

“IT’S MY PAIN, NOT YOURS”
UNDERSTANDING THE ILLNESS EXPERIENCES OF PEOPLE WITH FIBROMYALGIA
SYNDROME

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ABSTRACT

Fibromyalgia syndrome (FMS) is a chronic illness characterized primarily by widespread pain, fatigue, and sleep disturbances, although it is also associated with a wide variety of other symptoms such as cognitive dysfunction, nausea, and sensitivity to certain stimuli. Biomedical research has yet to find an organic cause for FMS. The lack of a clear biological etiology, combined with diagnostic difficulties and the condition's association with certain psychological disorders, has generated controversy in the field over whether FMS is a "real" biomedical disorder with an organic cause or a condition that is primarily psychosocial. This controversy has high stakes for those diagnosed with FMS, who face significant stigma from both health care professionals and lay people. Through participant observation of FMS online support groups and social media platforms and semi-structured interviews with FMS patients and health care providers who treat FMS, this thesis explores how a variety of factors like mind-body dualism, the opioid epidemic, and gender may influence how FMS patients and physicians experience and respond to the ongoing controversy surrounding the condition. I also examine how social media and online support groups can be mobilized as sources of support, expression, and resistance against biomedical power, although based on how they are utilized they can produce both positive and negative effects on users.

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INTRODUCTION

A few years ago, I had the opportunity to shadow a primary care physician at a local clinic. I worked with her primarily during flu season, and most days were a blur of various patients coming in with headaches, fevers, and various aches and pains. One afternoon, a woman came in saying she was experiencing dull, throbbing pains throughout all her limbs and her back, with most of it concentrated between her shoulders. As a naïve undergraduate student with little medical knowledge, I found myself thinking that she was yet another flu patient like all the other ones I had encountered thus far. I figured to myself that her soreness and fatigue were likely just the flu setting in, and I prepared to hear the physician run through the typical conversation she had with flu patients. I was surprised to hear something entirely different. The woman and the primary care physician were instead discussing a condition called fibromyalgia, a condition I had never heard of before. Curious to learn more, that evening I scoured the Internet for information on fibromyalgia and discovered that unlike many of the other medical conditions I had previously encountered, this one was steeped in controversy and uncertainty.

Fibromyalgia syndrome (FMS) is a chronic widespread pain condition associated with a wide range of symptoms, most commonly muscle and joint pain, fatigue, and sleep difficulties (Bellato et al. 2012). It is the most commonly encountered pain condition in rheumatology, and it is estimated that 2-8% of the general population has FMS (Bellato et al. 2012; Cohen 2017). Nearly 90% of those affected are women (Cohen 2017; Yunus 2002). The controversy mainly arises from the fact that research has not yet completely uncovered a biological cause for the condition, leading medical experts to debate whether FMS is a “real” biomedical condition (i.e. one grounded in biological dysfunction) or one that is predominantly psychosomatic and which therefore should be addressed by a different field. Recent research has found some potential organic pathology associated with FMS, such as changes in brain morphology and chemistry, altered hormone patterns, and elevated inflammatory activity (Cohen 2017). However, these findings are not always consistent, and they have also been slow to influence diagnostic and treatment procedures (Cohen 2017). Currently, FMS continues to be referred to as a syndrome rather

than a disease, indicating that it is a collection of commonly associated symptoms rather than a discrete condition with a well-established biological dysfunction, and many health care providers may refuse to see FMS patients or treat their symptoms (Kleinman 1988; Sabik 2010).

Research Questions and Methods

Why does biomedicine continue to struggle to develop a unified stance towards FMS, despite the large number of patients who report suffering significant distress from the condition? What are the consequences of the controversy for both patients' and clinicians' experiences of dealing with FMS? How does the highly gendered nature of the condition play a role in these experiences? Finally, how can online health resources like online support groups and social media platforms help FMS patients convey and understand their experiences?

To address these questions, I conducted semi-structured interviews with three health care providers who commonly encounter and treat FMS patients. One is an internal medicine physician and another is an anesthesiologist specializing in pain management. The third health care professional is a licensed clinical social worker who also has a doctorate in sociology. She has worked extensively with the psychiatry outpatient program at a local hospital and has conducted individual and group therapy for adults with chronic pain conditions. Interview questions for the health care providers included questions about how frequently they saw FMS patients, some of the challenges they experienced in treating FMS, and how they felt online health resources influenced FMS patients.

I also interviewed eight FMS patients¹, seven of whom were women. All participants were white and had completed at least a high school education, although a majority had also completed or were pursuing a college education. In addition, because I was interested in online health resource use, I aimed

¹ Throughout this thesis, I refer to people with FMS as 'FMS patients' for brevity and ease of communication. However, I acknowledge that labeling people with FMS as patients can be problematic, as the term 'FMS patient' can define individuals and their identities by their illness. In addition, the term 'patient' can be associated with passivity and biomedical dependence, and some people with FMS will instead refer to themselves as 'fibro warriors' or 'fibro fighters.' My use of the term 'FMS patients' was largely a practical choice and is not intended to allude to these ideas or define individuals solely by their medical conditions. I ask that the reader keep this in mind.

to interview people with diverse experiences with online support groups and social media. Two of the patients reported not using in-person support groups, online support groups, or social media platforms at all, and another two patients reported only using online support groups. Two patients reported using a combination of support groups and social media, one relied on online support groups and social media, and the final patient used exclusively social media. All participants have been given pseudonyms to maintain confidentiality. Interviews with FMS patients included questions on how FMS has affected their daily life, what their interactions with health care professionals has been like, how they feel the controversy of their condition has impacted their experiences, and how different support resources have influenced their experiences if they were used.

I also relied on participant-observation of six online health resources: two online support groups and four social media pages consisting of two Facebook pages and two Twitter feeds. There is an incredibly large number of online support groups for chronic pain conditions, and an Internet search for FMS online support groups turns up many pages of results from a wide variety of organizations. There are also a large number of FMS pages on social media platforms, although they are more concentrated on Facebook and Twitter. FMS pages do exist on other platforms, such as Instagram or Pinterest, but they are less abundant and tend to have smaller user groups. For this reason, I chose to focus on Facebook and Twitter. When choosing the specific pages and forums I would follow, I tried to select sites that were as public as possible. I attempted to avoid sites where users needed to register to view content, and I tried to choose sites that were not run by larger private groups like WebMD. I also tried to find pages with a large number of users and fairly regular posts. Across all six sites, I reviewed all posts made in 2017 up until March of 2018. Because the sites are accessible by anyone, I have avoided using handles and usernames, instead identifying quotes and data based on which type of site (online support group or social media platform) they came from whenever I pull from these sources. When using online quotes, I have also left them unedited and in their original form to try to best preserve the author's intended meaning. As a result, some quotes may have grammatical and spelling errors.

Over the course of my work, I found that not only were online health resources fascinating communities to study on their own, they also provided a valuable lens onto other FMS issues I was interested in. Posts in online support groups and Twitter are anonymous, with users being identified primarily with a username and a very brief biography should they choose to use it. On Facebook, moderators of the pages are often identified by the page title, and while other users' comments, likes, and shares may be identified by name, they are able to protect their personal profiles so that all that is visible to outsiders is the name. Studies have found that in online groups where there is anonymity, users feel more free to discuss potentially taboo topics or sensitive health information because there is less fear of judgment (Merolli, Gray, and Martin-Sanchez 2012). Thus, using online health information as a lens onto various FMS topics may provide insight into issues that people may not otherwise be comfortable sharing in interviews. However, using online data also poses some limitations. There is no opportunity to follow up for clarification on potential implied meanings of a user's post, and because I focused exclusively on public data, I was unaware of how private communications between site members could change user experiences and post meanings.

In my interviews with both health care professionals and FMS patients, I was often asked if I thought FMS was a "real" medical condition. As a student with no medical training and no experiences treating or living with a chronic pain condition, I feel that I am neither qualified nor in a position to make judgments of that nature. In addition, my thesis does not aim to determine the biological realities of FMS. Instead, I hope that taking an anthropological and ethnographic approach that focuses on patient experiences of suffering will open up dialogue about the complexities of chronic pain conditions that extends beyond biomedical definitions of reality. In my interviews and analysis of online resources, it was clear that the suffering and experiences of FMS patients are very much real to them, and I want to emphasize that biomedical definitions of reality are only one way of thinking about distress.

Overview of Chapters

In Chapter One, I explore some of the assumptions that are key to biomedicine and show how these assumptions work poorly when applied to chronic pain conditions like FMS. This leads to controversy that generates significant stigma around having the condition, and FMS patients may react by asserting the biomedical reality of their condition in a variety of ways. In Chapter Two, I analyze health care providers' perspectives on the FMS controversy and unpack some of the tools and models they use to understand FMS. In Chapter Three, I turn to the gendered nature of FMS and explore how gender affects the care that FMS patients receive and the ways they express distress. In Chapter Four, I look at online support communities and examine how social media platforms facilitate new ways of expressing distress, garnering support, and finding solidarity and discuss how the perceived effects of online forums depend on the level of participation.

CHAPTER ONE: BIOMEDICINE AND THE FIBROMYALGIA CONTROVERSY

“You need a doctor who believes fibromyalgia is real, even though there is no test to prove it is.”
-Online support group post

“You know you’ve not communicated well when the patient responds with ‘So you think it’s all in my head.’”

-Dr. Richards, primary care physician

Biomedicine has massive cultural power and authority in contemporary America, and it is often considered the ultimate judge of bodily realities (Foucault 1963; Greenhalgh 2001; Kleinman 1988). For instance, students missing class must often produce a physician’s note confirming sickness to have an absence be excused. A subjective report of sickness from the student or even the student’s parents is rarely enough, and biomedicine gets the final say in whether the student is truly sick and justified in missing school. But what does it mean to be “actually” sick? How does biomedicine determine the reality of a condition? Part of biomedicine’s power comes from our belief that it is a universal, purely objective discipline that can identify real and discrete health conditions. However, it relies on several assumptions that are far from universal (Kleinman 1988). In this chapter, I examine the hidden assumptions that biomedicine operates on, with a particular focus on mind-body dualism. I show that these assumptions work poorly when applied to fibromyalgia, a chronic widespread pain condition, leading to intense medical controversy about the reality of the condition. This controversy has significant implications for people with fibromyalgia, and I explore the ways that they adapt and respond to biomedicine’s ambivalent stance towards their condition.

