "it does help. Also, with the mental health aspect, to really try to talk about it, and allow others to know what it's about." Similarly, Fred shared:

"I got some reasonable accommodations, which brought up the quality of life.

And that became a period where I shared a little bit more. If people asked, I would tell them what was going on. So more of my co-workers were aware of my situation... the more open I've been about it the better people have reacted to it."

Having an understanding employer and being granted reasonable accommodations served as a corrective experience for him. Moreover, this helped him feel safer to disclose about his FM, which in turn lessened the likelihood for people to make faulty assumptions.

Fred also shared strategies he has developed to help him navigate how much to share with people when they ask how is doing. For example, on bad days he will respond using phrases like, "'I've been better, I've been worse," or "I'm in good shape for the

shape I'm in." He explained how this helps him, "get to be honest to myself, without burdening somebody unnecessarily." He noted how this gives others the opportunity to ask what he means "if they care enough. And if they were just saying that as a way of saying, hello, it's no skin off their nose, and I still get to express myself." Stan and Fred noted how their comfort of making their FM known is highly motivated by their efforts to reduce stigma of men with FM by educating others about what FM is, that it does indeed impact men, and how it affects them.

**Therapy.** A majority of the participants (Trevor, Fred, Matthew, and Jim) shared openly about being in therapy to help them learn strategies to manage pain. Based on what men shared, a large part of therapy was helping them cope with the psychosocial impact of FM. This included learning how to cope with life adjustments and emotional distress related to FM, which often involved navigating experiences of stigma and FM's impact on men's identity and self-esteem.

Men who were actively engaged in therapy noted the benefit of having someone to openly talk with about the impact FM had on their sense of self-worth, and to cope with the subsequent impact low self-worth had on their moods. For instance, Matthew stated, "being able to talk about it, and find some direction to allow myself to fix myself, per se, mentally because this is a very devastating illness towards yourself." When talking about feeling like "less than the man I should be," he stated, "Oh, that's an ongoing thought. That's one of the reasons I'm talking to therapist. Trying to get through that." He shared how therapy provided him a space to cultivate self-awareness, which strengthens his use of other coping strategies (e.g., meditation) when needed. When Fred

was asked what it is like talking about the impact FM has had on his role as a father he noted, “That's what my therapist is for. He's my objective third party who can help me take the emotions apart and look at them... my takeaway from it is that I can work through some of these thoughts and some of these issues that I maybe didn't think of before.” He also noted the benefit of “just being able to talk to somebody and discuss what is bothering you” on helping him combat the depression related to FM. Matthew similarly noted how therapy has served to help him find a sense of control over pain by “trying to keep good attitude.” Trevor shared how not only has his pain psychologist helped him come to terms with having this chronic disease and making adjustments, it has also helped him better cope with the guilt he experiences by remembering to “don't beat myself up so much.” Jim also sang praises to the positive effect of being in therapy. He noted, “therapy opened doors which allowed me the strength to cope with fibromyalgia. Leaving darkness to embrace the light.” He also encouraged:

“I think that anyone who has Fibromyalgia should be in counseling. At least in the beginning. And if you're having some real difficulties, if you're having self-image problems, and you're having just feelings, you can't deal with what's going on. You need somebody to talk to.”

**Regaining a Sense of Self Through Purpose and Acceptance.** This theme represents ways that men with FM have worked to re-establish their sense of self that FM shattered at times. One of the ways men accomplished this was by finding new ways to meaningfully engage in life. As mentioned, Gregory began re-building his ego through growing a vegetable garden. Showing off his vegetables on social media served as a

symbolic way of showing to others he was okay and “on top of something.” This helped him re-establish his self-efficacy and positive sense of self. Moreover, he gained a sense of purpose by contributing his excess harvest to the community. Gregory also found purpose mentoring newly diagnosed men with FM and spoke of how eager he was to return to work. Similarly, Fred and Trevor have transitioned to new work roles that are sustainable and can flexibly accommodate their needs. Trevor shared he maintains a positive sense of self by “Keeping busy. Reinventing myself. I was doing a little bit of teaching bridge classes... Rebuilding my career. Finding a different path.” Fred shared, “what I've been doing recently, has been just setting small goals, just setting, you know, these are two things I want to get done this week.” Finding a new sense of purpose and accomplishment that was *not* dependent on traditional masculine ideologies like how much they could do physically or provide financially helped men with FM maintain a positive sense of self and establish a sense of self-acceptance.

Acceptance was discussed previously as a general coping response for coming to terms with life changes resulting from FM. This coping style was also used by men with FM in response to experiences of social stigma to protect against internalized stigma. Acceptance also helped men preserve a positive self-identity against experiences of masculine gender role strain. Interestingly, the ways acceptance manifested as a mechanism towards regaining a positive sense of self for men with FM was either a combination or vacillation between integrating FM as part of their identity and depersonalizing FM from defining them. Fred stated this best when he asserted, “it defines me, and it doesn't.”

*Integrating FM Minus the Stigma.* was expressed by adopting a “self-as-context” perspective that helped them detach from experiences or internalized feelings of stigma. Additionally, taking a “self-as-context” perspective involved men distinguishing between the symptoms they experience and their sense of self. Some men did this by reminding themselves that having FM is not a personal failure, which assisted them in relinquishing self-blame, guilt/shame, and protected against internalized stigma. Trevor captured this when he was asked how he copes with feeling devalued and shared:

“I would say the overall answer would be poorly but trying to get better at coping with it. But knowing I'm not alone, that's a big part of it. Knowing that it's not a character flaw... it's very reassuring from a mental standpoint to know that this isn't a failure, this isn't a reflection on me. I can, at least on a mental level except that, which over time helps ingrain it a little bit better. I still have my moments of doubt and darkness. The thoughts 'I should be doing much more.' But overall, I think that these days I'm much more accepting of it and realize that there are just times I have to ask for help. And that's just the world. And it's okay.”

Men also demonstrated this acceptance stance through their recognition that other people's thoughts and behaviors are beyond their control. Reminding themselves of this helped men with FM detach from derogatory comments that felt stigmatizing or emasculating. For instance, Stan shared, “I just got to remind myself that it's nothing that I'm doing wrong. Other people's non-acceptance of me... Like the people that walk away from me. It's not my problem, it's their problem, their way of thinking.” Reminding himself when other people's thoughts and actions are out of his control helps him deflect



this from negatively impacting his sense of self. Similarly, when Jim was discussing his response to people giving him “the side eye” when he is using a scooter he stated:

“I just can't take that personally, you know? That's on them if they want to act like there's something wrong with me. That's on them. I know that I'm disabled, and I have fibro, and that's just the way it is. I can't change how other people view me.”

Matthew echoed this in the following statement:

“I don't really care if you think it's real or not. I know it's real. So, the rest of y'all that don't believe it, you can all just you know kick bricks and get on down the road because I ain't got time to worry about you thinking that I'm faking my condition cuz that's too much brainpower to waste on s\*\*t like that.”

Although it is a constant process, men with FM described how acceptance also allowed them to integrate the grief of their changed abilities, roles, and identity. For some men this involved embracing their disability identity or accepting FM as part of their identity without attaching negatively to it. For instance, Fred shared, “I guess that's been an evolution of, maybe the meaning of fibromyalgia in my life, is that it's part of me.”

Similarly, Jim stated:

“As far as having a true sense of identity, I see myself as disabled. I don't see myself as crippled. But I see myself as disabled. That's my identity now... I wish I could have a different view of myself than a disabled person, but I don't take it in a negative way.”

Embracing FM as part of their identity also allowed them to “come out of hiding” by publicizing their FM without shame. For instance, Stan shared how he now has a

tattoo that says “FM” on his forearm. In a similar way, Fred noted he will wear certain shirts that indicate he has FM, put up FM fundraiser posters at work, or wear the purple ribbon for FM support.

Several other men noted how they have come to accept FM and the changes it has brought as part of their life while working to not allow FM-related changes to completely define their self-worth. This is very much intertwined with the more general coping response of perspective taking, but highlights how this helped men cope with stigma and identity concerns in men with FM. These processes of finding new purpose and meaning, acceptance, depersonalization, and integrating FM as *part* of their identity or lived experience were important coping methods for men with FM.

**Challenging Traditional Masculine Ideologies.** Another way men coped with stigma and masculinity concerns was by deconstructing and renegotiating their beliefs about how men “should be” and confronting stigmatizing messages. Several of the ways men demonstrated this are captured across other themes in this section (e.g., *coming out of hiding, communicating challenges and needs, therapy*). Additional ways men in this study exhibited this was by being in touch with their feeling, relinquishing the need to be stoic all the time, viewing help seeking as a positive, un-equating vulnerability with weakness, and abandoning the dichotomy of men work and women’s work.

Stan talked about how by not associating certain types of jobs with a certain gender it minimized feelings of masculine gender role strain. He shared:

“Doing jobs and doing stuff around the house really didn't bother me because I did 'women's jobs' too. Actually, I think helped me out with transitioning from

work outside the home, to work in the home. Because I knew how to clean. I knew how to do laundry. I knew I already knew how to do things.”

Moreover, by engaging in something that provided him a greater sense of accomplishment and self-efficacy, it helped him reinstate his pride rather than let thoughts about doing “women’s jobs” negatively impact his masculine identity or self-esteem.

Another way men demonstrated this was by challenging some of the traditional ideas they were brought up with or socialized to have about masculinity. For instance, Trevor asserted, “It's not being me being weak. It's me being sick, and there's difference.” Additionally, he shared how not conforming to traditional masculine ideologies has helped him make sense of his experience in this way. Matthew noted how despite the way he’s been socialized to avoid help-seeking and the “masculine idea that you don't complain about it,” he talks about his FM much more openly now days. Similarly, Fred offered how he arrived at a positive reconstruction of masculinity when he shared:

“Men should talk it out, not tough it out. My dad's generation was raised on the [idea] crying never solved anything. Well, I got a few years of therapy, and quite a bit of crying under my belt to argue that point [shared laughs]. I don't think there's anything manly about dealing with pain stoically. I can point to a number of men that I know that don't show their emotions that have unhealthy characteristics and behaviors as a result... So, I share that because to me that is being a man. Being a man is being in touch and taking apart who you are and trying to be a better person for it.”

## Summary

In attempting to make sense of the experiences of men with FM's noted in the study, initial words that come to mind are complex, dynamic, intricate, and idiosyncratic. Despite the similar experiences captured by the overarching themes, it is imperative to understand and honor each individual's variety of lived experiences and perspectives. Participants presented varying experiences related to their FM onset, search for a diagnosis, and adjustments over time. Some men have gained a greater sense of control over their FM over time, some continue to feel a lack of control. For most men, their sense of control fluctuated over time depending on several factors. Their illness perception of control was impacted by pain and fatigue symptoms as well as other psychosocial factors. Moreover, participants varied across their personalized experiences of stigma and masculine gender role strain related to FM.

Participants also shared a multitude of ways to cope with their FM experiences cognitively, emotionally and behaviorally. The experience of stigma and masculine gender role strain seemed to impact the participants in personally and interpersonally remarkable ways. Moreover, the intersectionality of identities showed the relationships between identity and the power of socially constructed masculine norms on stigma across different contexts. It was interesting to understand how the experience of being a man in the U.S. was such a strong influence on the internalization of stigma when men were unable to adhere to traditional masculine norms in the same way as before their FM emerged. There was such a strong response to how men with FM encountered forms of stigma and masculinity threats, their impact, and forms of coping. While men with FM

can feel very alone in their experience, these participants narratives demonstrate how important sources of support and feeling validated in their experience are to navigating the life challenges imposed by FM.

The lived experiences of these men were so illuminating. I was moved by the thoughtfulness and willingness of participants to reflect and attempt to make sense of experience. The participant's acknowledgement and ongoing process of working towards acceptance of self and others demonstrated their resiliency. While these men's stories reflected many of the struggles and losses they have endured through the onerous battle of navigating life with an invisible and often contested chronic illness that many characterize as a "women's disease," these men articulated personalized examples of how strong, able, motivated, and resourceful they have been throughout the process.

## Chapter 4: Discussion

### Overview

Interpretative Phenomenological Analysis guided this study about the lived experiences of men with fibromyalgia. There were six total participants with ages ranging from 46-63. Each participant completed a 90–120-minute semi-structured interview and were given the opportunity to provide member reflections. Following the interviews and the member reflections, the data was examined and analyzed using NVivo 12 (2019) software. Nine superordinate themes were identified: *Precipitating Events; Pain Experience; Psychosocial Stressors; Emotional Impact; Impact on Identity; Social Impact; Adjusting to Physical Aspects of Fibromyalgia; Coping with Psychosocial Aspects of Fibromyalgia; and Coping with Stigma and Masculine Identity Threats*. Primary and secondary subordinate themes were also established to explore cross-case convergence and divergence of the lived experience of men with FM in this study. The individual narratives of men with FM were woven together to underscore the underlying essence and shared collective experiences of what it means to be a man living with FM.