Biomedicine and Fibromyalgia

In *The Birth of the Clinic*, Michel Foucault (1963) argues that biomedicine’s power comes from its ability to see into the body and know it in ways that even patients themselves cannot. Physicians have both the knowledge and authority to translate a patient’s subjective, lived experiences of being unwell into objective entities of scientific knowledge, and the extraction of objective truth from subjective reports is a key aspect of “doing” biomedicine. The recasting of subjective patient accounts of illness into

objective diseases relies on one of biomedicine's most fundamental concepts: mind-body dualism. Mind-body dualism asserts that the mind and the body are two separate entities. In biomedicine, the bodily aspects of a person's condition are considered more "real" because they can be measured, observed, and quantified. In other words, they can be translated by physicians into objective measures. The mind, and the subjective mental and emotional experiences associated with it, are not only less valued but are also considered less "real" because physicians cannot confirm or otherwise easily define them.

For many medical conditions, particularly acute ones, the emphasis on objective bodily states works well for biomedicine. However, with chronic conditions, the situation becomes more complex. In *The Illness Narratives*, Arthur Kleinman (1988) argues that chronic illnesses transform patients, who must reconstruct their ideas of self around the knowledge that a health condition will affect them for many years. They must also reconfigure their sense of time and learn to re-imagine their past, present, and future in light of their chronic illness as day-to-day living becomes more challenging and precarious (Charmaz 1991). Given these intense challenges, patients with chronic illnesses are difficult for biomedicine. Not only is biomedical treatment unable to completely resolve the condition, but it also has few tools to address the complex psychosocial dimensions of living with chronic conditions. Biomedicine's intense and exclusive focus on biological dysfunction becomes even more problematic when it comes to chronic conditions that lack a clear biological etiology.

Fibromyalgia syndrome (FMS) is a chronic illness characterized primarily by widespread pain, fatigue, and sleep disturbances, although patients may also experience any number of a wide variety of symptoms, such as cognitive dysfunction, nausea, and even temperature sensitivity (Bellato et al. 2012). It is currently the most commonly encountered chronic widespread pain condition in rheumatology (Cohen 2017). Although reports of FMS's prevalence vary widely, it is estimated that 2-8% of the general population is affected, and 90% of those affected are women (Bellato et al. 2012; Cohen 2017; Yunus 2002). Despite the increasing commonness of FMS, biomedical research has yet to pinpoint an organic cause for the condition. Recent research has suggested that everything from enhanced brain responses to pain stimuli, altered inflammatory activity, sleep cycle disruptions, and hypothalamic-pituitary axis

dysfunction may play a role in generating FMS symptom (Bellato et al. 2012; Cohen 2017). However, the relationships between these potential causes and FMS have not always been consistent or particularly strong, and they may only be present in a subset of the FMS patient population. Thus, a clear organic pathology has yet to be established.

Other studies have demonstrated an association between FMS and certain psychological disorders, particularly anxiety and depression, and mood regulating drugs are some of the most effective pharmacological treatments for FMS (Cohen 2017). Again, however, the association is not particularly clear, and the directionality of the relationship is also uncertain. Does FMS cause psychopathology, or are FMS symptoms a byproduct of psychological conditions? The lack of a clear biological cause, combined with the illness' ties to several psychological conditions, has generated debate in the medical field over whether FMS is primarily a "real" biomedical disorder with a true organic, bodily cause or a psychosocial disorder whose cause is "all in the head." At the more extreme end, some physicians have argued that FMS is neither and is actually just a pattern of biomedicine-seeking behavior for patients who struggle to cope with pain and have exhausted all of their other outlets and resources (Hadler 2003; Hadler and Greenhalgh 2005). Even FMS's name reflects the controversy surrounding the condition. Fibromyalgia is currently classified as a syndrome, a term referring to a cluster of commonly associated symptoms. It is not yet recognized as an official disease, which implies that there is a clearly established organic cause (Kleinman 1988).

Further complicating the debate is the difficulty of diagnosing the condition in patients. Formal diagnostic criteria for the condition were first established by the American College of Rheumatology (ACR) in 1990. FMS was diagnosed if a patient reported widespread pain over a period of several months and demonstrated pain in a certain number of tender spots on the body when the points were pressed (Cohen 2017). These criteria were recently revised by the ACR in 2010. Physicians are now supposed to use a widespread pain index and a symptom severity scale to determine whether an FMS diagnosis is warranted (Cohen 2017). In practice, however, many physicians simply make a clinical diagnosis as there is incredible variation in the number, type, and severity of symptoms that patients present with, so most

cases do not align perfectly with the diagnostic criteria (Kumbhare et al. 2017). Regardless of whether or not formal diagnostic criteria are used, the diagnosis always relies on the subjective report of patients. There is no medical test available to confirm the presence of FMS, and the symptoms are often invisible. Patients themselves must report their subjective sensations of widespread pain and their own judgments of the severity of their symptoms. Physicians are able to guess at pain levels through procedures like tender point exams, but the patient is ultimately the one providing information on how often symptoms are present and how intense they are. The physicians must take these reports at face value. This presents a major challenge for biomedicine, which privileges and relies on objective bodily symptoms as evidence of truth. A patient is deemed sick when a physician can find something to prove biological dysfunction. The forced reliance on subjective patient reports of sensations and the lack of an organic etiology both contribute to the questioning of FMS as a legitimate biomedical diagnostic category. By extension, the legitimacy of patients presenting with FMS-like symptoms is also called into question. Patients seeking care for FMS-like symptoms are often treated with skepticism and disdain by both physicians and lay people, and in light of the ongoing medical controversy surrounding the condition, patients find that their morals and bodily experiences are routinely called into question.

Consequences of the Controversy

Biomedicine's ambivalence towards FMS has severe consequences for those living with the condition. Receiving a diagnosis is a key event in chronic illness, because it collects a wide range of diffuse symptoms under a particular label that can help a patient reinterpret past events and make predictions for the future (Kleinman 1988). It also gives the patient a shared language to use with their physicians and social circle, allowing understandings of suffering to be shared. Diagnosis is thus an important first step in creating meaning out of illness (Kleinman 1988; Undeland and Malterud 2007). However, because FMS is not completely accepted by the biomedical establishment, it fails to carry the cultural power that other diagnoses might (Barker 2005; Undeland and Malterud 2007). Physicians may not accept the diagnosis, and family and friends may not be aware of what FMS is. The patients find themselves continuing to run into barriers in communicating and sharing their illness experiences

(Undeland and Malterud 2007). All of this generates illness uncertainty, where the patient struggles to determine the meaning of illness-related events. They may feel that they cannot assign definite values to objects or events, and they cannot predict outcomes of interactions because they do not have sufficient cues to do so (Johnson, Zautra, and Davis 2006). The illness uncertainty associated with FMS not only increases the burden of living with the condition, it also increases the perceived difficulty of coping while decreasing coping efficacy (Johnson, Zautra, and Davis 2006).

Many people also reported that once they had been diagnosed with FMS, they had a harder time getting quality medical care and treatment not only for their FMS symptoms, but also for their other conditions. Sarah, a woman with FMS and several other serious health conditions noted:

The controversy has made it harder to get care for some of the other things I have. The specialists look at you, they see the diagnosis of fibromyalgia, and then they dismiss you. If they don't believe in the diagnosis, then everything else you tell them is based off that. They're remembering that you complain about something that's in your head. So they treat you through that, which makes you a hypochondriac.

People with FMS often find themselves facing considerable opposition from health care professionals who continually question the reality of their experiences even after the FMS diagnosis is applied, and the ambivalence surrounding the specific condition of FMS can leak into patient-physician interactions about various unrelated health concerns as well.

The stigma associated with a vague diagnosis is compounded by the invisible nature of the illness. The most common symptoms of FMS (pain, fatigue, and sleep disturbances) are not easily visible to others, and they may oscillate between periods of exacerbation and quiescence. This can be quite confusing for the patient's family members and social circle. In addition, the accommodations that a person with FMS may need to function are often more apparent than the symptoms that necessitated them. For instance, a person who experiences significant pain when standing may have difficulty working long hours on their feet and may need more breaks during work shifts. The person's coworkers cannot see their pain, but they certainly notice that the person takes extra breaks. Circumstances like this can lead to the labeling of people with FMS as weak, lazy, or fraudulent. FMS patients are often aware of these

judgments and experience feelings of intense shame and guilt in response (Sabik 2010). One poster in an online support group wrote, “You always feel as if people believe you’re faking. You don’t look sick so you’re not. They see a healthy-looking person. There’s no physical signs on the outside so they think you want attention, or you are just lazy. It’s the worst feeling in the world to know they think you are lying.” The stigma leads to discrediting of the self and social isolation as people’s social circles shrink to those who tend to be supportive of their condition (Charmaz 1991).

The possibility that FMS might have psychological dimensions also generates significant judgment from both physicians and lay people. In our society, it continues to be much more acceptable to have a biological disorder than a psychological one. Historically, psychological disorders have been associated with everything from social deviance to moral weakness. Today, these conditions continue to be associated with negative attributes. The stigma attached to psychological labels is so heavy that most people are reluctant to even consider the possibility that FMS may be associated with particular mental or emotional states, and they vehemently deny any connection between their mind and body. Dr. Lee, an anesthesiologist specializing in management of pain conditions, noted in our interview that, “There are a lot of patients who will try to separate out the fibromyalgia from their anxiety or depression and will take as an affront any mentioning of them together as a questioning of their sanity.” Given the high stakes in the FMS debate, people with FMS are deeply invested in making FMS “real”: in proving that it is a “legitimate” bodily condition requiring biomedicine’s oversight and intervention.

Patient Perspectives

Debate about FMS’s status as a “real” condition rages on in the biomedical community, but what do patients make of the nature of their condition? I argue that the patients I interacted with are largely accepting of the diagnosis and tend to strongly believe in the biomedical reality of their condition, championing FMS as a discrete biomedical disease with an organic pathology that has simply not been discovered or accepted yet. Some also argue that the condition is not actually controversial at all and any remaining debates regarding FMS’s legitimacy are a product of poor medical education instead.