This study's goal was to explore the primary research question of: how does health-related stigma and masculine gender role strain relate to illness appraisals, coping behaviors, and health outcomes in men with FM? The four sub-research questions that guided this study were: How do men with FM experience living with an FM diagnosis?/

What are the illness perception of men with FM?; What is the experience of stigma (induced identity threat) in men with FM?; How does FM-stigma threaten their sense of self or masculine identity? and; What coping strategies do men use to navigate FM, stigma, and masculine identity threat/strain? The discussion that follows is framed to provide answers to these questions. Specific themes that help to answer these questions will be referenced. Moreover, how these findings connect to previous research will be discussed, as well as how these themes illuminate new findings or contributions to the literature. Strengths and limitation, implications for clinical practice, and future directions will also be discussed. Finally, this chapter will conclude with my reflections on the research process.

### **Connections to Theoretical Frameworks and Previous Literature**

To explore men with FM's experiences of stigma and masculinities, this study utilized the following theoretical frameworks: the Common-Sense Model (illness perception), Stigma-Induced Identity Threat Model, and the Gender Role Strain Paradigm. Those frameworks, in addition to the previous literature about the illness perceptions of individuals with FM, experiences of health-related stigma, and masculine gender concerns of men with FM and other chronic illnesses, support many results of this study. Several results from this study coincide with findings from previous research, while some results contributed to novel understandings of the lived experiences of men with FM. Overall, participants offered many examples of how stigma and messages around masculinity influence the way men experience and cope with FM, and how these phenomena can evolve over time.

## **Illness Perception of Men with FM**

### ***Cognitive Illness Representations***

Men seemed to make sense of their FM by viewing it as a complex, difficult to treat, chronic condition that changed their views of themselves and what they pictured their life to be. This is consistent with previous research by van Wilgen and colleagues (2008) that found FM patients considered the disease to be chronic and have serious consequences on their quality of life. However while most (92% women) participants in Wilgen et al. attributed the cause of FM to external somatic causes (e.g., muscular disease, rheumatism, tendon/joint overuse), surprisingly all the men in the current study attributed the cause of their FM to a combination of factors. All participants identified a precipitating physical injury or illness (external somatic cause) as well as a significant life stressors or traumatic experience (internal or external psychological cause), and half the participants referenced genetic predispositions. This reflects a potential shift in patient's understanding about the cause of FM being from purely biomedical to now being more aligned with a biopsychosocial understanding. This finding is relevant because patient's understanding of the cause of FM can influence their receptiveness to treatments, as they will likely search for treatments that fit their attribution (Wilgen et al, 2008). This also helps explain why the men in this study emphasized the need for greater focus on the psychological impact of FM, which many of them felt was lacking from healthcare encounters.

Domains of the illness perception model (i.e., cause, identity, timeline, consequences, control) that appeared most salient to men living and coping with FM in



the current study were those pertaining to control and consequences. Wilgen et al., (2008) concluded that individuals with FM perceived little control over the illness. In the current study, men's perceptions about how much they believed they and/or healthcare providers could control the outcome of FM seemed to fluctuate over the course of the disease process. Similar to the five Finnish men with FM in the Sallinen and Mengshoel (2019) study, men in the U.S. reflected dualistic experiences that described both the negative and debilitating impact of FM contrasted against their ongoing efforts of adjusting their lives to live successfully with FM. Consistent with findings from Mengshoel and colleagues (2018), during the initial onset of FM before having a diagnosis, men felt confused and frustrated and felt very little control over the changes they were experiencing. Over time, as they gained clarity through receiving a diagnosis, this brought an initial sense of relief by having a name for their experience, which they hoped would provide direction for them to begin learning how to manage what was happening.

Perceived control varied depending on factors like their pain and symptom severity, emotional distress, internal and external coping resources, and perceived levels of support. On "bad days," which almost always corresponded with weather or followed a high activity day, men perceived very little control over their pain and pain related functioning. However, the knowledge and awareness of their FM triggers and patterns helped them to mentally prepare and have a sense of control by planning around rest-time or pain flare-ups. Men felt much less able to predict and control the fatigue and cognitive symptom of FM ("fibro fog"), as this seems to have less identifiable triggers. Participants expressed that these symptoms seem to be much more prominent in the FM experience of

men compared to women. Thus, with the lack of research on men with FM, it is not surprising there is a dearth of understanding on how to help men manage their symptoms such that they feel controllable.

Another factor that influenced perceived control for men with FM was understanding and support they received from friends, loved ones, medical providers and employers. Congruent with prior studies (e.g., Armentor, 2017; Maraleethran et al., 2018), this was negatively impacted by having an *invisible illness* and more so by the *lack of representation of men with FM*. Due to the limited visibility of FM in men, helpful guidance from medical providers and healthcare materials/resources specific to men with FM are lacking. This left most men on their own to research and self-experiment through an ongoing process of trial and error to figure out how to control and manage FM. Moreover, Muraleetharan et al. (2018) noted the lack of healthcare educational resources for men to be a factor contributing to the perception of stigma in men with FM. This was reiterated by men in the current study and stigma was highlighted as an aspect of FM which they had little control over.

The current study adds to the existing literature by highlighting men's perceptions of control throughout the disease process, and psychosocial factors that influenced perceived control. According to participants, learning ways adapt and gain a sense of control over the physical aspects of FM is much easier than adjusting to the collateral psychosocial consequences of FM. Similar to previous qualitative findings on the experiences of men with FM, the physical changes men experience from FM significantly impact men's identities (Wilde et al., 2019), interpersonal relationships, and work and

family roles (Furgeson, 2014; Sallinen & Mengshoel, 2019). These consequences account for the considerable emotional impact of FM on men. This study expanded on these prior findings by revealing how the inter/intrapersonal and emotional consequences men with FM experience are highly shaped by their experiences of stigma and its relationship to masculine gender role strain.

### ***Experiences of Stigma and Masculine-Identity Threat***

This study went deeper into exploring how masculinity concerns relate to stigma-induced identity threat in men with fibromyalgia. As expected, men's experiences of stigma were very intertwined with experiences of masculine gender role strain (perceived stress arising from gender-nonconformity to traditional masculine ideologies (TMI) or gender role norms). A majority of the men with FM endorsed experiencing stigma directly through their interactions with others, or indirectly by witnessing or talking to other men with FM who have experienced it firsthand. Collectively, all the men with FM in this study experienced social and/or internalized stigma that disrupted their masculine identities. Moreover, perceived stigma was often amplified by masculine gender role strain, highlighting the intersecting nature of these factors. Participants experiences of stigma also highlighted how embedded traditional masculine gender norms are within the U.S., and how deviations from these norms and/or social expectations played a large role in the internalization of stigma and other psychological and social consequences for men with FM.

**Collective and Emotional Illness Representations of FM Stigma.** All of the men with FM acknowledged how *Cultural Pressures and Expectations of Men*

contributed to experiences of social/internalized stigma and identity threat. This reiterates prior findings that have linked men's masculine ideologies, conformity to traditional male roles, and gender role stress and strain with self-stigma (Booth et al., 2019; Vogel & Heath, 2016). The current study expands on this by delineating which particular masculine ideologies and norms were disrupted most within the context of living with FM. Commonly endorsed cultural messages participants noted included expectations of men to be physically able, healthy, and strong, to be self-reliant and emotionally stoic, and to be the "bread-winner." These represent "collective representations" of the SIIT model. As expected, these cultural expectations threatened their masculine identities when they experienced strain in their ability to uphold those expectations due to the impact of FM on their physical abilities, their mental health, and their work/financial contributions. The subordinate themes *Physical Limitations*, *Emotional Impact (Depression and Anxiety)*, *Self-reliance and Stoicism*, *Work Challenges*, and *Financial Strain's Negative Impact on Self as a Provider* depict the specific ways men experienced masculine gender role strain connected to the collective representations they personally held for themselves as men, or perceived society to expect of them.

Living with FM was also portrayed as a constant emotional battle because of how it disrupted men's ability to maintain their physical abilities and important social roles linked to their masculine identities and esteem, such as work and family roles. This mirrored the experiences of men with FM from previous studies by Ferguson, (2014) and Sallinen & Mengshoel (2019). Participants described a grief process of coming to terms with FM that involved *grieving one's past and future self*, which included their previous

physical and cognitive abilities, emotional wellbeing, and social role functioning at work and at home. This aligned with early research by Charmaz (1994) on the processes men with chronic illness used to navigate identity dilemmas. The experience of *identity loss* was strongly tied to masculine gender role strain and *internalized stigma* that men experience. This was displayed by the high degree of overlap between men's statements encompassing the themes *cultural expectations of men*, *identity loss* and the *internalized stigma* that often ensued when men experienced disruptions in their ability to conform to the cultural expectations of men. This finding also highlights how gender-role discrepancies influenced many of the mental health outcomes men with FM experienced (e.g., depression, anxiety, frustration, anger) that have been noted in previous research (Yang et al., 2018).

Moreover, the engrained social expectations for men subjected participants to experience stigma and invalidating responses from others when they were not working and making money, experiencing debilitating physical or psychological symptoms of FM, or displayed physical limitations. Men experienced other negative social consequences from FM including loss of status, employment, income, friendships, and divorce. Social pressures contributed to difficulty emotionally adjusting to physical limitations and the loss of independence when men internalized these messages and formed negative views of themselves. Some men saw themselves as “less of a man/person” when they could not engage in physical activities, work roles, or financially contribute in the same ways as before. These types of gender role strains were connected to feelings of shame, guilt, anxiety and depression. Thus, the predominant emotional representations of men with

FM were a consequence shaped by the psychosocial processes that men were navigating. Consistent with the negative associations found by Wong et al, (2017) between strong conformity to masculine norms, mental health and social functioning, men with FM that conveyed strong adherence to TMI appeared to influence internalized stigma and be associated with greater difficulty accepting limitations and maintaining a positive sense of self-worth in the face of FM.

**Situational Cues.** Stigma was a considerable factor within the *Social Impact* theme. Medical encounters, workplace settings, and situations that raised men's awareness of masculine gender role threats/strain were the situational cues that elicited the greatest stigma-induced identity threat for participants. Almost all the participants experienced *Frustration with Healthcare Experiences*, much of which was attributed to feeling misunderstood, lack of empathy, and low perceived support. Men with FM experienced stigma by having the legitimacy of their illness questioned, discounted, not believed, or told it was "all in their head" by medical providers. This finding is consistent with previous research by Alameda et al (2019) and a meta-ethnography of 18 studies consisting of 450 of women and 25 men by Mengshoel and colleagues (2018). In prior research as well as in the current study, men attributed experiences of stigma in medical encounters to FM lacking a clear etiology and the invisibility of the disease, which aligns with broader experiences of health-related stigma in people (though mostly women) with chronic pain (e.g., De Ruddere, et al, 2012; 2013; Taylor et al., 2016).

**Stigma Activated in Healthcare Encounters.** Findings from this study also parallel those of Muraleetharan et al. (2018) where men with FM reported fear of stigma

from having a condition primarily affecting women and a lack of health education resources catered towards men. When some men disclosed about their FM to strangers or co-workers, they were at times responded to with surprise or statements like – “isn’t that a women’s disease?” Several men also felt a sense of skepticism, not belonging, and dejection by some of their women FM counterparts when they were seeking online support and connection. Men also shared how after being diagnosed, they struggled to find healthcare materials or information that were not catered to women or depicted women’s bodies. Men noted the stigma-inducing potential of not having healthcare materials that were representative of men to share with friends or family.

Men in this study also highlighted how societal messages men have internalized about not showing weakness or seeking help may have resulted in behaviors that contributed to provider’s disbelief of their complaints. For example, consistent with the vast literature demonstrating low help-seeking in men (e.g., Himmelstein & Sanchez, 2016; Vogel & Heath, 2016; Kivari et al., 2018) some men with FM in the current study acknowledged how they themselves have delayed seeking treatment because they internalized masculine ideologies of *self-reliance and stoicism* like “don’t complain,” and “don’t show weakness.” This is consistent with early research on men with FM that found men postponed seeking medical treatment due to concern about being perceived as “whiners” (Paulson et al., 2002). In many ways, the lack of support men felt within the healthcare system also reinforced their adherence to traditional masculine ideology of *self-reliance*. At times self-reliance served as a strength for men when it helped them build self-efficacy in learning self-management strategies. However, at other times this

left men *feeling alone*, led to emotional distress, and amplified feelings of stigma and masculine strain when men construed emotional vulnerability as a sign of weakness.