Most FMS patients experience a sense of relief when they are diagnosed (Choy et al. 2010; Undeland and Malterud 2007). Because of the challenges associated with the diagnosis, patients often suffer for years and must see multiple physicians before receiving the diagnosis. A recent international survey found that it took FMS patients an average of 2.3 years and visits to 3.7 physicians before receiving the diagnosis (Choy et al. 2010). FMS patients are often told their nonspecific symptoms will eventually go away, or they find themselves being dismissed as overly sensitive hypochondriacs. Finding a physician who is finally able and willing to diagnose their wide range of troubling symptoms and label it all as FMS is relieving, and many people expressed how happy they were that someone would finally take them seriously. One online support group user posted, “When I was first diagnosed, it was a bit of a relief that someone took me seriously about the pain. I went for about 7 months from doctor to doctor, had X-rays, CT scans, the works, before I finally found a doctor who also had fibromyalgia and knew right away what I was suffering through.” Sarah felt similarly, saying that receiving the diagnosis “was just like a giant FU to the medical community, which had blown off people for so long.”

Other patients are relieved to finally have a label so they can move forward. For instance, Peggy recalled that when her physician finally diagnosed her with FMS, she felt “really happy that I had a name to put to what was wrong with me.” Having a biomedical label for symptoms not only restores others’ faith in the patient’s report of symptoms, but it also gives patients themselves confidence that their symptoms are genuine (Charmaz 1991). The FMS diagnosis is particularly potent, because it relieves its patients from what Kristin Barker (2005) has called “epistemological purgatory”: the contradiction between the patients’ subjective certainty of their suffering and the inability of physicians to confirm FMS’ symptoms through any tests or diagnoses (Barker 2005). Both Lisa and Sarah described their relief at receiving acknowledgment that their experiences were not “all in their heads.” For Lisa, “Once they diagnosed it, it was kind of like everything clicked and it was like, ‘Okay, I’m not crazy, I’m not going to have to deal with this for the rest of my life with no answers and no help.’” Sarah expressed a similar sentiment, saying “It was like, ‘Ok this is not in your head and you’re not making this up.’”

The FMS label confirms patients' bodily distress, provides a powerful framework for organizing their experiences, and legitimizes suffering that has long been ignored or dismissed by biomedicine. After receiving the diagnosis, patients typically come to accept that FMS is a "real condition" and will defend the reality of label. One user in an online support group posted, "You need a doctor who believes fibromyalgia is real, even though there is no test to prove it is." Another user agreed, saying "Keep talking about FM and don't ever let anyone tell you that it's in your head or you will get over it. People are stupid, and I feel sorry for those who are not connected to the real world." Other FMS patients draw on recent biomedical research to support their point, and one poster stated that "Fibro is considered a nervous system disorder due to central nervous system sensitization....They do not know why this is happening BUT IT IS NOT A PSYCHOLOGICAL ISSUE."

All three of these posts not only powerfully assert the "realness" of FMS, but they also draw on the mind-body, subjectivity-objectivity dualisms that are deeply entrenched in biomedicine and thus our broader culture. The assertion that FMS is real despite a lack of objective biomedical tests for the condition implies that real conditions typically can be confirmed via tests, and again a line between the subjective and objective is drawn. The second user's statements draw on mind-body dualism. If FMS was in the patient's head, and therefore psychological, it is less valid and could be overcome through mental fortitude. However, anyone "connected to the real world" would be able to see that FMS is not in the head, is bodily, and therefore not something one can easily "get over." The third user's post is very clear in establishing FMS as a biological issue based in an organ system's dysfunction. Interestingly, in the process of asserting the reality of FMS and defending biological explanations for FMS, FMS patients inadvertently reinforce the very dualisms through which biomedicine invalidated their suffering in the first place. By arguing that FMS is biological and therefore must be real, they conform to the notion that there really is a divide between the mind and the body and that psychosocial experiences are less legitimate and more easily overcome.

Some patients argue that FMS is actually no longer a controversial condition since biomedical research has begun to uncover some potential biological causes for symptoms. Physicians' continued

reservations about the condition are instead attributed to a lack of proper training in the medical field on FMS and chronic pain conditions more generally. George described to me his experience with trying to find a physician to properly treat his condition, saying:

There are a lot of doctors who think they can treat things but don't know what they're doing, and they put you through routine after routine that doesn't do any good. You have to get to a specialist who knows what they're doing, and it can be a difficult journey. I got to a rheumatologist who specialized in fibromyalgia, and they are able to treat it fantastically, so it's less so a matter of fibromyalgia being controversial and more of a matter of training. I had to find a doctor who knew what he was doing. There's a lot of arrogance in the medical profession and a lot of doctors are unwilling to admit they don't know things.

Many other patients I spoke with also felt that they might know more about their condition than their physicians did. Lisa made it a priority to keep up with the latest information of FMS, and she brought that information forward to her physicians: "I read about fibromyalgia all the time, especially any new research that's going on, any new medications. I just have to go in there fully prepared. A lot of the time I find that I'm telling the doctor more than they're telling me."

The Opioid Epidemic

The recent national conversation surrounding the opioid epidemic has given the controversy around FMS a new urgency. It has given physicians a new reason to doubt patients reporting chronic, widespread pain and has added pressure on physicians to be very careful in discriminating who has a "real" condition that can and should be treated with pain medications and who might just be looking for opiates. If only patients in "real" pain deserve opioids and all others should be treated as potential addicts, it becomes even more important that FMS is regarded as a legitimate condition so patients can both continue to access pain medications they may need and so they can avoid the added layer of stigma that being associated with medication-seeking can add.

It has become common knowledge that prescription opioid medications can both lead to and fuel addiction, and people regularly reporting high levels of pain to physicians are increasingly being regarded with suspicion as potential "med-seekers." Sarah expressed to me her frustration with the judgment she often encountered whenever she even brought up her FMS, saying "For a physician to tell me that I'm a

med-seeker just because I'm telling you about my pain is really frustrating." Though prescription pain medication use varies widely in the FMS population, some patients do rely on opioids or similar medications to manage their pain. For these patients, the push for regulation of pain medications has been challenging and frightening, and some are worried they may be denied the medications they need.

In response to these new pressures, FMS patients have tried to distance themselves from addicts by arguing that they are not the type of people who become addicts and that they need access to pain medications because they have a biomedically recognized condition. In the process of doing so, they draw a clear dividing line between popular notions of what addicts are like and FMS patients who use opioids. Cory discussed her frustration at having her medication use become increasingly monitored and restricted. "Oh man, it is just so frustrating. I was on an opioid-type medication for several years. So I just think to myself, 'Look, not all opioid takers are addicts.' Not everyone gets that, and it's really frustrating." Christine, who uses tramadol to manage her pain, also discussed her misgivings about tightening opiate regulations. "The percentage of people like myself who go and overdose is low compared to recreational users, who I think are the vast majority of people dying from this. It paints with a broad brush and doesn't take into account people with pain issues." One online support group user was even more explicit in dividing FMS patients from addicts, saying "I am not an abuser and I am not sure why these heroine junkies who get laced drugs are being compared to those of us who really need our opioids and who do not abuse them.... There are always going to be addicts, but they should not lump us all together."

At the same time however, many of the same people expressed fears of becoming addicted to their medications and wanted to get off their opioid medications. Lisa, Peggy, and Christine all use tramadol, an opioid-like medication, and all three women were worried about the potential for addiction, with Lisa pointing out that "It's a very slippery slope when you have chronic pain. If you do take something that makes you stop hurting, it can become a real problem." Peggy was especially wary. She had only started using tramadol for two months and had already noticed a decrease in the medication's efficacy, and she discussed her fear of being "addicted to pills for the rest of my life." Christine was so concerned about the possibility of becoming addicted that she had actually started reducing the doses of

her tramadol on her own, only taking a fraction of the amount she usually did and struggling through some days with pain in order to decrease her reliance on the medications. She told me, “It’s been a pain, but I’m determined to get off of it.”

Though it may seem contradictory that FMS patients argue that they are not addicts while also having intense concerns about addiction, I argue that it is not. Having an addiction does not necessarily entail being an addict. In technical terms, an addict is someone with an addiction. However, when FMS patients are distancing themselves from addicts, they are drawing on popular notions of what a typical addict person is like. Addicts in our society are often associated with moral weakness, criminal activity, and lower socioeconomic status. We have historically thought of their drug use as stemming from individual, freely made poor choices, rather than starting from misuse of prescription drugs given by physicians. When FMS patients say they are not addicts, they are asserting that they are not like the stereotypical addict. Being an addict would be thoroughly discrediting, but having an addiction seems softer. A FMS patient who becomes addicted to opioids would not necessarily be an addict, because it occurred as an accidental result of trying to manage a biomedically labeled condition that opioids are allowed (although not typically recommended) to be used for.

In this chapter, I have examined how biomedicine assumes a divide between subjectivity and objectivity, mind and body. FMS fits poorly into these assumed divides, generating substantial biomedical controversy over the condition’s legitimacy, with significant consequences for FMS patients. This places patients under pressure to prove that their condition is biological and “real,” and I have examined how patients legitimize their condition, particularly now that the opioid epidemic has added new pressures. In the next chapter, I reflect on physicians’ thoughts on FMS and focus on the tools and language they use to address the FMS controversy. I will also examine how patients respond to these methods.

CHAPTER TWO: HEALTH CARE PROFESSIONALS' PERSPECTIVES

“Even if it’s in your head, it’s in your brain and not your head. That’s different.”

- Sarah, FMS patient interview

Many FMS patients express intense frustration with health care professionals. Indeed, the patients I spoke with described their interactions with health care professionals as everything from “somewhat challenging” to “an absolute disaster.” Nearly everyone stressed to me the importance of finding a good physician (one who believes FMS is a real biomedical condition and is willing to treat it), and one patient mentioned to me that her support group even kept a running list of good and bad physicians. FMS patients largely regard health care professionals with ambivalence and caution, but how do health care professionals approach FMS and those with FMS? In this chapter, I examine how current trends toward patient-centered care have facilitated the use of explanations for illness that attempt to move biomedicine past mind-body dualism. I also explore how physicians leverage these explanatory models in their interactions with FMS patients and how FMS can be challenging not only for patients, but also physicians.

Models of Illness

In recent years, there has been a shift in the medical field towards more holistic, patient-centered care (Kupfer and Bond 2012; Laine and Davidoff 1996). Patient-centered care is care that is respectful of a patient’s experiences and addresses their care through clinical, social, and emotional perspectives rather than solely clinical ones (Kupfer and Bond 2012; Laine and Davidoff 1996). A patient’s individual preferences and values are also considered, and patients are encouraged to play an active role in their health care decisions (Kupfer and Bond 2012). The overarching goal is for patient-centered care to increase both the quality of care that patients receive and patients’ satisfaction with their medical care (Kupfer and Bond 2012).

As part of the push toward patient-centered medicine, medical education has increasingly incorporated biopsychosocial perspectives, and many physicians express interest in and support for the

biopsychosocial model (Laine and Davidoff 1996; Weston 2005). The model was first proposed by George Engel in response to the mind-body dualism and biological reductionism that he believed were dehumanizing biomedical care (Borrell-Carrió, Suchman, and Epstein 2004). The model asserts that health is affected by multiple levels of organization, from the societal to the molecular, and that mind, body, and environment are all intertwined (Borrell-Carrió, Suchman, and Epstein 2004). With this model, a problem such as hypertension may be understood as more than a biological abnormality in blood pressure. Explanatory factors like stressful occupations, poor access to nutritious foods, or lack of accessible exercise spaces may also be considered and addressed in patient care.

New neuroscientific research has also allowed physicians to extend the biopsychosocial model in new ways. Freudenreich, Kontos, and Querques (2010) recommended thinking “neuroanatomically” when trying to apply the biopsychosocial model by conceptualizing the brain as the site where biological, psychological, and social factors can interact to modulate behaviors, experiences, and health conditions. Several research studies suggest that brain models of pain may better explain chronic pain syndromes and that these conditions may occur when neural networks are more sensitive to pain or respond more dramatically to it (Bellato et al. 2012; Cohen 2017). In addition to its biomedical value as a potential etiological explanation, the brain model also has significant cultural value. Mara Buchbinder (2015) has shown how brain models of pain can help facilitate explanations for pediatric pain. By locating pain in the nervous system and brain, brain models legitimate pain by giving it a biomedically acceptable source while simultaneously allowing emotional and psychological experiences to play a less stigmatized role (Buchbinder 2015). They can also facilitate patient-physician communication by providing a shared metaphor for understanding how pain works (Buchbinder 2015).

Applying the Models to Fibromyalgia

Interestingly, although FMS patients often defined a good health care professional as one who believed that FMS was “real,” that is, having a biomedically verifiable organic pathology, none of the health care professionals I spoke to came down strongly on either side of the debate. They all expressed

that whether the condition was real or unreal in strictly biomedical terms made few differences in their interactions with FMS patients, and that they focused primarily on alleviating the patient's suffering regardless of what the biomedical community might argue. This may have been because all three of the health care professionals I interviewed did not assume a mind-body divide and instead subscribed to biopsychosocial and brain models of pain. Since the primary debate surrounding FMS's biomedical reality revolves around its psychological versus physical origins, these two models may offer health care professionals a different perspective on the debate and allow them to move past the question of biomedical legitimacy when doing their everyday work with patients.

These models were not only privately used by the health care professionals. All three of them brought up these models in their interactions with patients and other health care professionals for a variety of purposes. Dr. Richards, a primary care physician, often alluded to mind-body connections to legitimize patients' pain no matter where the origin might be. In our interview, he said:

I'm always careful to validate the pain and say, "I know this hurts." I try to get patients to understand that the mind and body are not separate entities, that they're connected, without trying to imply that this is all in their head. We don't know how much of it is a psychological process and how much of it is a physical process. And you mix into that social stressors, emotional issues, and sociocultural issues.

Along similar lines, Dr. Lee, an anesthesiologist specializing in pain management, spoke about how he focused on the complex nature of pain when teaching in order to emphasize the importance of trying to understand patient experiences. He told me, "I'm more cognizant of trying to educate my fellows, the people I'm training, and other physicians about the importance of acknowledging the patient experience. I try to avoid terms like 'real pain' or 'organic pain' because pain is a very complex physiological phenomenon that is inseparable from the emotional component of it." Finally, Dr. Jamison, a clinical social worker who conducts individual and group therapy for chronic pain patients in a psychiatry outpatient program, uses the brain model of pain as a way to think about treatment and overcoming the pain. In our interview she described her approach to pain by saying:

When I work with people, I don't really get into the either/or. The position that I take with everything I do is both/and. If you think about it, all pain is located in the brain. Our perceptions are all there. If you think about something like tissue damage, it really is ultimately what the brain is perceiving. And emotions are very somatic. So we can play with some of that. We can do things to change how our brain makes predictions.

In each case, the models of illness and pain are used for the health care professional's own understanding of FMS, but they are also deployed strategically to validate patients' pain, encourage acknowledgement of patient experiences, and suggest potential treatment strategies.

How do FMS patients respond to these new models? Though there is a push in the medical field towards using these integrated models, they still have not completely replaced mind-body dualism among lay people or health care providers, and the stigma associated with having a condition that is not purely biological is ongoing. Many FMS patients continue to face physicians who subscribe to mind-body dualism and have strong opinions on the reality of FMS as a biomedical condition. FMS patients' reactions to the use of these new models by some health care providers reflect the ongoing challenges they face. The patients I spoke to largely embraced the brain model of pain, primarily because it can provide a biological explanation for the condition, and several referenced it to describe their symptoms and condition to me. In my interview with Taylor, she mentioned how the brain model fit for her because it explained both her depression, anxiety, and chronic pain by tying them to similar neurological dysfunctions without implying that one had caused the other.

In contrast, the biopsychosocial model can be received poorly by patients, as just the mention of psychological or social factors can be seen as questioning the "realness" of patients' condition. As Dr. Lee noted, "There are a lot of patients who will try to separate out the fibromyalgia from their anxiety or depression and will take as an affront any mentioning of them together as a questioning of their sanity." Paradoxically, clinicians' attempts to be more understanding of the patient's experiences and life circumstances can be misinterpreted as suggesting that their condition is a mental health issue. A model that is meant to be more sensitive to patients and their experiences can actually backfire when applied to certain, more controversial conditions where biological explanations are preferred by patients.

The FMS patients I interviewed suggested that they often react to hints that their condition may be caused by mental health issues by referencing the boundaries of their health care provider's expertise and by asserting that embodied experience is more valuable than expert knowledge. Nick Crossley (2004) has shown how various social movements have challenged psychiatric power by asserting the power of lay illness experiences. He argues that mental health survivor groups have turned their personal experiences with illness into a form of cultural and symbolic capital that can be leveraged against medical authority because survivors of illness have an authenticity of experience that most health care professionals will never have (Crossley 2004). I argue that FMS patients resist biomedical power through similar assertions. Taylor discussed how she confronted a clinician who told her that her symptoms were due to anxiety by saying, "It's my pain, not yours." Sarah's rheumatologist also suggested that some of her symptoms might be a result of her depression. In response, she told me:

He's a rheumatologist. Depression's not in your scope of practice whatsoever. All you can do is tell me whether or not I have a rheumatological condition. You can say no and move on, but fuck you and all you stand for if you think you have any better concept of my own neurological and mental illness than I do because you took one semester's worth of rotation in psychiatry back in 1980.

One online support group poster expressed the same sentiment, saying "It is NOT your fault that the doctors can't see it and it is NOT your fault that they can't fix it! DON'T let them intimidate, make you feel bad about or minimize your pain because it is not theirs, it is yours." A social media post was even more explicit, featuring an image with the phrase, "My invisible disease is more real than your imaginary medical expertise." In all three cases, patients are asserting that the actual experience of pain trumps medical knowledge about the condition, particularly if the health care professional works in an area that does not deal with mental health.

Health Care Provider Frustration

FMS can be a frustrating condition for health care providers. Many physicians describe disliking situations where they are not in control, and with FMS they often find that they cannot provide patients with causal explanations or answer all of a patient's questions, provoking feelings of insufficiency,

helplessness, and guilt (Asbring and Närvänen 2003; Brauer, Yoon, and Curlin 2017). Diagnostic difficulties also contribute to frustrations. One survey of American primary care physicians found that physicians found it more challenging to rely only on patients' subjective experiences, and they often feared potentially missing a more pressing diagnosis (Brauer, Yoon, and Curlin 2017). One of the major causes of frustration is the lack of treatments for FMS. Because health care providers cannot treat FMS and fully alleviate the suffering of their patients, there is a discrepancy between their ideal physician role and what they are actually able to do to manage the chronic pain (Asbring and Närvänen 2003). The health care professionals I spoke to alluded to this discrepancy when describing the challenges they faced in managing FMS. When I spoke to Dr. Richards, he told me "There are many challenges. There's no real test to give you a diagnosis. There's really no cure for it. We don't even know what causes it." Dr. Jamison described how some of the stigma FMS patients face can be a product of these frustrations, saying "There's a lot of invalidation of their experience, from multiple places. In the medical field, practitioners obviously really want to be helpful and see that they can do something, and when that doesn't happen, it can be extremely frustrating."

In addition, patients and physicians may often disagree on the best course of treatment. The current recommendations for treatment are to combine nonpharmacologic and pharmacologic approaches, with a focus on nonpharmacological measures (Cohen 2017). Nonpharmacological treatments typically involve lifestyle changes like increased daily exercise or psychological treatments like cognitive-behavioral therapy, which have been shown to be effective in some patient groups (Bellato et al. 2012; Cohen 2017). The evidence for pharmacological therapy is mixed and tends to be poor (Cohen 2017). Few medications are approved for the treatment of FMS, with most being prescribed off license (Cohen 2017). Opioids and opioid-like medications are not recommended, and it is cautioned that if pharmacological treatments are used, the health care provider should ensure there is patient education and monitoring to check proper use (Cohen 2017).