Men also noted how providers themselves may hold biases in their expectations for men to uphold traditional masculinities of strength and not take their pain complaints seriously. Moreover, several men experienced provider bias in that they did not think FM was a legitimate disease, and that it was a “woman’s disease.” It stands to reason that because of this many men who may suffer from FM go unnoticed and untreated. This has been noted to occur with other conditions considered to be “women’s health issues.” For instance, men with irritable bowel syndrome (IBS) face an increased risk of being undetected and undiagnosed due to gender stereotyping of the illness (Halpert, 2018). Under-detection of mental health conditions in men is also common due to socially constructed ideas about how men are, which can contribute to subconscious bias in providers to overlook distress in men (Smith & Elliot, 2018). Several men in this study indicated how this occurred in medical encounters where they felt they had to significantly fight and advocate for their distress to be fully acknowledged. When men with FM go unnoticed, this in turn may perpetuate the belief that FM is not legitimate, or a “woman’s disease,” thereby perpetuating stigma experiences for men with FM. When men experience this kind of marginalization in healthcare settings it heightens the stigma that they are likely to encounter in other social settings.

***Stigma Activated in Work and Community Settings.*** Stigma-induced identity threat was most prominently activated for men with FM in the context of work and other social situations that activated or heightened their awareness of masculine strains. As



discussed above, being a man with an invisible illness elicits stigma in situations when FM prevents them from being able to carry out certain activities and/or social roles expected of men. Examples of such situations include when having difficulty lifting/carry things or walking (especially in the presence of others), experiencing sexual dysfunction, when comparing their physical abilities to other men or (even more so) to women, or when seeking out information on FM and only finding images of women.

Work settings (or having to leave work settings) presented a major threat for participants. Men viewed work as something that provided them a sense of meaning, purpose, identity, and pride. Moreover, as noted by Paxman (2019), U.S. cultural values of hard work and independence make individuals with FM highly susceptible to societal stigma. This appeared to play out for the men with FM in the workplace and society more broadly. As they were experiencing physical and mental limitations and no longer able to work, they experienced social stigma in the form of being perceived as “lazy” or “broken,” socially abandoned by previous friends, having their illness treated with sarcasm or skepticism, and/or viewed by strangers with despise. Without full awareness of the pain experienced by men with FM, men were susceptible to many forms to stigma. Such *invalidating responses* from others led to the outcomes of loneliness and efforts to hide pain to mitigate anticipated stigma. Men made sense of the experience of stigma and social losses as resulting from the lack of empathy and understanding from others. This is consistent with the responses of women with FM who perceived a lack of understanding from friends and family in the context of having an invisible illness, and their avoidance of social interactions to protect themselves from such experiences (Amentor, 2017).

**Personal Characteristics and Intersectionality.** This study helped to shed light on how intersecting identities can influence the experience of stigma, masculinity strain, illness perceptions, coping and health outcomes for men with FM. For instance, men's upbringings and personal values impacted their appraisals and coping with stigma induced identity threats. Men who had family member with FM had an idea of ways their life would change. While this allowed them to pre-emptively plan for the physical limitations they expected, it did not necessarily prepare them for the emotional experience embedded in the identity adjustments they were forced to make, especially since none of them had family member that were men with FM. Most participants noted messages they internalized about men and masculinities from observing their own fathers growing up. Men that identified more with traditional masculine norms expressed stronger feelings of internalized stigma of FM. For instance, participants who associated "being a man" with hard work (i.e., physical labor, high work productivity, being a financial provider) and dealing with physical and emotional pain by "sucking it up," or "pushing on," expressed more self-deprecating beliefs when they experienced challenges holding up these self-expectations.

Additionally, men expressed more feelings of inadequacy in the context of identities that they strongly tied to their masculine abilities (e.g., veteran, father, factory worker, athlete, analyst). One factor that stuck out in the current sample was how this manifested in the dichotomy of white collar and blue-collar workers. While men across job types experienced a sense of identity loss, gender role strain, and self-stigma in response to work disruptions, the three men who held more physically laborious positions

notably experienced greater consequences. They all were on disability while the other three men who previously held white collar jobs were either still working part or full time or were looking for work. Similarly, when men's changes in work status were not as visible, they experienced less social and internalized stigma. Having a non-physical job was noted as a protective factor from health-related stigma. Additionally, several men shared how being diagnosed during the pandemic when work-from-home and social distancing orders were in effect made their changes in functional status less on display. One participant acknowledged how his financial privilege that allowed him to take a break from work entirely shielded him from anticipated public criticism at work.

In addition to job type and socioeconomic status, other social factors participants noted to influence the experience of FM related stigma and masculinity threat were age and sexuality. Multiple participants stated how younger men with FM are likely to experience greater masculinity threat and stigma because there are even greater expectations for them to uphold normative gender role expectations of working and being a provider. While there was only one participant who identified as gay, he recognized through his mentoring of many men in heteronormative relationships that there is much overlap in the cultural pressures to sustain traditional masculine gender roles of working and making money. However, he acknowledged that in contrast to him, hetero-men seem to face even greater immense pressure to maintain their masculine roles, which causes them further feelings of embarrassment, shame, and psychological anguish when they cannot.

## **Coping Strategies Used to Navigate FM, Stigma, and Masculine Identity**

### **Threat/Strain**

Participants conceptualized their FM as having multiple contributing factors, which reflects their biopsychosocial understanding of FM. This influenced their ability to take dynamic and balanced approaches to coping. Men utilized analytical problem-solving strategies to help predict and mitigate pain through planning, while emphasizing the need to have flexibility. Results from this study revealed how illness perceptions of men with FM were shaped largely by experiences of stigma and threats to their masculine identity. For most men, quality of life was related more to adjusting to the psychosocial impact of their physical limitations vs. the disease itself. Thus, strategies aimed at adjusting to the affective and social impacts of FM were equally (if not more) important as those aimed at coping with physical pain.

Men utilized various coping strategies at various points in their FM journey. At times, and especially in the initial stages after being diagnosed, men negatively interpreted their pain experience in several ways that contributed to the behavior of *hiding pain*. This parallels findings by Armentor (2017) on women with FM who avoided social interactions to hide from the stigma. Novel findings that the current study adds is a better understanding of what experience, perceptions, and internalized messages contributed to men with FM's efforts to conceal their pain from others. Similar to the Norwegian men with chronic muscle pain in the Ahlsen et al (2012) study, the primary motivators for men with FM to hide their pain were typically to avoid potential stigma threats and to preserve their masculine identities. As noted, it was important for the men

to be able to work and be a financial provider, feel esteemed in their physical body's and "push on," feel emotionally strong, and not feel like a burden – all factors that impacted their sense of self as a person or as a man.

These internalized messages influenced many men to hide their emotional pain at times as well. A majority of men discussed difficulty they had sharing how they were feeling with others. Several men endorsed socialized masculine norms that inhibited them from sharing their emotional pain with other (e.g., "it's not macho," "men shouldn't complain"). One participant noted how this is reflected on the online men with FM support groups by the type of support provided being more physically than emotionally focused. One way this may have similarly manifested within the interviews was when men would focus on discussing details of their pain experience and their medications, as the physical adjustments to FM may have been an easier topic to discuss than the psychosocial changes. This in some ways paralleled the way men's chronic pain narratives in the Ahlsen et al (2012) study concentrated on objective facts and the function impact pain had on them physically as opposed to emotionally. Men in the current study were asked directly about their emotional experiences to attempt to shed further light on this. For the most part men were very open about discussing the emotional impact of FM during the interview, provided they viewed it as an invitation by someone who cared to hear about it.

Men note how hiding pain contributed to more negative outcomes when it compelled them to physically over-exert themselves, increase their mental exhaustion, delayed treatment seeking or collaboration with healthcare providers. Moreover, when

men felt alone in their experience it caused greater difficulty in their overall emotional adjustment to living with FM. Over time, men found themselves feeling more empowered to cope with their FM when they were more open with others about their FM. However, due to invalidating responses and lack of understanding men often experienced they were selective with who they were more open with about their condition. In addition to *coming out of hiding*, men cited several strategies that helped them reconcile experiences of stigma and masculinity threats/strain including; *regaining a positive sense of self through purpose and acceptance, perspective taking, meditation and spirituality, therapy, challenging traditional masculine ideologies, social support, and communicating challenges and needs.*

One way that men cope with FM stigma and masculinity strain is through an ongoing process of grieving their past and future self, balanced with finding ways to reconstructing one's self-esteem, identity, and purpose. This finding is consistent with earlier findings that as men gained greater acceptance of themselves and their limitations their negative moods resolved (Paulson et al., 2002). This study contributes further to the current literature by illuminating what processes help men with FM achieve a sense of acceptance. Grieving one's past and future self is one processes that helps men gain acceptance of themselves. Men expressed how acceptance ebbs and flows and is an ongoing process. Many of the men utilized meditation or spiritual practices to cope with stigma and acceptance challenge. Additionally, most men found therapy helped with adjusting to the impact FM had on them physically, emotionally, socially and with working through identity concerns to regain a positive sense of self. Men who were able

to find new experiences of joy, meaning, and purpose experienced benefits beyond mere acceptance of FM, they developed a positive perspective of ways FM has benefitted them- such as increasing their ability to slow down and be present, experiencing more gratitude, or experiencing a sense of personal growth from navigating hardships. In many ways, this corresponds with the phenomenon of post-traumatic growth (Calhoun et al., 2010).

Other men experienced growth in the face of stigma and identity renegotiation by engaging in new roles or helping others. Consistent with findings from Furgeson (2014), connecting with other men with FM was an important part of coping. In the current study, receiving and giving support was also an essential component to helping them rescind the stigmatizing notion that FM is a “women’s disease,” recognizing they are not alone, and gaining a sense of control through shared advice and problem solving. For men that were actively engage on support forums, connecting with “newbies” with FM to provide mentorship or involved with advocacy work related to FM gained several benefits. This allowed them to turn their focus outward, building social connections, and gain a renewed sense of meaning/purpose, all of which helped minimize their focus on pain and experience more positive emotions and wellbeing.

Acceptance was another strategy men used to mitigate and cope with experiences of stigma and masculinity threats. This mirrors the findings by Wilde et al (2019) on how men with CFS coped with experiences of masculine identity loss and the sense of marginalization attached to their illness. However, it expands on the specific ways that acceptance took form for men with FM. In this study, one way men with FM

demonstrated acceptance was through a process of simultaneously integrating FM as part of their identity/experience while embodying a sense of detaching from letting their FM define them in negative ways. For instance, men were able to better let go of judgments from themselves or others by depersonalizing them and reminding themselves, “there’s nothing wrong with me.” Additionally, when they felt devalued or mistreated by others, they often took the approach of recognizing this as “their problem” and focusing on their control over their own responses. Men also found it useful to educate others who were misinformed about FM. Some men found communicating openly with family, friends, and employers about their limitations and needs helped foster understanding and reduce negative assumptions.

Shifting away from traditional masculine ideologies was another helpful way men coped with stigma and masculinity threats. For instance, several men recognized how they (and other men) have been socialized to think about masculinity in ways that created tension when FM disrupted their ability to uphold these ideals. When men were able to relinquish or reconstruct ideas about how men are “supposed to be,” it reduced barriers to help-seeking. This in turn allowed them to experience benefits from being vulnerable and talking more openly about their FM experience with supportive family members, friends, employers, medical providers and therapists.

While masculine ideologies and role strain at times amplified stigma and influenced avoidant coping styles (e.g., efforts to hide pain), it is important to also underscore the way masculinities have been adaptive to men through the process of living with FM. Previous studies have shown constructs like masculine norm conformity to be a



protective buffer against distress in some cases and connected to health promoting behaviors (Levant, & Wimer, 2014; Wong et al., 2012). This was observed in the current study when men's conformity to masculine ideologies reinforced positive coping in some contexts. For instance, men talked about how "pushing through pain" helped them avoid getting pulled into negative cycles of pain-related distress, depression, and fear-avoidance behaviors. This is important given previous findings linking pain catastrophizing, avoidance of movement, and impaired functioning in FM patients (Estévez-López et al., 2015; Pastor-Mira et al., 2020). Moreover, recent studies indicated activity avoidance is associated with increased fatigue and pain severity in FM (Velasco et al., 2022). Thus, when men used their masculine ideologies to help them engage in helpful behaviors or active coping strategies (e.g., pushing themselves to get out of bed when they were feeling depressed, pushing themselves to engage in exercise despite temporary pain, utilizing self-reliance to build self-efficacy in self-management strategies), masculinity served as a protective buffer. The finding that masculine ideologies functioned as both a risk and a protective factor for men with FM underlines contextual nature of masculinity factors on health outcomes that others have emphasized (Wong et al., 2017; Isacco, 2015; O'Neil, 2015; Gerdes & Levant, 2018).