As a result, many physicians are reluctant to prescribe pain medications, even though patients may want them as part of their treatment plan. However, physicians have used the recent spotlight on the opioid epidemic to their advantage. Providers I spoke with appeared to use the opioid epidemic as a justification for not prescribing pain medications that they may not have originally wanted to in the first place, and in the process they can shift the onus for denying pain medications from themselves to the state for imposing and encouraging stricter regulations on prescriptions. In our interview, Dr. Lee said:

The epidemic has not changed the way I treat patients because I have long been a proponent of avoiding the use of opioids in patients with fibromyalgia. However, I use it to my advantage in terms of explaining to patients that I don't think this will work for this condition in the long term and that there's also a lot of pressure not to prescribe opioids. So there's two reasons for me not to prescribe opioids rather than just the one, which is the softer argument that you had to bring to patients before all this was coming out about opioids.

Dr. Richards expressed a similar sentiment, saying

It has made it a little easier to not prescribe narcotics. Because I can say, 'You know this is a big problem. It's all over the news. These drugs are not good.' That was harder to do ten years ago than it is now. A lot of doctors are feeling more empowered to say no. It's something that maybe they always wanted to do and now this gives them a little backbone.

In *Emptying Beds*, Lorna Rhodes (1995) deploys the Foucauldian idea that power exists in fluid and diffuse grids within relationships to show that power in a psychiatric ward does not exist in a unidirectional flow that points exclusively from physicians to patients. She argues that patients are not passive objects of biomedical power and are instead engaged in constantly shifting relationships with physicians (Rhodes 1995). I argue that FMS clinicians' frustrations in treating the condition may arise from trying to negotiate continually shifting power relationships with patients. For instance, Dr. Richards' and Dr. Lee's comments about feeling empowered to say no to prescribing opioids points to the ways that FMS patients can place pressure on physicians to adopt certain treatment protocols. Patients can exert considerable power through their position as consumers, and they have certain expectations about what a physician can provide. When a FMS clinician fails to provide a satisfactory diagnosis or explanation of the condition, patients may feel dissatisfied and physicians may feel unable to achieve their own ideals for providing care.

In this chapter, I have examined some of the models health care providers may use to understand and explain FMS. These models can elicit mixed reactions from FMS patients, who may challenge health care providers' assertions by drawing on their embodied experiences of FMS. I have also explored some of the frustrations that health care professionals may experience in treating FMS and discussed how physicians may use the opioid epidemic to their advantage in conversation with FMS patients about their treatment options. In the next chapter, I move past health care professionals' experiences to return to the experiences of FMS patients and examine how gender can play a role.

CHAPTER THREE: FIBROMYALGIA AND GENDER

“I have seen doctors from one end to the other and many years ago it was called ‘psychosemantic,’ a word in the medical profession used to describe women who were not handling life.”

- Online support group post

FMS is a highly gendered condition. It is estimated that around 90% of FMS patients are women, and some studies have found that women tend to have more severe cases with greater total numbers of symptoms and more intense fatigue, pain, and tenderness (Cohen 2017; Bellato et al. 2012; Yunus 2002). Despite these striking findings, it is still unclear why FMS disproportionately affects women, although some have proposed that cycling levels of hormones like estrogen may be responsible (Bellato et al. 2012; Yunus 2002). Regardless, it is apparent that gender is a significant component of FMS. In this chapter, I explore the gendered dimensions of the FMS controversy and the ways gender affects FMS patients’ medical encounters and experiences of being ill.

Gender and the Fibromyalgia Controversy

Biomedicine has historically been unfriendly, and even dangerous, when it comes to treating women (Barker 2005; Greenhalgh 2001; Kempner 2014; Manderson 2010). For most of medical history, the male body was accepted as the biological standard, and research on normal bodily states, diseases, and treatments was largely done with men (Barker 2005). Women are also often assumed to be prone to exaggeration and to have low tolerance for symptoms like pain. Several studies have suggested that women’s pain is undertreated, and when women do receive attention for their pain, they are more likely to be prescribed sedatives while men receive pain medications (Hoffman and Tarzian 2001). A whole host of theories have been offered to justify this discrepancy in medical treatment. Some have argued that women complain more often of pain, women are less accurate reporters of pain, women’s bodies are intrinsically better able to tolerate pain because their bodies are built for processes like childbirth, and that men are more reserved so if they are reporting pain it must be very intense (Hoffman and Tarzian 2001).

Because of these factors, many women's reported symptoms may be dismissed as simply being a normal part of being a woman (Manderson 2010). Several of the women I spoke to in interviews mentioned that their FMS pain was initially ascribed to other female conditions like premenstrual syndrome or menopause, which added to their difficulties obtaining the FMS diagnosis and getting proper treatment. One woman I spoke to struggled with infertility, and when she began reporting FMS symptoms, her pain and fatigue were often ascribed to her infertility issues. At the same time, women's bodily processes are increasingly being medicalized and treated as abnormal bodily states requiring biomedical intervention (Barker 2005; Greenhalgh 2001). For instance, menopause is now typically viewed as a medical condition and is often treated with hormone therapies. Medicalization is partly driven by the biomedical field and pharmaceutical industries, but women themselves are also contributing to the process (Barker 2005). It has been argued that because the medical field has historically been so dismissive of women's complaints, medicalization of certain conditions is one of the few ways women can get access to serious medical care (Barker 2005).

However, medicalization is often incomplete. Women have historically been, and continue to be, the majority of patients with contested diagnoses like neurasthenia, hysteria, and migraines (Barker 2005, Kempner 2014). Because these conditions are contested in the biomedical field, diagnosis fails to provide patients with the legitimacy that other diagnoses often do. Women diagnosed with FMS continue to be treated with suspicion and their symptoms continue to be ascribed to negative personality traits or weakness rather than biological causes, despite the biomedical label that their condition now has. As one woman in an online support group posted, "I have seen doctors from one end to the other and many years ago it was called 'psychosemantic,' a word in the medical profession used to describe women who were not handling life."

FMS patients are often characterized by physicians using negative, traditionally feminized labels such as neurotic, perfectionistic, and illness-focused, and some studies have attempted to describe a "fibro personality" (Da Silva et al. 2017). In one recent biomedical study, researchers sent FMS patients and

controls personality questionnaires and then asked physicians to select the personality traits they thought were most discriminating for FMS. These traits were then used by the physicians to evaluate the patient questionnaires and physicians attempted to determine if the questionnaire was completed by a person with FMS. The goal was to try to determine, as objectively as possible, if health care providers could pick out a “fibro personality.” The researchers concluded that there was a slight relationship between FMS and personality and that health care providers could sometimes recognize FMS patients based on certain personality traits (Da Silva et al. 2017). The most commonly chosen and discriminatory items were from the neuroticism domain of personality (Da Silva et al. 2017). Interestingly, all of the FMS patients and all of the controls in the study were women, and the physicians choosing traits and evaluating questionnaires were informed of this (Da Silva et al. 2017). It is unclear how this may have affected the physicians’ responses, and the study does not address the gender issue. However, in the process of trying to search for an objective FMS personality that can be applied across all patients, biomedical research may actually reinforce gendered ideas about women’s pain and personalities.

The gendered labels associated with FMS are problematic and discrediting not just for women with FMS, but also for men. Because the condition is disproportionately diagnosed in women, it may be harder for men to get a diagnosis. One online support group poster lamented his struggles in obtaining a diagnosis, saying “I find that my doctor does not take me seriously if I talk about chronic pain and something like fibro. I think it’s because I am a man...I feel like there is a lot of stigma attached to a man having this condition so I rarely talk about it to anyone.” Even after the diagnosis, physicians and lay people may not take men seriously because FMS is a “woman’s problem.” An online support group poster described his experience with talking to his father about FMS, and said “But lately he’s been so judgmental over this. He said, ‘It’s a disease that typically affects women. How did you get it?’” Men are thus emasculated not only by their symptoms, which can make it difficult to perform traditionally masculine traits such as strength, but also by the negative labels that come with having a condition associated with women and negative, feminized personality traits.

Gendered Experiences of Fibromyalgia

In my research, I found that FMS patients often express their distress through gendered idioms. Women often expressed their sadness at not being able to interact with their family or keep up with the household chores they were accustomed to being in charge of. For instance, one support group user described how difficult it was to keep up with her children, saying “I play with my kids on my good days but they notice the bad days, and it makes me sad because all I can do is sit with them while they play...I want to play too!!” Another poster described her feelings of guilt and not being able to contribute to chores and her relationship with her husband, saying “I always feel guilty. Guilty whenever I talk to my friends and husband about fibro (don’t like being a downer), guilty for not doing more around the house, guilty for canceling plans with friends.” In my interview with Lisa, when I asked her how FMS had affected her life, she immediately mentioned the severe effects it had had on her relationships to family:

There are days where I just have to lay under an electric blanket and not do anything. I mean literally, I can’t even clean my own house. It’s like having a one-thousand pound weight laying on your body. I have my daughter and she and my husband have had to just learn that if mom’s on the couch with her blanket on, you just leave her alone. It’s challenging to feel that way.

In *The Illness Narratives*, Arthur Kleinman argues that in addition to expressing distress through traditional notions of family care, middle-class American women also increasingly express their suffering in the context of the modern American ideals of independence, personal freedom, and discovery (Kleinman 1988). Many of the women I interviewed and the posts I saw on online resources supported this assertion. One online support group user stated, “I’m not the wife, mother, or career woman I want to be, or once was. I feel sorry for my husband and kids. They don’t deserve this, and neither do I.” Another group user seconded the statement, describing her shame and sadness at being forced to rely on her mother and son to perform basic daily tasks that people her age should be able to do themselves:

I feel awful that my mother and my son have to care for me like I’m an invalid. I should be the one taking care of my boy, not the other way around. My poor mother has a multitude of her own health issues to deal with, as well as running her own business and making sure the house is kept up. At 31 years-old, I shouldn’t even be living with her in the first place. I should have been on

my own years ago, with a job and an apartment of my own, if not a house. I should be self-sufficient and teaching my son to be the same. Instead, here I am.

Men also expressed their suffering through gendered idioms, and they often spoke about how the symptom of fatigue could be felt more disabling than the pain because it prevented them from performing the strength and independence that is expected of men. One online support group user described his struggles of being a man with FMS, saying:

I know what it feels like to not be taken seriously, or to be seen as healthy and normal...until I try to get out of bed, or up from a movie theater seat after sitting for almost 2 hours. Or going through a grocery store loading up a cart and having it get progressively heavier and struggling to push it despite the pain in my arms and legs because, well, I'm a guy and I can't look weak.