### **Implications**

The current study demonstrated that like other chronic pain conditions, the illness perceptions, coping behaviors and health consequence for men with FM are undoubtedly influenced by an array of biopsychosocial factors. However, existing research has predominantly focused on the experiences of women. This study helped reveal

psychosocial challenges specific to men living with FM, with an emphasis on how men experience and navigate stigma and masculine gender role strain. Understanding the lived experiences of men with FM can help inform more culturally sensitive care and improve healthcare experiences for this population. Implications from this study may apply to healthcare (medical and mental health) training, clinical assessment and practice, and future research.

### **Improving Patient-Provider Relationships**

Based on participants collective experience of having negative interactions with healthcare providers that left them feeling dismissed, frustrated, misunderstood, disrespected, unsupported, and stigmatized, formation of a strong relationship should be a priority when working with men with FM in healthcare settings. While medical providers are most likely to have initial encounters with men with FM, it is important for all healthcare providers (medical and mental health) to reinforce help-seeking in men through initial relationship building. Quality patient-provider relationships can improve patient health outcomes including increased adherence, symptom improvement, and adaptation to illness (Duggan & Street, 2015; Epstein et al 2005; Zolnierek & Dimatteo, 2009). Psychotherapy literature has also demonstrated that the therapeutic alliance accounts for 5% to 8% of the variance in treatment outcomes (Horvath et al., 2011). Moreover, findings from a systematic review on patients with chronic musculoskeletal pain found working alliance to have significant effect on patient pain severity, pain interference, and physical functioning outcomes across studies (Lakke & Meerman, 2016).

There are several ways healthcare providers can work to establish trusting, collaborative relationships with men with FM. First, healthcare providers should be trained in how to convey foundational interpersonal skills of effective listening, non-judgement, and empathy in their communication with all patients (Duggan & Street, 2015), and the results of this study suggest these skills are especially important for enhancing patient-centered care with men with FM. McAndrew and colleagues (2019) provide a set of treatment recommendation to assist providers for helping patients with medically unexplained syndromes (MUS) and related conditions. Regarding relationship building, the authors stress the importance of first validating patients' perspectives and experiences. To do this, providers first need to assess patients understanding of their condition/symptoms. The DSM-IV cultural formulation interview can serve as a helpful resource for eliciting patient perspectives. Additionally, based on a scoping review on communication skills and patient-provider relationships Drossman and colleagues (2021) developed a table of recommendations for optimizing patient provider relationship that outlines methods, techniques and helpful examples. For instance, they provide example statements to reflect empathy and validation such as "I can see you are frustrated when people say this is due to stress, and you know it's real."

Another important part of validating men in healthcare encounters involves communicating belief that men's FM is real and demonstrating empathy for the impact FM has had on their life. This is emphasized in the recommendations by Drossman et al (2021). Moreover, in a study on improving communication with veterans with MUS, veterans' perceptions that providers believed them about the severity of their illness had

the strongest relationships to expectations-for-improvement (Laman-Mahargd & Bloere, 2017). It is also important to normalize the condition of FM for men to reduce masculinity threats and feelings of stigma. Moreover, findings from the current study emphasize how providers can validate men's experiences by acknowledging and normalizing common feelings like frustration, fear and uncertainty, depression, and shame. When healthcare providers are able to effectively interact with patients in ways that make them feel heard, believed, validated, and not judged, they are able to better able to understand the illness context and better address patient needs.

Another recommendation for building relationships with FM patients is to “develop a shared understanding of symptoms,” (McAndrews et al., 2019, p. 748) by either giving their experience a diagnostic label (like fibromyalgia) or a functional explanation (e.g., overactive nerves). They caution against attributing symptoms to a psychological cause as this can be problematic because patients may interpret it as an invalidation, insinuating the idea that “it’s all in your head.” Moreover, when providers attribute FM symptoms to psychological or personality factors patients are more liable to receiving poorer care (McAndrews et al., 2019). A more effective approach is to assess and understand the psychosocial consequences they have experienced from FM (Burke, 2019; Turk et al., 2016). Once the psychosocial impact of FM is acknowledged patients may be more receptive to psychosocial ascriptions as a contributor to their symptoms later on (Anastasides et al., 2019; Stortenbeker et al., 2020). This can help lay the groundwork for patients to be on board with treating FM from a biopsychosocial approach. Ultimately, initial concordance of illness perceptions between the patient and

provider is a key factor in improving the therapeutic relationship and ongoing healthcare for men with FM (McAndrews et al., 2018).

The final relationship guideline provided by McAndrews and colleagues is to “give specific recommendations to help the patient feel empowered in managing their health” (p. 748). Men in the current study noted this could be done by providing information to help them manage their expectations, or directing them towards helpful guides, resources, and supports specifically for men. In addition to improving men’s healthcare experience, this has the potential to positively alter illness perceptions of men with FM by a) enhancing their sense of control and b) minimizing negative consequences by reducing emotional distress and potentially abating masculine identity threats and internalized stigma.

## **Implications for Psychological Practice**

### ***Culturally Responsive Care***

In addition to informing healthcare providers on improving working relationships with men with FM, psychologist can familiarize themselves with the APA Guidelines for Psychological Practice with Boys and Men (APA, 2018). These guidelines were developed with recognition that while men historically have held power and privilege in society, there are significant sociocultural factors that contribute to physical and mental health disparities in men (Gough & Robertson, 2017; O’Neil, 2015) The document helps acquaint clinicians with many of the relevant concepts pertaining to masculinities that have been addressed in this study (e.g., gender role strain/conflict, masculine ideologies,

gender-sensitive treatment) and offers 10 over-arching recommendations to support practitioners awareness, knowledge, and skill when working with men.

A key takeaway from this study is the importance of considering sociocultural factors and intersectionality in conceptualizing patients' illness perceptions, coping behaviors, and healthcare outcomes. This aligns with the first APA psychological practice guidelines for men, which notes the need to “strive to recognize that masculinities are constructed based on social, cultural, and contextual norms” (APA, 2018, pg. 6). While many shared experiences of stigma induced identity threat and masculine gender role strain were noted across the men with FM in this study, findings also reflected unique individual and contextual factors that resulted in varying degrees of these experience or their impact on men's lives. For instance, social class, sexuality, and age were a few notable factors that contributed to experiencing more or less cultural pressures for men to uphold traditional masculine gender norms, and thus to more or less stigma when they were unable to. Therefore, while it is important to have awareness of the potential stigma and masculinity concerns men with FM may experience, it should not be assumed that these experiences will emerge in similar ways for all men.

Developing a multicultural orientation (MCO) - or an other-oriented “way of being” with clients marked by cultural humility, capitalizing on opportunities to address cultural content, and comfort during those discussions (Davis et al., 2018) – may promote the necessary openness and curiosity to aid psychologists in examining how intersecting multicultural factors uniquely shape the experience of each individual man with FM across their lifespan (APA Guideline 2).

### ***Tailored Interventions for Men With Pain***

In addition to these more general guidelines for working with men, the *Coping with Psychosocial Pain* theme derived from participants provides clinicians direction for interventions to consider when working with this population. Participants collectively conveyed strategies that appeared helpful (and unhelpful) to living with FM. These included various cognitive, emotional, and behavioral strategies to help them manage both the physical and psychological challenges of living with FM. As mentioned, the greater challenge for men with FM is the secondary impact of navigating the psychosocial challenges that come from the physical limitation rather than the physical adjustments themselves. Psychotherapy can provide a safe environment for men with FM to address psychological and social wounds.

Cognitive Behavioral Therapy (CBT) is the most widely studied treatment for medically unexplained symptoms (Van Dessel et al., 2014) and has shown to be effective in reducing the impact of physical symptoms, psychological distress, and improving quality of life (Kroenke & Swindle, 2000). By understanding the illness perceptions of men with FM and the sociocultural factors that influence them, psychotherapists can effectively utilize evidenced-based CBT strategies to help alter maladaptive illness perceptions or modifiable correlates, which may improve patient treatment outcomes (Arat et al., 2018). The current study highlighted that internalized stigma is often shaped by feelings of low self-worth resulting from masculine gender role strain, and how cultural pressures on men to conform to masculine gender norms can further influence stigma. While men may not have control over social stigma they experience in the

context of living with FM, this study highlights several adaptive ways men cope to preserve their self-esteem and positive masculine identities (e.g., acceptance, perspective taking, meditation, challenging traditional masculine ideologies, finding a renewed a sense of purpose).

Pain psychologists would benefit from training in therapies that facilitate these processes such as Acceptance and Commitment Therapy for Chronic Pain (ACT-CP, Vowles & McCracken, 2008). Many of the psychological processes of ACT align with the coping strategies men identified were helpful for managing the impact of stigma and masculinity strain on their identity and wellbeing. For instance, helping men gain acceptance of their limitations while finding ways to rebuild their sense of self, meaning, and purpose in life can help them process their grief. Psychologists can also help men honor the pain associated with the changes and loss they experience, while simultaneously helping them flexibly defuse from difficult thoughts/feelings when they become a barrier to engaging in valued life directions.

Additionally, it is important to recognize ways that FM infringes on men's abilities to participate in behaviors aligned with their values. Men may benefit from engaging in perspective taking to notice ways they continue to fulfill valued masculine roles like fathers, spouses/partners, financial providers, or hard workers, even if these enactments look different than before they had FM. It may also be useful to explore with men with FM how their condition provides opportunities for them to enact different values. For instance, while they may experience a sense of loss related to the value of independence and experience discomfort around asking for help, prompting them to use



perspective taking to see how eliciting assistance can enact alternative values such as connection, teamwork or intimacy, could aid their illness adjustments. As indicated by men in the current study, aiding men in adopting a self-as-context perspective that allows them to detach from self-deprecating thoughts by distinguishing who they are (the experiencer) from their experiences (e.g., FM-stigma, masculinity strain due to FM) could serve as a useful way for men to preserve a positive sense of identity while adjusting to FM-related changes.

Another potential direction in therapy with men could be exploring with them the ACT concept of workability in regard to masculine ideologies and norms. For example, adherence to ideologies of self-reliance and stoicism in some contexts empowered men to push through physical and emotional pain in helpful ways that prevented the cycle of pain and disability. Yet at other times adherence to these ideologies contributed to challenges men experienced with openly communicating about their FM and asking for or accepting help. This often led to over-exertion that exacerbated physical and emotional problems. Hoffman and Addis (2020) emphasized the utility of exploring beliefs and enactments of masculinities bearing in mind one's values, and assisting clients in processes of reconstruction or deconstruction of masculinities through the lens of workability. Psychologists can use the concept of workability to help men recognize when it is helpful to leverage their masculinities to cope with FM, and when they may be over-applying masculine ideologies in a rigid manner that is moving them away from valued living. This approach can help men gain psychological flexibility that cultivates healthy masculinities.

### ***Integrated and Interdisciplinary Care***

The psychosocial impact of FM further highlights the need for comprehensive care focused on the whole person and interdisciplinary pain teams, marking the benefit of having psychologists and other clinical practitioners integrated into medical settings. This offers opportunities for collaboration between medical and mental health providers to treat the whole person. Such approaches to care have demonstrated promising outcomes among chronic pain populations. For instance, when comparing veterans with chronic pain who were enrolled in the VA Whole Health services to those who received usual care, the Whole Health veterans were found to report greater engagement in healthy behaviors, healthcare decisions, and experienced enhanced purpose in life, quality of life and wellbeing (Bokhour, et al., 2020). Improvements in Veterans ability to manage chronic pain were also noted. Similar approaches to care have also been linked to improved health outcomes within the general population including improvements in physical, mental, and overall health (Crocker et al., 2019) and patient satisfaction (Crocker et al., 2017). There are also findings from large scale primary care systematic reviews and VA studies on the efficacy of interdisciplinary pain rehabilitation programs demonstrating significant improvements in pain severity, pain interference, sleep, mobility, and reductions in pain catastrophizing (Connell et al., 2022; Murphy et al., 2021). While VA studies are veteran specific, they are promising for the fact that the majority of patients served by this institution are men who are often enculturated into hyper-masculine ideologies through the military.