What is striking in these quotes is the intense guilt and sadness that both men and women experience when their condition prevents them from performing expected social roles and forces them to depend on others for care as a result. In fact, many people were willing to exacerbate their pain in order to do things like push a grocery cart so they would not appear weak or dependent. Women who are unable to be as involved in their home life as they used to be or who have had to give up career aspirations allude to these limitations when describing how FMS has changed their life. Men described feeling emasculated because they were unable to be the strong providers that men are expected to be. In both cases, FMS patients are distressed not only because they cannot provide the care that their gender roles expect them to, but also because they require care. Perceptions of symptom severity are thus dependent not only on bodily sensations, but also on their impact on the person's ability to perform expected social roles.

Gender in Health Care Professional Interactions

Gender plays a role in interactions between patients and health care professionals. Susan Greenhalgh (2001) argued that women are doubly silenced in medical encounters. Not only do they face the imbalance of power that exists in all physician and patient interactions, but they must also contend with gendered power differences since most physicians are men (Greenhalgh 2001). Greenhalgh argues that in medical situations where the stakes are high and the condition is chronic, women may try to take a

relational approach to their interactions with health care professionals and will focus on cultivating a good relationship with their physician even at their own personal cost (Greenhalgh 2001).

However, in interviews I conducted and on online support group and social media sites, women with FMS regularly reported contesting their health care providers' judgments. This may partially be due to the contested nature of the condition. Lisa described how the controversy surrounding FMS forced her to stand up:

It's made it so I understand beyond a doubt that I have to be my own advocate when it comes to my health. I can't be someone who just goes to a doctor and listens to everything they say and follows their instructions blindly. We recently moved, and the first physician I saw here actually told me I didn't have fibromyalgia. I was like, 'Mmm, no.' I don't listen to them.

Many FMS patients are also empowered by participation in support forums, whether online or in person (Barker 2008; Uden-Kraan et al. 2008). These communities help confirm for the patient that their suffering is a legitimate biomedical condition deserving and requiring medical intervention, and they can empower users by giving their lived experiences of suffering authority over medical knowledge (Barker 2008; Crossley 2004). One online support group described her irritation at her physicians and referenced her personal experiences by posting:

Also, do your doctors tell you to "keep moving"? I've decided they don't know what they're talking about. If I move too much (exercises and daily activity) I feel worse than when I just relax and do some light household chores and maybe some light stretching. Those docs can tell me to go for a walk when they experience fibromyalgia for themselves!!!

Here the user is very explicit about how her own experiences with fibromyalgia give her more authenticity and legitimacy in judging treatment protocols than clinicians because the vast majority of them will never personally experience the burden of FMS.

The shared experiences of being disparaged by health care providers also bring FMS patients together, and stories about how a patient moved from clinician to clinician before finally receiving a diagnosis powerfully unite patients and provide a sense of vindication. Members also encourage each other to search for physicians who will recognize their condition, and they even make suggestions for

how to confront their physician and what treatments to inquire about. On one online support group, there was even a posted guide for how to interview a physician to determine their stance on FMS. Even if FMS patients are not confronting their physicians directly in encounters, they can resist biomedical power through support groups and social media. Support groups and online resources allow patients to express their frustration with the medical field, and users can indirectly challenge health care providers by offering negative reviews of them. Thus, support groups and online resources may provide patients with empowerment and alternative means of resistance against biomedical power.

Online support groups and social media pages can also play into gender issues in another way. The vast majority of FMS support groups and social media sites that I encountered were run by women and were composed mostly of women, although men also participated and commented. Many of the articles posted in the groups addressed women's issues, such as how FMS might affect pregnancy or how menstrual cycles can influence FMS flares, and images often depicted women. Figure 1 is an image from the Facebook support page Living with Fibromyalgia Net, and it aims to explain what FMS is. The image depicts a woman, and the caption includes a sentence stating that most FMS sufferers are women, a true statement. However, several people reacted to the post's mention of gender. One woman commented that she knew several men who had it, and a man commented that not all FMS patients were men.

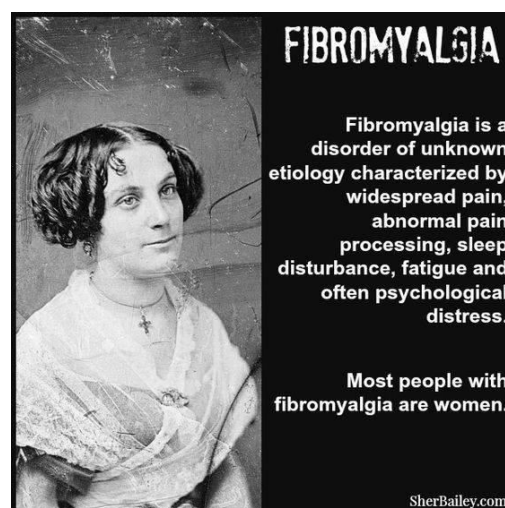


Figure 1. Living with Fibromyalgia Net post

As a result, men may not necessarily identify with the posts, questions, or images used by online pages. One man commented on a social media forum, “Wish some of your ads showed men. I have recently been diagnosed after years of not knowing what was causing my horrendous leg pain. Of course I know it’s harder to diagnose in men since probably 80% are female. I do love the site!”

Support groups and online resources can be places where FMS patients can express their distress through gendered dimensions while experiencing less stigma at admitting they struggle to fulfill expectations associated with their gender. Groups can also be empowering and encourage resistance against biomedical power that has historically be dismissive of women’s suffering. However, the overall impact of the resources on FMS patients can vary depending on a user’s gender. In the next chapter, I explore in more depth the other ways social media, online support groups, and regular support groups affect FMS patients and how patients and physicians use and perceive them.

CHAPTER FOUR: THE ONLINE COMMUNITY

“Sometimes you’ve got to dwell and go eat worms with your friends and say, ‘Nobody understands, everything hurts.’ But other times you just have to say bye to it.”

- Taylor, FMS patient interview

The past decade has seen an explosion in the number of online health resources available to patients. Not only are there more informational websites run by health care providers, but there are also more online support groups and social media platforms where patients can interact with each other and discuss their conditions. Online support groups are sites that support basic online conversations, and they typically take the form of bulletin boards, newsgroups, listservs, and chat rooms (Merolli, Gray, and Martin-Sanchez 2012; Barker 2008). Social media platforms take the level of social interaction that can occur one step further by allowing users to create and exchange their own content (Hamm et al. 2013). The main difference between the two thus lies in the types of media that can be created and the degree of interaction, although as online support group sites become more sophisticated, the difference has closed somewhat (Merolli, Gray, and Martin-Sanchez 2012).

Chronic pain patients are one of the leading user groups of online support resources, potentially because they have poorer health status and experience more stigmatization and isolation because of their condition (Merolli, Gray, and Martin-Sanchez 2012). Studies have found that users typically have positive experiences and report feeling more hopeful, socially supported, and informed about their condition (Barker 2008; Hamm et al. 2013; Merolli, Gray, and Martin Sanchez 2012; Uden-Kraan et al. 2008). But what is usage like when the chronic pain condition is also medically controversial? In this chapter, I explore how and why FMS patients use online support groups and social media platforms and discuss how the unique features of online resources can allow for new ways to communicate illness experiences. I begin by providing a general overview of the support groups and platforms I studied in my research and then shift to looking at how they are used by patients. I argue that the use of social media can help convey the experience of living with chronic pain by making pain visible and concretizing suffering by describing the functional, everyday consequences of pain. I also argue that though these forums are often found to be

empowering for users, the use of online resources can actually be a double-edged sword depending on a patient's level of participation.

Overview of Sites

For this study, I looked at two online support groups and four social media platforms. The two online support groups I chose to study had similar setups. Both were almost exclusively text-based and interactions occurred when a single user wrote a post and then others commented or replied to the post. Despite the similarities in setup, they turned out to produce slightly different interactions. The first online support group, Living with Fibromyalgia, tended to be more utilitarian. The user base seemed large and diverse, and the site was also regulated by moderators, who responded to posts with their own thoughts and also imposed some limitations. For instance, their "Physician Recommendations" page accepts only positive reviews, and negative review posts in other categories are often prohibited from mentioning physicians by name. Oftentimes users would ask questions or seek recommendations for alleviating symptoms, finding physicians, or trying new treatments. Users new to the diagnosis would also explain their symptoms and ask for information about how to adjust. However, there was still a significant amount of sharing of personal experiences. People often posted about their "fibro story" and other users would comment with support and encouragement. Daily Strength, the other online support group, seemed to be less of a site for questions and answers (although there were several posts like this) and more of a forum where users could vent and share their deeply personal experiences. Perhaps because of this setup, the majority of posts seemed to come from the same several people who would sometimes do "check-ins" that were updates about their lives and which were not necessarily related to FMS.

For my social media platforms, I chose to study two Facebook pages and two Twitter pages that were FMS themed. I focused on Facebook and Twitter because from general searches for accounts and pages, it seemed that these two platforms had the largest volume of FMS pages. The two platforms are also reasonably different in their format. Facebook is considered to be a social networking site, whereas Twitter can be described as a blog or microblog format (Hamm et al. 2013).

For my two Facebook pages, I chose Living with Fibromyalgia Net (not run by the same group that runs the Living with Fibromyalgia support group) and Fibromyalgia Support. Both pages tend to share FMS related articles and images. There are very few text posts, and even when text is used, they are often three sentences or shorter. Both pages can also sometimes have a support group feel because they allow users to message the owners of the page with questions. The page creators then post the questions and allow others to respond to the question. Fibromyalgia Support did this more often, and their images and articles also tended to be focused on positive, inspiring, and hopeful sayings, whereas Living with Fibromyalgia Net's images and articles tended to try to depict what it feels like to have FMS and live with pain.

The two Twitter pages are much more text-based than either of the two Facebook pages. The advantage to this is that the posts sometimes have more of a narrative feel, particularly because the pages are chronologically organized. In addition, while the Facebook pages often posted new content every few hours, the posts on Twitter were much more sporadic. Depending on the page owner's health and availability, Tweets could be very frequent or even completely absent for a few months. The page titled Fibromyalgia is run by a small group of women sharing their personal struggles with FMS, which helps give readers a sense of what a FMS illness journey might look like. In contrast, the second page, Fibromyalgia Wellness, tended to post less original content and many of their posts are retweets of articles and information from other FMS sites. Both sites used hashtags like #fibromyalgia to help organize and structure their posts.

Interestingly, all the FMS patients I interviewed who did use social media platforms reported that they preferred to use Facebook. One reason for the preference was that Facebook was more conversational than Twitter, which has character limits. The interactions on Twitter also tend to be more about liking and retweeting rather than responding with comments directly to posts. The preference may also be due to age, since FMS tends to affect middle-aged women most. When I asked one interviewee

why she had chosen to use Facebook over Twitter, she laughed uproariously and told me, “Oh honey, it’s my age. I don’t know much about those other sites.”

Now that I have provided an overview of each of the online support groups and social media platforms, in the next section I explore some of the content being posted on each site.

New Forms of Expression: Making Pain Accessible

Pain is a complex, multidimensional, and invisible experience, and it can be extremely difficult to capture it completely. Elaine Scarry (1987) argued that pain resists language and can only be partially objectified through language. As a result, pain patients can struggle to convey their pain to health care providers, and health care providers in turn struggle to translate subjective reports of pain into objective biomedical measures. Pain assessment in clinical encounters also often focuses only on intensity and ignores the other aspects of pain, such as when it is felt, its quality, and its functional impacts (Lichter-Kelly 2007). Thus, patients seeking to understand and express their suffering more fully may have to turn to other outlets.

One of the great advantages of new social media platforms over traditional online support groups is the ease with which images can be generated and shared. Gonzalez-Polledo and Tarr (2016) argue that because social media allows the incorporation of visual and multimodal elements, it has the power to extend traditional illness narratives. They examined posts by chronic pain patients on Flickr and Tumblr and found that images helped to make pain felt through metaphors, portrayed the experiences of living with pain, and emphasized the chronicity of it (Gonzalez-Polledo and Tarr 2016).

I argue that the images on FMS Facebook pages work in a way similar to the ones on Flickr and Tumblr. Many of the images I came across aimed to depict what it felt like to live with pain and did so by illustrating for viewers some common cultural metaphors for pain that Americans use in lay and medical interactions. For instance, Figure 1, an image from Living with Fibromyalgia Net, draws on typical descriptions of pain as “burning” by depicting and referencing an actual fire. The crackled and smoky

nature of the image adds to the fire references, and the widespread distribution of the fire alludes to the widespread pain that is a hallmark of FMS. Finally, the body is splitting apart and the posture of it evokes tiredness and despair, creating an overall effect that makes the caption ‘Pain wanders through my bones like a lost fire’ significantly more powerful.



Figure 1: Living With Fibromyalgia Net image, fire

Figure 2, another post from Living with Fibromyalgia Net, works similarly. Tingling or sharp, concentrated pains are often described using phrases like experiencing ‘pins and needles’ in a particular body area. This image takes a body and covers it entirely in actual needles. The post evokes pain not only through the needles metaphor, but also its strategic use of posture. The person is lying on the ground in fetal position with their hands on their head. Overall, the effect is to create an intense dialogue between the caption of ‘Sick of hearing I don’t look sick’ and the image it is found on, which makes aims to make the sickness and pain that is often invisible much more understandable and present.



Figure 2. Living with Fibromyalgia Net image, pins and needles

People respond strongly to these images. Posts like this receive many likes and shares, and people often comment that they can identify with how this image makes them feel or that the image accurately depicts their pain. This identification may be facilitated by the fact that bodies in images like these often lack faces, allowing users to read themselves into the bodies and the pain. By combining phrases with images, posts can express dimensions of pain that could be less impactful if said with words exclusively. Many of us may describe our pain as burning or feeling like pins and needles, but to see images of these things breaking through and embedded in bodies uniquely conveys the extent and intensity of pain. The severity dimension may be particularly important. Some FMS symptoms like headache or joint pain can sound like issues that affect everyone. By showing that these symptoms are much more intense than the occasional headache everyone else may get, these images may help to better communicate the FMS experience.

Shared Symbols and Narratives

In addition to depicting or evoking sensations of pain in viewers, images can also become symbols or content that a wide number of FMS patients can rally around and find solidarity in. Looking through the Facebook pages, I often encountered memes about chronic pain and FMS more generally. Memes are images or pithy phrases that are continually ‘remixed’ and changed to encompass a wide range of particular experiences associated with a basic, overarching theme (Wiggins 2014). They promote

participation through the imitation and remixing of the original meme, and because they typically draw on humor and sarcasm, they can be spread quite rapidly and generate support through shared amusement (Wiggins 2014).

Memes in the FMS context often allude to the day-to-day challenges of living with the condition. For instance, uncertainty about the nature of pain, the progression of symptoms, and what to expect from the body on a day-to-day basis is a central part of most chronic pain conditions (Charmaz 1991). The meme in Figure 3 alludes to this uncertainty. Similarly, the meme in Figure 4 references the challenges of the fatigue that is a major symptom of FMS, while Figure 5 alludes to the struggles that many FMS patients face in their encounters with health care professionals. All three convey the day-to-day concerns of FMS patients, and many patients find recognition of their experiences in these memes that outsiders may not be able to. The power of memes thus seems to be that they are specific enough to the FMS experience that FMS patients can rally around them, but still ambivalent enough that they allow individuals to read their own experiences into the meme.



Figure 3: Living with Fibromyalgia Net meme



Figure 4: Living with Fibromyalgia Net meme

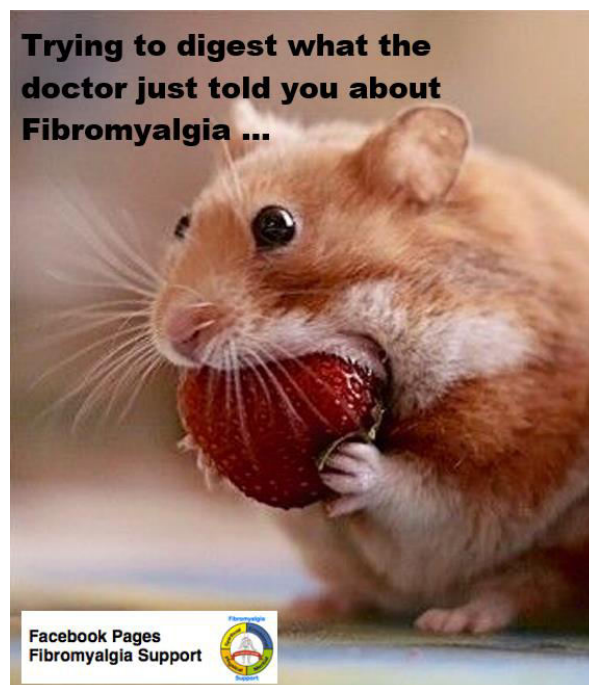


Figure 5: Fibromyalgia Support meme

Beyond memes, hashtags are also an important vehicle for sharing experiences and building solidarity over a shared phrase, while still being vague enough to let each user have their own individualized input. For instance, the Twitter page Fibromyalgia started an awareness campaign called the #hurtswithfibromyalgia challenge where she called on followers to use the hashtag to post about what experiences were painful for FMS patients. The main account would then retweet the posts. People responded to the challenge with everything from “#breathing #hurtswithfibromyalgia” to a photo of an electric blanket with the caption “#resting #hurtswithfibromyalgia.” Hashtag or content sharing

campaigns like this one work in a way similar to memes. In this instance, #hurtswithfibromyalgia specifically references the challenges of everyday living with FMS and becomes something a wide community can bond over. At the same time, by inviting other people to participate and use the hashtag, the hashtag provides wiggle room for FMS patients to assert their individual experiences of living with pain.

Hashtags and content sharing campaigns can also be powerful advocacy tools. Something like a hashtag or meme can be spread very widely and rapidly, to the extent that they are no longer limited to only the people who are viewing the page but also to anyone who is checking for tags related to FMS, pain, medical conditions, or even completely unrelated topics. Twitter posts trending hashtags, so if enough people are using a particular one, it can be viewed by a very large number of people. In addition, by combining hashtags, topics become linked. For instance, if someone posted that #breathing #hurtswithfibromyalgia, another random user looking at #breathing as a hashtag could come across the linked FMS tag.

This points to another important feature of social media and online support groups. Content created by FMS patients can very easily be shared with those who do not have FMS in order to help them understand what it is like to have the condition. When I spoke to Peggy, she mentioned that this was one of the main reasons she used online support groups and social media, saying “One of the things that the support groups and social media have helped me with is sending the posts to other people. Sometimes when I don’t have the words to describe how I’m feeling, it turns out someone else does and I can send along a link to some post instead.” Research has also found that many FMS patients report wanting more information online that is intended for readers other than themselves so they can share it with others and increase public awareness of the condition (Chen 2012).

Searching and Sharing Information Online

Besides being a forum where people can try to share and bond over their experiences, online support groups and social media sites are also valuable places for FMS patients to not only find existing health information, but actually create new knowledge based on their personal experiences (Barker 2008; Sosnowy 2014). Many online resource users report finding support groups and social media platforms to be helpful for obtaining medical information, and some users stated that it was even more helpful than information they got from physicians or health care information websites (Barker 2008, Chen 2012, Hamm et al. 2013). This may be because these sites privilege embodied experience over expert knowledge and make the process of understanding a condition collaborative and public. On both online support groups and social media platforms, people frequently ask questions about symptoms and treatments and seek answers from others with FMS. For instance, one online support group user posted, “I was just wondering if anyone else has experienced unintentional muscle jerks. I get them quite often and wasn’t sure if it was related to fibro or not...”. Other support group users then responded that they had experienced this and that they believe it was indeed caused by FMS, adding muscle jerks to the already long list of symptoms grouped under FMS. The same process happened with many other symptoms, such as chest pain and cold feet. In addition, the moderators of social media platforms often retweet or post articles about FMS, and many of the articles suggest connections between a wide range of symptoms and FMS. Articles I came across linked everything from inflamed rib cartilage, amenorrhea, eye problems, cancer, and temporomandibular joint pain to FMS.