Psychologists working in integrated care settings can promote improved care for this population in several ways. First, they can provide trainings to medical providers on ways to enhance the patient-provider relationships when working with men with FM or other MUS conditions. As noted by several participants, it is important that medical training programs are not only teaching future medical providers how to treat diseases, but also how to treat people. Counseling psychologists' expertise in therapeutic relationship building coupled with their astute ability to conceptualize how psychosocial factors impact patients' illness perceptions, health and health behaviors (and vice versa) can serve as an asset to medical education and subsequent patient care. This may help reduce stigma or masculine identity threats elicited in medical encounters, thereby potentially modifying men's illness perceptions about control and consequence in a more positive direction (Arat, et al., 2018).

Lastly, pain psychologists can work with FM patients directly to provide psychoeducation and strategies to cope with the physical and psychosocial adjustments to the illness. Similarly, it is equally important that mental health professionals do not to neglect the biomedical aspects of treating FM. Medical providers can provide essential consultation to psychologists to enhance their understanding of medical strategies to mitigate the physical pain or fatigue symptoms. Moreover, this study highlights the potential benefits of moving beyond an interdisciplinary approach towards the formation of transdisciplinary care of FM, where medical and mental health providers continue to create a unified intellectual framework of medically unexplained syndromes like FM.

### **Strengths, Limitations, and Future Directions**

This study expanded the research on the experiences of men with FM living in the U.S., as many previous studies concentrated on men from the U.K. Moreover, it added an additional layer of understanding how FM-stigma overlaps with the masculinity concerns that arose for men previous studies (e.g., Ahlsen et al., 2012; Furgeson, 2014; Sallinen & Mengshoel, 2019; Wilde et al., 2019). The shared experiences also included the intersectionality of multiple social/cultural identities. Another strength of the study was that the utilization of qualitative methods helped empower the participants. All of the men voiced how much they appreciated the interview as it served to create a space where they could share their experience with someone who had a shared interest in helping other men with FM. Using Zoom for completing the interviews provided strong benefits for accessing participants who lived throughout the United States. This expanded my ability to include greater geographical variation in the sample. Additionally, the audio-only interview format seemed to strengthen the study by minimizing discomfort for men to share vulnerably about difficult feelings and experiences.

This study also had several limitations. One inherent limitation of IPA is its heavy reliance on interview data for analysis (Tracy, 2010). While use of participant mementos served as an additional source of data, discussion of these symbolic representations of men's experiences of living with FM were ultimately integrated as part of the interview. Despite the lack of varied data sources, the method allowed me to incorporate multiple participants' views and experiences to cultivate collective overarching themes. This study provides qualitative data about how stigma and masculinity concerns intersect to shape

the illness perceptions of men with FM. Utilizing information from this study can help inform future quantitative studies. For instance, future quantitative analysis studies could further examine whether patient-provider communication, being directed by healthcare providers towards FM resources tailored to men, or specific psychotherapy interventions that help counter restrictive masculine ideologies moderate the impact of stigma and masculine gender role strain on men's illness perceptions.

Another potential limitation was created by the phone interview format. Due to this format, the researcher was unable to see participants' non-verbal reactions to questions or while making statements. The format was an intentional effort to lessen any potential discomfort and guardedness that may have been activated by the visual gender differences between the researcher and participants. This did appear to have a positive impact on the study by allowing participants to feel less self-conscious and disclose moments of vulnerability more authentically. However, due to the limited ability to observe men's facial expressions or emotional reactions to certain questions or as they were sharing certain responses, I was unable to ascertain any non-verbal information that may have arisen. Nonverbals could have provided information on signs of discomfort or other emotional expressions that could have indicated topics men were less comfortable discussing.

The interpretative nature of IPA represents another methodological limitation. Tentativeness and caution are encouraged when formulating findings and conclusions from interpretative approaches (Rossman & Rollis, 2010). While I aimed to draw my interpretations and conclusions deliberately from staying as close to the data, coding, and

themes as possible, there is inevitably a degree of researcher bias that can influence the findings (Finlay, 2002; Shaw, 2016). As touched on in my autobiographical statement, my background, values, beliefs and prior experiences may have influenced my perspectives. As a counseling professional who has worked substantially with Veterans with chronic pain, my views on this subject have also been influenced by the ongoing information I receive from the clients I interact with. For instance, veteran men with chronic pain have consistently endorsed how the hypermasculine norms embedded in military culture created a sense of stigma related to changes in their physical status and in relation to mental health. Biases were monitored and limited during each stage of the research by reflecting on and bracketing my perspectives to ensure trustworthiness.

In addition to reflecting on my perspectives and positionality as an individual and researcher before conducting the study, an interview guide was reviewed by faculty and IRB to remove potentially biased/leading questions or language. During interviews, open-ended questions and an interview guide were used to support structure and consistency across participants. Throughout the data collection and analysis phases, bracketing and consultation were used to help avoid or at least acknowledge how personal factors could influence the research. For instance, I made annotations while re-reading the transcripts when I had concerns about how my responses to participants could have been leading and sought out consultation and feedback regarding the potential impact on the research. Furthermore, participants were given the opportunity to review their data prior to analysis to offer changes or edits to what they shared during the interview. None of the men suggested any drastic changes or removal of data points. Some men provided clarification

on certain things they said or gave additional explanations and examples. Despite efforts to prevent biased influences, unknown or underlying personal biases may have affected the findings.

A convenience sample was implemented to recruit participants. This involved advertising to organizations, social media and online support groups, and individuals with connections to potential participants. As a result, several of the men from the study were affiliated with the Men With Fibromyalgia Facebook group. This similarity may have been a major factor contributing to similarities in their experiences. Moreover, several men discussed their interactions with other men from online forums, which likely influenced their perceptions and views they chose to share. However, men were clear in distinguishing when they were sharing accounts of their own personalized experiences of stigma and masculinity related concerns as opposed to sharing experiences they have heard about from others.

The small homogeneous sample is another limitation. It would be useful to study a larger sample to further establish if the current findings are representative of men with FM. Additionally, the diversity of the sample was limited by gender and age. I aimed to recruit a sample with differences in other demographic variables such as race/ethnicity, socioeconomic status (SES), religion, sexual orientation, and geographic location in the United States. Efforts were made to use snowball sampling to recruit additional ethnically diverse participants, as well as capitalize on network connections to advertise the study through healthcare Networks that primarily served indigenous populations. Unfortunately, the study sample was exclusively white men, thus limiting the ability to

capture the voices and experiences of stigma and masculine identity concerns in men of more diverse or marginalized identities. Minority men may experience additional layers of masculine identity challenges and stigma related to racism/discrimination (Coleman-Kirumba et al., 2022). Future research could focus on selecting a more balanced sample of men with different races/ethnicities to provide additional insight around the chronic pain experience in men from a wider intersectional lens. To accomplish this in future studies, it would be useful to focus initial recruiting efforts towards healthcare agencies located in more regionally diverse areas and those that serve traditionally underserved populations (e.g., Federally Qualified Health Centers, United Indian Health Services).

The current study served as a next step in expanding our understanding of how gender intersects with the experience of FM. Yet, the existing FM research has used the gender binary, and not yet explored the experiences of people who identify as non-binary. Thus, the results should be cautiously applied to men outside of the participants age range; transgender men or gender non-binary individuals who use he/him pronouns; or non-hetero men considering there was only one participant representative of the queer community. There is a need for future research to expand beyond the gender binary to more fully capture the continuum on which gender identity may fall.

Another potential area of future research would be to explore how geographic diversity factors may influence men with FM. While men did not disclose their exact locations, many of the men working in blue collar positions tended to live in more rural and conservative states. As mentioned, men in these job positions seemed to experience greater work disruptions, and therefore greater masculinity strain and stigma. It is



unknown how much sociopolitical factors like TMI values reflected by the communities they are located in, or their own political ideologies may influence their experiences. This may reflect another psychosocial element for future research to consider. One participant also noted how healthcare providers knowledge and access to healthcare resources can influence men's experiences in receiving a diagnosis and support. Thus, future research comparing the experiences of rural vs. urban men with FM could help uncover additional factors that impact men's FM experience and illness perceptions.

### **Summary**

This study added to the literature by deepening our understanding of the determinants, mechanisms, and personal impact of stigma on well-being and functioning in men with FM that was previously lacking (De Ruddere & Craige, 2016). Masculine gender role strain was most prominent for men with FM in the context of lost physical abilities, lost work and financial contributions, and the subsequent identity loss and emotional sequel. The emotional illness representations of men with FM were in part formed by the distress of the physical pain they are in; however, most of the emotional representations in response to FM occurred in the context of the psychosocial impacts of FM. Men experience significant uncertainty, anxiety, frustration, depression, guilt and shame when FM negatively impacted their ability to work and feel productive, financially contribute, or engage in relationships or activities to the degree that they previously could. Masculine gender role strain for men with FM was elicited by perceived social stigma and internalized stigma that was cued most often in healthcare encounters, workplace settings, and in general when interacting with people who lacked empathy or

understanding about FM. The degree that men internalized stigma seemed to be dependent on: internalization of traditional masculine ideologies, the importance of certain masculine roles that were disrupted, and their ability to engage in coping responses that helped them restore a positive sense of self.

### **Personal Reflections about the Research Process**

The process of conducting this dissertation study has been such a valuable learning experience that has helped me grow personally and professionally. Designing a qualitative study then carrying out, transcribing, and analyzing the interviews involved a great deal of planning, time and energy. Even with a small sample of participants, there was so much data to sift through and make difficult decisions about what to/what not to code, what was/was not relevant, what themes to/to not combine, what to name them, etc. There are so many critical decision points in qualitative research, so many directions you can go, and while many of my decisions were guided by expert recommendations, there were still so many times I questioned myself in the process.

I experienced several moments of frustration and exhaustion from how immersed I was in the data while coding and extracting themes. One of the greatest challenges I experienced throughout this process was decision making about which theme best classified specific quotes by participants. The heavy overlap and interaction between the concepts of interest was the main contributor to my indecisiveness. This led me at times to getting hung up on over-analyzing smaller details during my coding process. I had to be diligent about recognizing when this was happening, take a step back, and shift my focus toward a big-picture perspective. It helped to remind myself that in qualitative

research there are unlimited ways of looking at the data given the nuances of experiences. Therefore, sometimes I just need to make a choice and have a reason for why I made the choice I did.

Another thing I learned from this process was how much I value the team aspect of research. Having prior experience conducting qualitative analyses on research teams was extremely helpful for providing me with foundational understanding and experiences with utilizing qualitative methods. However, for this project I was working very much independently, and I believe this contributed to experiencing more (or at least more prolonged) stuck points. One of the things I would have done differently was establish a coding team. I believe this would have had several benefits to my study. The study likely would have progressed faster by increasing accountability, keeping the momentum going, and helping resolve stuck points. Additionally, having varying perspectives can help minimize bias (although it could have the capacity to introduce group think too at times). Lastly, working with a team tends to make research more fun. Although I did not have a coding team, I did utilize a small “community of practice” by meeting with other students who were in similar phases of their dissertation research once a week for several months to check in on how we were progressing, challenges we were running into, and helping one another work through them by providing feedback, ideas, or morale support. In some ways too these meetings served to further engage in reflexivity, as I often discussed some of my initial thoughts and feelings that occurred in response to the interviews and when revisiting the data.

While conducting a qualitative study at times felt extremely labor intensive and frustrating, it was also a very rewarding experience to connect with these six men and be invited into a glimpse of their world. I was reminded of the dualistic nature of the common humanity of pain in the human experience, yet at the same time how unique, dynamic, and multifaceted everyone's experience can be. I felt very gratified in my choice to conduct a qualitative study after each interview because of how appreciative these men were to have a space to share their experiences and have it felt heard, acknowledged, validated, and cared about. Each person's narrative was so engaging. To hear about how men navigated such an incredibly life altering condition evoked my sense of empathy for how confusing, overwhelming, and disparaging it was for them at times. I was impressed with their ability and willingness to reflect and share how these events impacted their sense of self as men and as people in general. Participants collectively revealed how FM-related stigma experiences were heightened in contexts that threatened their masculinities, yet so many factors influenced the degree and severity of impact this had.

I learned through this research is how valuable it was for men with FM to feel validated and accepted by self and others. Their shared experiences often highlighted their search for finding a sense of understanding, empathy, and belonging. Participants revealed the gratifying nature of having online support groups specifically for men with FM, and signified the dire need for more men-focused healthcare materials and guidance about FM. Yet, as they described their experiences and interactions across various contexts, they simultaneously showcased the intrinsic and extrinsic strengths and

resources they ignited in their illness adjustment journey. Despite the hardships they have faced and continue to face daily, men with FM were able to share slivers of light that have kept them going. As a (soon-to-be) counseling psychologist, the process of qualitative inquiry profoundly connected me with my deeply held value of developing interpersonal relationships build on trust, understanding, respect and acceptance. Additionally, it provided an avenue to provide service to others through sharing the lived experience of these men with the impact to improve care for other men with FM.

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## Appendices

### Appendix A: E-mail to Potential Recruitment Sites

Dear \_\_\_\_\_ (Site Name),

I am a doctoral student in Counseling Psychology at the University of Denver and I am currently seeking help with recruiting participants for my dissertation, under the supervision of Dr. Trish Raque. My dissertation is a qualitative study aimed at understanding the experiences of men with fibromyalgia. I will be asking participants to complete an interview that would last approximately 60-90 minutes, and possibly a brief follow up interview.

Would you be willing to post the attached recruitment flyer at your clinic or share it with patients who might be interested in participating?

If you have any questions, please let me know. Thank you in advance for your help with my research.

Best,

Chrissy Motzny, M.A.  
Counseling Psychology Ph.D. Candidate  
University of Denver

## Appendix B: Recruitment Flyer

Attention: men living with fibromyalgia

I am seeking participants for my dissertation, which is a qualitative study looking at the experiences of men with fibromyalgia. I am seeking individuals who:

- (a) identify as a man,
- (b) reside in the United States,
- (c) are between the ages of 45-65, and
- (d) have a confirmed medical diagnosis of fibromyalgia

Participation in the study will include an audio-recorded interview (Zoom/Skype/phone) in which you will be asked to describe your experiences of being a man diagnosed with fibromyalgia. I will ask that you share an item that holds meaning related to your experience as a man living with fibromyalgia, such as an object, photograph, piece of art, fibromyalgia related healthcare materials, or other media (websites, ads, etc.). Additionally, I will ask that you later review interview transcripts and my data analysis to ensure the accuracy of your stories and experiences. Eligible participants will receive a \$35 Amazon gift card for your involvement in the study.

If you meet the above criteria and are interested in taking part in this study please call me at (408) 981-7579 or email me at [chrissy.motzny@du.edu](mailto:chrissy.motzny@du.edu) to schedule a brief phone screening. You will then receive a Qualtrics link to read and sign the informed consent form and complete a brief demographic questionnaire.

If you have any further questions about the study, please do not hesitate to contact me at [Chrissy.Motzny@du.edu](mailto:Chrissy.Motzny@du.edu)

This study has been approved by the Institutional Review Board at the University of Denver (INSERT NUMBER HERE).

Thank you for your time and interest in my study!

Best,

Chrissy Motzny, M.A.  
Counseling Psychology Ph.D. Candidate  
University of Denver

## Appendix C: Consent Form

**University of Denver**  
**Department of Counseling Psychology**

**Principal Investigator:** Christine Motzny, M.A., University of Denver

**Faculty Advisor:** Trish Raque, Ph.D., University of Denver

**Title of Research Study:** Exploring the Intersections of Stigma and Masculinity in the Illness Perceptions of Men Living With Fibromyalgia

You are invited to participate in a dissertation research study being conducted by Christine Motzny in partial fulfillment of the requirements for the doctoral degree in Counseling Psychology in the Morgridge College of Education at the University of Denver. This study is being conducted under the supervision of Trish Raque, Ph.D. of the University of Denver. This consent form is designed to provide details about the research study and inform you about your research involvement as a participant. Please review the document carefully and feel free to ask questions for additional clarification.

**Description:** You are being asked to participate in a research study. The purpose of this study is to learn about the experiences of stigma and masculinity concerns of men living with fibromyalgia, and give voice to this understudied phenomenon.

**Procedures:** If you agree to be a part of the research study, you will be asked to complete at least one interview (via Zoom or Telephone), lasting around 1.5 hours, in which you will share your experiences of what it is like to be a man with fibromyalgia. You will be asked to share mementos if you desire, such as an item that holds meaning related to your experience as a man living with fibromyalgia, such as an object, photograph, piece of art, fibromyalgia related healthcare materials, or other media (websites, ads, etc.). You will also be asked to review transcripts of the interviews to assess for accuracy and make changes as you see fit. Finally, you will be asked to review the transcripts of the interviews for to make corrections or edits, and review the data analysis to make sure your experiences have been accurately captured.

**Risks or Discomforts:** Overall, your participation in this research study has minimal risks. One potential risk will be disclosing information that may be recognizable by other people. However, in order to protect your confidentiality, you will be given a pseudonym and remove other identifying information from our conversations. Additionally, all audio-recordings and collected information will be saved in password-protected files on my password-protected laptop, or locked in a file cabinet.

Due to the subject areas and interview questions, there may be the potential risk that discussing certain issues about your experience may be upsetting. If this occurs, I will

assist you in locating professional mental health care in your area. I want you to feel comfortable only disclosing information you wish to disclose during our interactions.

**Benefits:** Sharing your experiences of living with fibromyalgia may have benefits for participants such as feeling empowered by telling their story aloud or providing cathartic relief. It also may be validating to hear about other men's experiences of living with fibromyalgia when you review my final analysis. Lastly, the findings may offer important information to inform strategies for improving the treatment and health outcomes of men with fibromyalgia.

**Incentives to Participate:** You will receive a \$35 Amazon gift card for participating in this research project.

**Confidentiality:** Interviews will be audio recorded for the purpose of transcribing. All research records will be kept private and secure in password-protected files on the researcher's password-protected laptop, or in a locked file cabinet. Files will be backed up on an external hard drive, which will also remain password-protected.

Only the Faculty Advisor, Dr. Trish Raque, and the Principal Investigator, Christine Motzny, will have access to the raw data. Participants will be given a pseudonym to protect their anonymity. Confidential information will not be shared with anyone outside of the dissertation committee. Any identifying information will not be published, but solely used for data analysis.

If you choose to share personal mementos, they will not be published in the dissertation without your separate consent.

**Voluntary Participation:** You may choose not to continue with the interview or withdraw from the study at any time and have your data (personal information & interviews) destroyed. If you choose to withdraw from the study at any point, I will not use any of the data collected. However, gift cards will only be given to participants who fully complete the study.

**Questions:** If you have any questions about this project or your participation, please feel free to ask questions now or contact Chrissy Motzny at 408-981-7597 or [chrissy.motzny@du.edu](mailto:chrissy.motzny@du.edu). You can also contact the Faculty Advisor of this project at [trisha.raque@du.edu](mailto:trisha.raque@du.edu).

If you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by emailing [IRBAdmin@du.edu](mailto:IRBAdmin@du.edu) or calling (303) 871-2121 to speak to someone other than the researchers.

**Statement of Consent:** I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. By signing, I also give permission for audio taping during the interviews.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study. If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

\_\_\_\_\_  
Signature of Study Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

## Appendix D: Demographic Form

Thank you for your interest in this qualitative research study examining the experiences of men with fibromyalgia. Please fill in the information below to assess your fit for the study. The brief survey should take 3-5 minutes to complete.

By providing the information below, you are consenting for me to contact you to learn more about the study. All information you provide below will be kept confidential and will solely be used to contact you and learn more about you and your fit for this study.

**Please provide demographic information by self-identifying in the text boxes below:**

Age: \_\_\_\_\_  
Race/Ethnicity: \_\_\_\_\_  
Gender Identity: \_\_\_\_\_  
Socioeconomic Status: \_\_\_\_\_  
Relationship Status: \_\_\_\_\_  
Sexual Orientation: \_\_\_\_\_  
Religion/ spiritual orientation(s): \_\_\_\_\_  
Please list any other important identities: \_\_\_\_\_

**Please provide your name and contact information:**

Full Name: \_\_\_\_\_  
E-mail: \_\_\_\_\_  
Phone Number: \_\_\_\_\_

**Please provide information about your FM diagnosis:**

When did fibromyalgia first start to affect you?/ Interfere with your functioning?

\_\_\_\_\_  
What is the approximate date you were officially diagnosed with FM by a qualified medical provider? \_\_\_\_\_

Please list all other comorbid conditions, including comorbid pain conditions:

\_\_\_\_\_  
If you listed other comorbid pain conditions, which one has the most significant impact on your functioning?

\_\_\_\_\_  
On a scale from 0-10 (0= no pain), rate your average level of physical pain: \_\_\_\_\_

On a scale from 0-10, rate your average level of emotional pain: \_\_\_\_\_

Thank you for completing this survey! I will reach out to you within the next week to follow-up, discuss the study with you in further depth, and review the consent form if you are interested in participating. If you need to reach me before then, feel free to contact me at [chrissy.motzny@du.edu](mailto:chrissy.motzny@du.edu).

Please click on the arrow below to finish the survey.

## Appendix E: Invitation E-mail to Participants

Dear [insert name],

Thank you for your interest in my dissertation research on the lived experience of men with fibromyalgia. I am writing to formally invite you to participate in the study. I am excited to meet with you and hear your unique story and perspectives.

You will be participating in a qualitative study. The primary aim of the study is to offer descriptive information and personal meaning related to your experiences as a man living with fibromyalgia. My hope is to understand the essence of what it means to be a man living with fibromyalgia as it reveals itself in the shared stories of you and other men with fibromyalgia.

I hope to have more of a conversation than a formal interview. I want you to feel comfortable, valued, and heard during our time together. During the interview, I will ask you to share about your experiences of living with fibromyalgia, and what these experiences were like for you which may include your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experience. I will also ask you to share any personal mementos you feel comfortable sharing with me that feels relevant to your experience. I may invite you for a brief follow up interview if I have to clarify information you provide, or ask follow up questions.

I will strive to work with you in a collaborative and empowering manner. I will ask for your feedback in the analysis process to ensure the information we spoke about is accurate and reflective of your experience. If you have additional thoughts or ideas beyond our interviews, I encourage you to contact me so I can fully capture your experience.

I truly appreciate your willingness to spend time speaking with me about your life. Moreover, I look forward to learning from personal experiences. Please refer to the informed consent form your completed for additional details about this study and let me know if you have any additional questions. If you still agree to participate, please send me dates and times that you are available to interview and let me know if you would prefer to interview via Zoom, or phone. Also, please indicate if you would like me to send you the interview questions prior to our meeting.

Sincerely,

Chrissy Motzny  
chrissy.motzny@du.edu  
408-981-7597

## Appendix F: Interview Guide

1. Tell me about your experience of being diagnosed with fibromyalgia.
2. Tell me about the memento you choose and how it holds meaning to your experience of being a man with FM.
  - a. Prompt (if no memento shared): If you had to describe what being a man with FM means to you, what would you say?
  - b. prompt: What other words or images come to mind?
3. To what extent do you feel like you have control over the impact fibromyalgia has on you/your life?
4. What is it like discussing this topic/feelings with me? Who do you feel more/less comfortable talking about this with (e.g., other men with Fibro, women)?
5. Has having fibromyalgia made a difference in how you see yourself?  
prompt: If so, how do you see yourself as different from before you had fibromyalgia? How would you say you have changed? How much do you think about these things (e.g., stigma, gender role strain)?
6. What has been your experience of how others see you or treat you (differently) based on being a man with FM?  
Potential prompt(s):
  - a. At work/with employers
  - b. At home/with members of your family
  - c. Friends
  - d. Romantic partners
  - e. Healthcare encounters (providers, materials, support groups, FM related media)
  - f. Others? (people/settings/situations?)
7. What other messages are conveyed about men with FM in society?  
Potential prompt(s):
  - a. At work/with employers
  - b. At home/with members of your family
  - c. Friends
  - d. Romantic partners
  - e. Healthcare encounters (providers, materials, support groups, FM related media)
  - f. Others? (people/settings/situations?)
8. How have these messages you've received or experiences affected you? (physically, emotionally, behaviorally, socially)?  
Potential prompt: Do any of these bring up negative feelings for you?



9. What feelings do you experience most strongly in response to being a man living with FM?  
Potential prompt: When/where have you felt \_\_\_\_ the most?
10. How do you cope with stigma (e.g., being put down, devalued) you've experienced from being a man with FM?  
Potential prompt: Do you have particular strategies for helping you? Practical or mental ways of coping?
11. What helps you feel good about yourself as a man with FM/since your Dx?  
Potential prompt: How has that helped you live and cope with FM?
12. Anything else that I have not asked you that you think is important for me to know about your experiences related to being a man with FM?