These sorts of articles and posts contribute to the medicalization of FMS. Medicalization, the process by which a wide range of experiences comes to be classified as medical conditions, was historically driven by physicians’ professional power (Barker 2008). However, it is now increasingly done by patients in defining their symptoms and issues as medical, a phenomenon called ‘consumer-driven medicalization’ (Barker 2008). Through online forums, FMS patients collectively argue that their condition is truly a biomedical problem with biological origins, and in the process they medicalize the

condition. In addition, through symptom sharing, an ever-wider range of bodily experiences come to be collected under the FMS label. Barker argues that as a result, patients using online resources have the power to simultaneously define and authenticate the existence of FMS (Barker 2008).

The Double-Edged Sword

Many studies have found that participants in online support groups and social media support pages report gaining valuable social support that can significantly alleviate their distress and help them feel empowered (Barker 2008, Merolli, Gray, and Martin-Sanchez 2012, Uden-Kraan et al 2008). As I studied the various online support group and social media pages, I saw many posts that seconded these findings. For instance, one online support group user posted, “This is the beauty of the support group: aside from the information and the experiences we share, just knowing that people “get it” is helpful and makes you feel less alone.”

However, most of the studies reporting improved social support and user satisfaction have been done with active participants in support groups. In reality, the vast majority of users of online support groups and social media pages are lurkers (Nonnecke and Preece 2001). Lurkers are individuals who read posts but do not write any of their own, and it is estimated that the ratio of lurkers to posters could be as high as 100:1 (Uden-Kraan et al. 2008). All of the FMS patients I interviewed were lurkers. Some reported posting very occasionally, but most only followed the sites and read others’ posts. In my interviews with both physicians and FMS patients who used these online resources, I found that the majority regarded online resources with ambivalence and felt that groups could both harm and help. I argue that the discrepancy between reported feelings of support and empowerment and the reality of ambivalence may be due to differing patterns of use.

What counts as support depends on the level of investment in the community and the position in the online interactions. A poster who airs their grievances or questions may feel very empowered and supported when people respond with encouragement or answers. However, as a lurker who sees other

people frequently posting about their troubles or symptoms, it can sometimes be disheartening, force a focus on the negative aspects of the condition, and feel repetitive. Thus, lurkers may experience some of the positive effects of support groups and social media pages while also experiencing additional negative effects. Lisa mentioned to me that she initially liked keeping up with support group pages, but soon grew tired of them:

I kind of feel like when I'm talking what the fibromyalgia does it feels like I'm whining. I know with support groups there's supposed to be people there who are going through the same thing. I talked to some people online who also had fibromyalgia, and I ran into a lot of people who mostly wanted to talk about how angry they were that they couldn't get more pain meds or how angry they were that their doctor wasn't listening to them. It just seemed like the same thing over and over again. It didn't seem like there was a lot of progress, so I never really participated.

Sarah described to me a similar experience with online support groups and social media by likening it to yoga:

If you read too much of it, you can become too subconsciously focused on it. It's like yoga. There are two ways to do the meditation component of yoga. One is to use your mindfulness skills to focus on other things and distract yourself from your pain. Then there are times when you have to lean into it and feel all the pain and bad things. So most of the time the plan is to distract and focus on the positive and all that. But there are other times where it's necessary to be aware of everything, and that's important too because sometimes in order to get better you have to realize how bad you feel. That's how I feel about the social media stuff sometimes. It's a double-edged sword.

Another interviewee, Taylor, also drew on the idiom of a double-edged sword to explain why she felt ambivalent about using social media, saying "It's definitely a double-edged sword. Sometimes it makes me even more anxious about my condition but sometimes it's helpful to read about others going through the same thing you are." Thus, using a support group may sometimes be helpful and empowering when patients use it to find solidarity, encouragement, and validation of their pain, but at other times it can pull readers into an attitude of negativity or fear about their condition.

Interestingly, the health care providers saw online support groups and social media pages as both a potential help and harm for FMS patients for many of the same reasons. Dr. Lee expressed his concern that support pages may pull patients into a negative attitude:

The problem with social media is it's like a self-selecting confirmation. You might have thousands of friends but the ones you rely on and believe are going to be the ones who have your point of view. The danger is that if you tend to be more of a maudlin, glass-half-empty personality, then you're going to get a lot of people who may be trying to encourage you but may support and reinforce your point of view. If you look at some of the fibromyalgia support stuff online, you're going to have people who are like "Go for it! It's not devastating! You can do it!" and then you have a lot of people who are like "My fibro is devastating! I'm debilitated! It's terrible!" And if you fall into the wrong kind of website, then you're just going to go down that pathway.

Dr. Jamison described her thoughts about online support pages in a similar way:

It can really be like going down the rabbit hole. Support groups of any sort are only as good as the structure and culture that creates it. I think they can be really helpful when used well, and I think they can also get stuck and help solidify an identity that isn't so helpful.

Social media and online support groups are clearly a mixed bag among health care professionals and FMS patients, depending on how they are used. In some instances, they can be incredibly helpful and offer patients new ways to express their suffering, find solidarity, and share information with other patients and even people who do not have FMS. Paradoxically though, the same groups designed to provide support can become tiring and promote negative attitudes depending on the structure of the group and when and how they are used.

CONCLUSION

In this thesis, I have used an ethnographic approach to explore how FMS patients and physicians experience and react to the ongoing medical controversy surrounding the condition. To conclude, I briefly summarize my findings from each chapter.

Brief Summary

In Chapter One, I argue that some of biomedicine's fundamental assumptions, such as mind-body, subjectivity-objectivity divides, work poorly when applied to chronic conditions, particularly chronic pain conditions like FMS. This generates debates in the biomedical field over whether FMS should be classified as a "real" biomedical condition, one that has a biological etiology as opposed to a psychosomatic one. Without the cultural validity of biomedicine to back their diagnosis, FMS patients experience pressure to prove that their condition is "real" through a variety of means. These pressures have only increased with the opioid epidemic, and FMS patients must attempt to distance themselves from "addicts" in order to avoid additional stigma and combat limitations placed on their treatment options.

Chapter Two examined health care providers' points of view on FMS, and I discuss how trends in the biomedical field towards more patient-centered care have facilitated the increased use of biopsychosocial and brain models of pain. These models attempt to connect the mind, body, and environment and are designed to be more aware of patients' unique circumstances and experiences. However, when health care providers leverage these new models in their interactions with FMS patients, they can face pushback because the models can be misconstrued as suggesting that FMS has a psychological or environmental basis rather than a biological one. Miscommunications, diagnostic difficulties, and poor treatment options can all contribute to physician frustration when trying to tackle chronic pain conditions.

In Chapter Three, I explore some of the differences in pain treatment in men and women and discuss reasons that women have historically filled the ranks of medically controversial conditions such as FMS. I argue that FMS patients express their suffering through gendered idioms of distress. I also argue that as biomedical research progresses and the search for a correlation between an “FMS personality” and FMS continues, research may actually reinforce gendered ideas about women’s pain and personalities while hiding it under a mask of scientific objectivity. However, online health resources may provide FMS patients with subtle forms of resistance against biomedical power that tends to be unfriendly toward women.

Chapter Four provided a general overview of several different online support groups and social media platforms. I argue that the multimodal nature of social media can help patients convey the experience of living with chronic pain by making pain visible and concretizing suffering by describing the everyday consequences of pain. I show how content like hashtags and memes are designed to be both specific to the FMS experience and vague enough for individualization, allowing for patients to rally around a set of shared experiences. However, I also show that while these forums can be empowering for many users, they can also be a double-edged sword depending on how users participate.

Limitations and Further Research

It is important to recognize that my ethnographic research was conducted with a relatively small group of study participants. Though my work aimed to explore the diversity and nuances of individuals’ experiences with FMS and was not necessarily meant to be representative of the experiences of all chronic pain patients or clinicians, the small sample size does pose some limitations. All of the FMS patients I interviewed had at least received a high school education, and quite a few had completed or were in the process of pursuing college degrees (perhaps because people with these sorts of educational backgrounds may be more willing to participate in research studies like mine). Educational levels may play a significant role in how patients interact with health care providers and come to understand their

illnesses. Sarah, who had completed a university degree, mentioned to me how grateful she was for her educational background:

Thank God I have the sort of mind that's capable of understanding higher order thought and that I have the education for it. I can't imagine what it's like for the average Joe who doesn't have anything higher than a high school education to navigate the challenges that come with living every day of your life in pain.

In this study I also analyzed posts from online resources, which I hope has helped to capture the experiences of people from a broader range of educational backgrounds. However, due to the public and anonymous nature of online posts, I could not confirm that this would be the case, and indeed some FMS patients of lower educational background may not have access to certain online platforms. Future research that explores the experiences of FMS patients from a larger range of educational backgrounds could add valuable insight to the work I have done.

In addition, all of the FMS patients I interviewed were white. FMS is a condition that primarily affects non-Hispanic white women, and studies have found that racial and ethnic minorities, particularly African Americans, are underrepresented (Barker 2005). As a result, many studies of FMS experience have been largely done with white people. Some have speculated as to reasons for the racial and ethnic discrepancies. For instance, some have argued that white women have better access to health care and therefore diagnoses like FMS (Barker 2005). However, little work has been done with minorities affected by FMS, and future work should certainly explore how these groups experience FMS.

Concluding Thoughts

During my interviews and in many online posts, FMS patients expressed their deep hope that biomedical research would soon progress to the point where an organic pathology for the condition could finally be discovered and thus successfully resolve the controversy. Indeed, several people argued that biomedicine already had found significant evidence for biological dysfunction, and it was only a matter of time before all physicians accepted it and the debate was resolved. But what if the research never reaches that point? Perhaps an alternative way out of the debate is to rethink what our culture considers to be

“legitimate” pain. Biomedicine’s incredible cultural power has led to its mind-body divide being adopted by many Americans. Even today mental pain is seen as less important and real than biological pain, and it tends to be blamed on the individuals suffering from it. As new models for pain like the biopsychosocial model or brain model of pain become increasingly popular, perhaps non-biological pain will finally come to be seen as equal to biological pain. I hope that my work using an ethnographic approach to understand experiences of pain may help illuminate the ways that pain exists in multiple realms that biomedicine may not completely capture, and I hope that continued exploration of online resources that promote new forms of patient expression and empowerment will become a way to rethink the ways we understand and treat pain.

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