## Appendix G: Pre-Interview Introduction Script Outline

- Thank co-researcher for taking time to interview
- Share general format for interview
  - I will share about myself & study
  - Review consent form together
  - Discuss interview format
  - Will begin the interview questions
- Feel free to interrupt at any point with questions
- Introduce myself and share about background
  - 4th-year doctoral student in Counseling Psychology at DU
    - I do not have fibromyalgia
    - Became interested in this topic after working at the VA with several men with various CP conditions
    - View pain from a biopsychosocial perspective. Validate that I understand that their physical pain is real- not in their head.
    - Purpose of dissertation is to better understand the experiences of men with fibromyalgia with the hope of illuminating ways to better support men in living with the condition.
- Briefly review consent form & method
  - I'm viewing you as the expert on this topic and will be considering you a "co-researcher"
  - This does not mean you have to write my dissertation for me - just that you have the power to edit my work, change, delete, etc.
  - I will ask you to the interview transcript and you can remove or add statements as desired
  - Please let me know if you feel I am doing injustice to your experience as it is very important to me to give your story voice and make sure my own biases do not impact your story
  - You are more than welcome to schedule additional interviews if needed beyond our interview today
  - Also can e-mail me in between interviews about other thoughts, ideas
    - I will protect your confidentiality in this study by assigning you a pseudonym and only using vague identifying information (race, age, relationship status). You will review everything before I publish
    - You've agreed for me to audio tape, all of these are saved on personal computer with your ID code, password protected
    - I hope this experience can be cathartic and empowering for you and other men; if you feel distressed by this experience, please let me know and I would be happy to help you find professional mental health care
    - After your full participation in the study, you will receive an Amazon gift card \$35; You are of course allowed to drop out at any time if you desire.

- Discuss interview approach
  - I'm hoping to make my interviews much more of a conversation, rather than just me asking you questions and you giving an answer
  - I'll be asking you questions I've developed, but you have the power to direct the interview in whatever way is important to you
  - I encourage you to share whatever comes up, even if it's not the question I ask
  - I will ask you about sharing any mementos related to your experience as a man with FM. If you don't have one today but find something later you want to share that is okay
  - You are the expert and I hope to not take up too much space in our time together so I can hear your story
  - I encourage you to answer as you feel comfortable

***Pause to explore any questions before beginning interview questions***

**Appendix H: Research Questions and Corresponding Interview Questions**

Research Question	Relevant interview questions
<b>1) How do men with FM experience living with an FM diagnosis?/What are the illness perception of men with FM?</b>	Tell me about your experience of being diagnosed with fibromyalgia.
	Tell me about the memento you choose and how it holds meaning to your experience of being a man with FM.
<b>2) What is the experience of stigma (induced identity threat) in men with FM?</b>	What has been your experience of how others see you or treat you (differently) based on being a man with FM (stigma)? prompt: members of your family, friends, employers, others?
	What messages are conveyed about men with FM in society (from family, friends, employers, healthcare providers, healthcare materials, support groups, media, etc.)?
	How have these messages you've received, or experiences affected you? (physically, emotionally, behaviorally, socially)? Do any of these bring up negative feelings for you?
	Has having fibromyalgia made a difference in how you see yourself? If so, how do you see yourself as different from before you had fibromyalgia?
<b>3) How does FM-stigma threaten men's sense of self or masculine identity?</b>	What is it like discussing this topic, feelings with me? Who do you feel more/less comfortable talking about this with (other men with Fibro, women?)
	What feelings do you experience most strongly in response to being a man living with FM?
<b>4) What coping strategies do men use to navigate FM, stigma and masculine identity threat/strain?</b>	To what extent do you feel like you have control over the impact fibromyalgia has on you/your life?
	How do you cope with (use their words – being put down, devalued, stigma, etc.) you've experienced from being a man with FM?
	What helps you feel good about yourself as a man with FM/since your diagnosis?

### Appendix I: Summary Table of Themes

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
<b>Pre-diagnosis and Early Onset</b>				<b>209</b>
<b>Precipitating Events</b>	Genetic predispositions (family hx); injury/illness; Stress/trauma (e.g., childhood trauma, series medical event, death of a parent, financial loss, accumulative stressors); Unclear etiology.	<i>“I can't change that horrific bereavement that I had when I was still in school. ... And I had a bad reaction to a cholesterol medication, and I lost \$60,000 on a bad pension investment. So, this was what I had about 18 months ago, which I felt that was the last straw for my body to contend with.” (Gregory)</i>	<b>6</b>	<b>33</b>
<b>Fibro Experience</b>	The constellation of sensations and symptoms men with FM experience and how they experience them.		<b>6</b>	<b>120</b>
Physical Pain Descriptions and Progression	Descriptions of what their pain sensations feel like day-to-day and during pain flare-ups; Progression of pain over time.	<i>“EVERYTHING hurts. Like I'm never not in pain. ... From my hair to my toenails hurts. And I don't know why, and that it doesn't feel right.” (Fred)</i>	6	41
Physical Limitations and Loss of Physical Control	Loss of control of their physical capabilities (e.g., walking, dexterity), and not being able to participate in physical activities in the same way they used to.	<i>“You can't go out running around all day. You can't go hiking through the woods and have fun and go fishing in a bass boat. Because that would hurt really bad. I'd be down for days. [Interviewer: Yeah] I can't hike that far in the woods anymore. I can't go fishing very long.” (Stan)</i>	6	43

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
Physical and Emotional Pain Linked	Mind-body connection; Vicious cycles; Worsening or improvements on one front linked to changes in other	<i>“In my head I was panicking, I was starting to panic. And what I didn't deduce at the time was that the panicking, and anxiety, and depression, and stress, manifests in pain within the body.” (Gregory)</i>	6	25
Cognitive Symptoms and Limitations	Fatigue, apathy and “fibro-fog” that interfered with functioning	<i>“Conversations get started. I don't hear em'. I get told about that often because I'm trying to concentrate on getting through this pain that's so overwhelming that it's shutting down my thought process basically. I think they call that fibro fog.” (Matthew)</i>	6	34
<b>Psychosocial Stressors</b>			<b>6</b>	<b>76</b>
Frustration with Healthcare Experiences	Feeling healthcare providers did not understand, believe them, were critical, judgmental, or dismissive of their pain; Feeling medical providers failed to treat them with empathy, failed to adequately address the mental health side of delivering a diagnosis of FM or the psychological impact of FM, and did not sufficiently prepare them for what to expect or how to treat FM.	<i>“You might have gone through the medicine handling. But I'm leaving here completely bamboozle and borderline angry. And I don't feel that's enough for me to handle the next phase very well... the doctors, they just they don't manage your expectations... they do nothing to manage your mental health, or how to manage possible expectations of your own recovery, or situation.” (Gregory)</i>	6	53
Uncertainty of Not Knowing	Uncertainty about what was happening to them when they started experiencing FM symptoms (before having a name for their experience); Uncertainty	<i>“No, it's very frustrating. I mean, it's frustrating to not know what's causing things. It's frustrating and not know how to treat it... so much trial and error and so much never knowing.” (Trevor)</i>	5	28

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
	about the cause of their FM; Uncertainty about how to treat or cope with it; Unpredictability of symptoms.			
<b>Post-diagnosis Living: Psychosocial Pains</b> (Personal, social, and emotional impact of FM)				<b>304</b>
<b>Emotional Impact</b>	Emotional responses to FM illness, FM-related stigma and masculinity threats.		<b>6</b>	<b>82</b>
Anger and Frustration	Related to healthcare encounters or responses from others and in response to physical pain, changes and limitations.	<i>“It's like trying not to let the inner being scream out, almost like that Edvard Munch painting - The Scream. That's what it feels like. For many people that are going through this, if they could just shed their skin and tear it right off. It's just basically every inch of your body there's some sort of pushback on. It gets to be irritating trying to deal with that.” (Matthew)</i>	5	17
Depression and Anxiety	Sadness, apathy, fear, overwhelmed, hopelessness	<i>“At the beginning it was very bad. I had serious depression, and you get the "why me?" and "why is this happening to me?" and all that. Especially from the point of work.” (Jim)</i>	6	33
Feeling Alone	Feeling like they couldn't talk to others about their FM or that others do not understand; Feeling ostracized or having more time alone due to changes in work status.	<i>“I was feeling very lost and alone.” (Trevor)</i> <i>“I can't go out and do activities that I used to do. So, I'm very largely alone. And it leaves a lot of time with your thoughts. And that that can be difficult when you're dealing with depression.” (Fred)</i>	5	14

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
Guilt and Shame	Guilt, shame, or embarrassment, about physical limitations, lack of financial contributions when not working, needing help; Doubting self-worth; Feeling helpless, dependent, infantile.	<i>“Families seem to be waiting for the male to have a good day, and have more credits in their bank, which they then blast through and do a big job. Then they have several days afterwards of being in a lot of pain and triggering a flare, but felt like they owed their spouses this kind of credit day. So, they feel like they're in some awful psychological anguish, that they feel embarrassed and ashamed about.” (Gregory)</i>	6	27
<b>Impact on Identity</b>			<b>6</b>	<b>127</b>
Masculine Gender Strain Influenced by Cultural Pressures and Expectations of Men	Threats to masculine identities and strain on important masculine gender roles; Social pressures to conform to traditional gender norms (e.g., to be breadwinners, providers, to not show “weakness”).	<i>“It's the stereotype of a man, you're supposed to be healthy, and the breadwinner, take care of everyone. It's hard to give that up.” (Stan)</i>	6	118
Self-Reliance & Stoicism	Challenges related to adjusting to the loss of independence, as well as accepting limitations and needing/asking for help including physical or emotional support; Not wanting to be perceived as a burden on others.	<i>“It's difficult because something that you once were able to do, now you have to sometimes depend on others. And that kinda takes away from the masculinity portion, I guess. Your supposed to be a strong silent type. My own my own outlook on masculinity may be different than others. That's probably something that I was brought up with. Don't complain.” (Matthew)</i>	6	29



Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
Work Challenges	Work related challenges, disruptions, adjustments; Having to change career paths; Lost sense of accomplishment, purpose, and enjoyment that was tied to work.	<i>“My job was the kind of job where you gotta move because we had so many customers. It was a very, very demanding job. So I went on disability and from there on, month, by month, by month, everything just kept getting worse. More pain, less mobility.” (Jim)</i>	6	36
Financial Strain's Negative Impact on Self as a Provider	Financial loss or worries about finances due to inability to work; Ways this threatened their role as a provider.	<i>“I guess from the man's side of things, there is some cultural stress that the man should be the bread winner/earner, that kind of thing. I feel I was making a good salary back when I was working in IT regularly, and now I'm bringing in a pittance. That is somewhat tolling on me. There's some [mental] adjustment there that has to happen.” (Trevor)</i>	5	15
Identity Loss	Changes men experienced in their identity, sense of self, or self-worth resulting from FM	<i>“I just don't feel like I'm productive. That my sense of worth has been destroyed because of the inability to perform. You know, jobs that would make me feel good... When you have that blank spot of accomplishment that's just there in front of you. Having to retire early. The lost sense of income, the lost sense of what could I have done in these last 10 years or next eight years if I was to work to retirement in my life. (Matthew)</i>	6	56
Internalized Stigma	Internalization of negative beliefs or stereotypes; shame about FM or its consequences. Negative impact of FM on self-concept; Negative self-descriptions (e.g., “defective,”	<i>“I come from a family of a very hardy stock. My father was an animal. He was so strong... Here I am a weakling now. What's wrong with me? Why am I so defective? You know, you point everything at you. What's wrong with ME?” (Jim)</i>	6	31

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
	“failure,” “broken,” “invalid,” “less of a person.”			
Grieving One's Past and Future Self	Grieving loss of one’s physical abilities, social status, and their ability to engage in hobbies and social roles in the way they would like to; Shattered assumptions and mourning the lives they envisioned.	<i>“There's a certain there's a certain amount of mourning the person that you used to be, and no longer are. There's a certain amount of mourning for, I'm less of a person than I used to be and that's hard to reconcile.” (Fred)</i>	6	33
<b>Social Impact</b>	Being treated different, social losses, partner frustration (skepticism, sarcastic remarks), guilt related to changes in financial contributions, needing assistance at home, or physical intimacy.		<b>6</b>	<b>101</b>
Social Stigma	Real or perceived FM-stigma experienced from others; Being viewed as “lazy,” “broken/damaged,” or as having a “women’s disease,”; Being treated differently, criticized, dismissed, ridiculed or devalued.	<i>“The way that I have been viewed by other people once they find out I have FM is not kind. I am viewed as broken, damaged, no fun, afraid they will hurt me if I'm touched. So, I'm left alone.” (Stan)</i>  <i>“I think it does affect a man's sense of well-being, of self. That they're they're told, 'oh, you're lazy.’” (Matthew)</i>	6	74
Factors That Influence Stigma			6	40
Invisible Illness	Pain not being obvious to others influenced negative assumptions and biases.	<i>“I think that it's very easy to fall into the trap of seeing someone, not knowing what's going on in their life, and saying, they're lazy, or they're a bum or, why are they working? Why aren't they doing this? Why are</i>	5	18

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
		<i>they doing that? I think that these kind of invisible diseases in general, man or woman, contribute to that.” (Trevor)</i>		
Lack of Representation of Men	How lack of representation, including the lack of information/resources specific to men with FM influenced internalized and social stigma. (e.g., internalizations of having “a women’s disease,” influenced others lack of understanding and healthcare provider bias).	<i>“...all of the body charts, the images that are used in all of the reports and the blogs, it was showing women's bodies. It wasn't showing any men's [bodies]... it made me feel, I have got women's disorder... And I was given no help, no resources by the specialists, so I was having to find my own. And the ones I was seeing, I couldn't identify with because they were showing you will get breast sensitivity, and you'll have urinary tract pain, and they were putting all these hotspots on these women's bodies and talking about women's issues. And physically I don't identify myself here. I've got very different behaviors in my body. And it just made me think there's a huge lack of male testimonies.” (Gregory)</i>	6	23
Invalidating Responses from Others	Others (healthcare providers, family, friends, co-workers, or strangers) discounting men’s pain, expressing disbelief; Others offering overly simplified advice/solutions, or making hurtful, misinformed, or unhelpful remarks.	<i>“As much as I talk to family and friends, they still don't understand what Fibromyalgia, or chronic pain, or chronic fatigue actually is. When you get, "Oh yeah, I did this and it does this," and trying to have competition on it, it tends to shut you up from wanting to say stuff, like talk to others.” (Matthew)</i>	6	47

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
People Don't Try to Understand	Lack of understanding and empathy; Wanting to be treated normal, with respect and understanding	<i>"It's just frustrating that people won't understand it or can't understand it. And most of the time, it's won't, because they don't want to believe that something like that can happen to a guy. Especially if it's another guy. Like, one guy said to me, 'That must be like stripping away your manhood.'"</i> (Stan)	6	20
Relationship Strain and Social Loss	Difficulties within relationships as they became less able to engage in social activities or roles at work/home because of their FM; Relationships deteriorating or difficulty forming new ones due to the burden placed on it or to FM-stigma; Impact on partners, partners being frustrated.	<i>"She punched out right at the beginning of a medical crisis. And I honestly believe that, among other reasons for divorcing, part of it was living with a guy with fibromyalgia. She didn't want to have to take care of somebody. So that's the single and most extreme [example of] being treated differently by somebody. She was okay when I first figured out what it was and got it under control, but when it started to slide, I think that was just one of many straws that broke the camel's back. And she peaced out."</i> (Fred)	6	22
<b>Post Diagnosis Living: Coping</b>				<b>0</b>
<b>Adjusting to Physical Aspects of FM</b>	Avoidance vs. activity-pacing/credit-system; finding what works; listening to your body while not always trusting pain sensations; adjusting flexibly to ever changing physical capacity, flexible with plans.		<b>6</b>	<b>139</b>
Navigating Physical Activity	Ways men responded to pain from a physical standpoint across time and contexts.		6	43
Activity Pacing	Finding a balance between complete avoidance of movement and over-	<i>"You've got x credits per day, if you're not flaring. If your body's in a flare it's in a punishment cycle, and</i>	6	23

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
	exerting themselves; using a “credit-system” to prevent flare-ups yet avoid muscle de-conditioning.	<i>you have none. So, you've got to find this line, your own line to stay underneath. And I really started to believe, and I supported this theory that you have a credit system within the central nervous system, once it's blown a fuse. The behavior has two patterns, if you stay under-exerted, then you've got this credit system in place... But if you exceed it, if you ignore the warning signs in your knees, or you do something which really compromises your body, you can really burn through those credits.” (Gregory)</i>		
Avoiding Movement	Fear-avoidance of movement	<i>“I felt I was becoming a prisoner. And you know, very, very cautious. Just didn't dare do anything. Didn't dare go out for the day to see a park or any of [the city's] beautiful things. I was becoming housebound through choice and nervousness.” (Gregory)</i>	4	7
Pushing Through Pain	Overcoming fear avoidance of pain/movement to disrupt the cycle of pain/disability; Willingness to have some pain; over-exertion at times; men socialized to push through pain.	<i>“Being a guy, you want to push through the pain. You want to work for your family, and provide for them, do the lawn mowing, and the house maintenance, and the car maintenance. You just push and push until it finally catches up to you and pushes back.” (Stan)</i>	5	13
Gaining Understanding and Control Through Trial and Error	Researching online and through forums, trial and error, and/or self-studies; Learning to tame it; Having flexibility; Recognizing triggers; Planning; Building knowledge through tracking or self-experiments.	<i>“...one thing to me, which I lent on all the way throughout my very fortunate amount of time of me being my own experiment... So, in my self-diagnosis, I would lean on Wikipedia... almost every day, reading up on medications and what they're intended to do. So, I nominate Wikipedia as my crutch, my token, my</i>	6	104

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
		<i>support. And I triangulate that with Web MD, and NIH, and the [redacted] med systems” (Gregory)</i>		
Medications	Trial and error of finding the right medication, medication side effects, positive effects of medications.	<i>“Pure trial and error. We’ll throw darts at a dartboard and see what sticks. There’s no rhyme or reason... I’ve tried four or five different medications. I’m still on three or four. One of them wasn’t working as well so I tried something different. And we’ve threatened to try yet another different one. It’s just a never-ending battle.” (Trevor)</i>	6	26
Identifying Triggers	Effects of weather (cold, rain, wind, heat, sun) on pain levels. Triggers that “open the pain gates”	<i>“I actually tracked barometric pressure and discovered that it’s a factor in my pain levels. It’s usually a pressure drop, usually when a storm comes it has an effect on me. So, I learned to keep an eye on the weather... three days out, five days out, so I can plan for - okay, the weather looks like it’s gonna go south, that may be a bad day.” (Fred)</i>	5	8
Making Plans and Preparing to Break Plans	Having to constantly plan ahead (for potential flares, needed breaks), yet always having to be ready to break plans; restricted freedom of being able to just do what you want.	<i>“I’m not free to do what I want any single day. You plan a day to go someone and if I get a huge wave of fibromyalgia, like where 3-4 times a day I’m napping, then I just have to say ‘no, I can’t do that today, sorry.’ It doesn’t happen too often that I have to cancel plans, but it’s always there in the background that it could.” (Jim)</i>	6	19

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
<b>Coping with Psychosocial Aspects of FM</b>	Coping with the personal (e.g., identity, social relationships, work, healthcare encounters), and emotional consequences of FM.		<b>6</b>	<b>225</b>
Perspective Taking	Finding ways to change their attitude about living with FM; Recognizing positive life changes that have come from having FM; Using humor, Practicing gratitude; Learning to live more mindfully in the present.	<i>“It just changes your outlook on life... It has, for me, I've slowed down quite a bit. And it's amazing how fast you move, and how much you miss. You miss your kid growing up. You miss all the beauty and nature. You miss the sunsets and sunrises. And now that I slowed down, it's like, wow, they are really nice.” (Stan)</i>	6	24
Working Towards Acceptance	Gaining acceptance of the chronicity of FM, the changes in their physical and cognitive functioning, and the changes in their social and occupational functioning; how acceptance was difficult, ongoing, fluctuating process.	<i>“It's not what I envisioned life to be, and it's not really what I want it to be... But at the same time, I understand that it is what it is, and I need to accept it, and kind of do my best.” (Trevor)</i>	6	27
Focusing Externally	Focusing on helping others by providing support; Engaging in advocacy or education re: men with FM; Engaging in activities that distract from and mitigating pain.	<i>“It was only when [name redacted] took very ill that it became external. And that's when I realized that if I could externalize the bulk of my thoughts in the day, then that would really mitigate my anxiety. If I could focus my thoughts on something external, I would get better comfort naturally, without leaning on the opioids.” (Gregory)</i>	5	28
Giving and Receiving Support	Group support, family support, direct support from others, concern from others, mentoring other men with FM	<i>“I'm fine. And it's probably because of being with these fibro groups... No one's hiding behind anything, because we're all suffering the same thing. And we all</i>	6	35

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
	or providing support on online forums and through advocacy work.	<i>want to help each other. So, there's nothing off limits. Everything is in the open for us in in a trusted space.” (Gregory)</i>		
Meditation or Spiritual practice	Practicing meditation, mindfulness, or other spiritual practices to achieve personal well-being in the face of FM related stressors.	<i>“What helped me a lot was meditation... Meditation helps... You just have to open up and say... this is the way it is, I can't change it. I can't change it. And everybody has to come to the realization on their own.” (Jim)</i>	5	16
<b>Coping With Stigma &amp; Masculinity Threats</b>	Various ways men with FM coped with the experiences of stigma and threats to their masculine identity resulting from FM.		<b>6</b>	<b>61</b>
Coming out of Hiding	Ways men concealed their FM or emotions at times to protect themselves from invalidating responses, stigma or identity threats; Selectively becoming more open over time.	<i>“One of the things you learn is just to be able to hide it. I mean, just socializing... Except maybe particularly on your very bad days, when it's beyond the level or you can hide it. But, when I'm out in public, I don't express nearly as much as I do in private, with just my wife around. So, I know that's sort of a mask that we all wear.” (Trevor)</i>	6	38
Communicating Challenges & Needs	Learning how to communicate with others about their challenges limitations, and needs related to FM; How they've actively navigated social situations over time.	<i>“I try not to lean on them, but I do in some cases. I want them to be kids, but there are sometimes where I really need to ask them to step up and I need their help.” (Fred)</i>	5	21



Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
Therapy	How therapy helped men learn to manage pain & how to cope with the psychosocial impact of FM (e.g., life adjustments and emotional distress, navigating experiences of stigma and FM's impact on men's identity and self-esteem).	<i>I think that anyone who has Fibromyalgia should be in counseling. At least in the beginning. And if you're having some real difficulties, if you're having self-image problems, and you're having just feelings, you can't deal with what's going on. You need somebody to talk to. (Matthew)</i>	5	20
Re-gaining Sense of Self Through Purpose and Acceptance	Ways men have worked to re-establish their sense of self; Finding new meaning or purpose in life; Finding a sense of accomplishment.	<i>"I've already had an uplift. I could live my life; I just need to have something. I don't have Alzheimer's yet, my brain is at its peak of wisdom, and it needs to sink itself into the right kind of stuff. And I want to help people. That's the only hole in my life. And I can now do that through supporting the fibro groups. Because I'm kind of a year ahead of all the newbies." (Gregory)</i>	6	31
Integrating FM Minus the Stigma	Self-as-context perspective (separating disease from sense of self/defining self-worth); Integrating FM as part of their identity or experience without negativity attached to it; Accepting they cannot control others' thoughts/actions but can control how much they allow it to impact them.	<i>I'm not less of a person, I just can't do some of the things I used to do..." (Fred)</i>  <i>"It's very reassuring from a mental standpoint to know that this isn't a failure, this isn't a reflection on me. I can, at least on a mental level except that, which over time helps ingrain it a little bit better." (Trevor)</i>	5	20
Challenging Traditional	Deconstructing and renegotiating their beliefs about how men "should be" and confronting traditional masculine	<i>"Men should talk it out, not tough it out. My dad's generation was raised on the [idea] crying never solved anything. Well, I got a few years of therapy, and</i>	6	20

Theme	Description	Exemplary Quote(s)	N Men Endorsing Theme	N Total References to Theme
Masculine Ideologies	ideologies and stigmatizing messages (e.g., being in touch with their feeling, relinquishing the need to be stoic all the time, viewing help seeking as a positive, un-equating vulnerability with weakness, and abandoning the dichotomy of men work and women’s work).	<i>quite a bit of crying under my belt to argue that point. I don't think there's anything manly about dealing with pain stoically. I can point to a number of men that I know that don't show their emotions that have unhealthy characteristics and behaviors as a result... So, I share that because to me that is being a man. Being a man is being in touch and taking apart who you are and trying to be a better person for it.” (Fred)</i>		

## **Appendix J: Acknowledgments (Continued)**

To my beautiful, intelligent, fun, caring, and all-around awesome cohort – thank you. Having each of you enter my life as part of this journey has been an incredible gift. We have all been through so much throughout this process and there could not have been any group better to go through it all with. Each of you have made this experience so much more interesting and enjoyable. I am so grateful for our friendships and so excited to see where we all go from here.

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