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Invisible Illness, Invisible Inequalities: Gender, Race, Class, and Fibromyalgia

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Invisible Illness, Invisible Inequalities: Gender, Race, Class, and Fibromyalgia

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Sociology

by

Sarah A. Devoto

Committee in charge:
Alicia D. Cast, Chair
Laury Oaks
George Lipsitz

September 2022

The dissertation of Sarah A. Devoto is approved.

Laury Oaks

George Lipsitz

Alicia D. Cast, Committee Chair

June 2022

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Sarah A. Devoto

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I am tremendously grateful to the fibromyalgia community, and to the individuals who agreed to participate in this study (which resulted in 804 survey responses and 30 interviews). This dissertation would not have been possible without their willingness to be vulnerable with me and to share personal aspects of their lives. *I see you and I hear you.* I am also incredibly appreciative to the Fibromyalgia Care Society of American (FCSA), National Fibromyalgia Association (NFA), Support Fibromyalgia, and all of the individuals, groups, and organizations who shared my research and expanded my reach. *I hope this process was has been as rewarding for you as it has been for me.*

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SARAH DEVOTO

Department of Sociology
University of California, Santa Barbara
sarahdevoto@ucsb.edu
(805) 585-7185

EDUCATION

2022	**Doctor of Philosophy (Ph.D.), Sociology** University of California, Santa Barbara *Dissertation Title: Invisible Illness, Invisible Inequalities – Gender, Race, Class, and Fibromyalgia*
2018	**Master of Arts (M.A.), Sociology** University of California, Santa Barbara
2014	**Bachelor of Arts (B.A.)** with High Honors, **Psychology** (Major) and **Black Studies** (Minor) University of California, Santa Barbara

RESEARCH INTERESTS

Social Inequalities; Health and (Dis)Ability; Gender, Race, and Class; Race and Racism; Social Psychology

PUBLICATIONS

(Forthcoming) Devoto, Sarah A. 2022. "Chronic Pain and Long COVID: Overlapping Racial Inequalities." *Disability & Society.*

(In preparation) Devoto, Sarah A. "Fibromyalgia, (Dis)Ability, and Identities: Intersectional understandings of health and well-being."

TEACHING EXPERIENCE

Instructor of Record
Social Inequalities – Summer 2021, Summer 2022
Methods of Cultural Analysis – Summer 2022
Social Psychology – Summer 2020, Fall 2020

Teaching Assistant
Self & Identity – Winter 2021, Spring 2022
Sociology of Education – Winter 2022,

Sociology of Families – Spring 2021
Reproductive Justice – Fall 2020
Social Psychology – Winter 2019, Spring 2020
Sociology of Girls – Winter 2020
Survey Research Methods – Fall 2016, Spring 2017, Fall 2018, Fall 2019,
Social inequalities – Spring 2018, Spring 2019, Summer 2019
Sociology of Deviant Behavior – Summer 2018
Theories of Gender Inequality – Summer 2018
Introduction to Sociology – Winter 2018
Social Psychology of Gender – Fall 2017
Social Theories of the Body – Spring 2017
Big Data – Winter 2017

Course Reader
Law and Society – Summer 2016

GRANTS, FELLOWSHIPS, AND AWARDS

2022	Post-Doctoral Research Fellow, Semi-Finalist, *Clayman Institute, Stanford University*
2021	Dissertation Research & Writing Grant, *Sociology Department, UC Santa Barbara*
2016	Travel Grant, *Sociology Graduate Student Association, UC Santa Barbara*
2014	Mini Grant to Present at Conferences, *Undergraduate Research and Creative Activities, UC Santa Barbara*
2014	Grant to Present at L. Starling Reid Conference, *Psychology Department, University of Virginia*
2014	Research Fellowship, *Undergraduate Research and Creative Activities, UC Santa Barbara*
2010	Academic Scholarship, *Colombo Club, Oakland, California*

CONFERENCE PARTICIPATION

2022	"Fibromyalgia, (Dis)Ability, and the Self: Intersectional Experiences of Chronic Pain." Paper presentation at 117th Annual Meeting of the American Sociological Association. Los Angeles, California.
2016	"Acculturation and Attitudes about the Death Penalty." Round Table presentation at the 72nd Annual Meeting of the American Society of Criminology. New Orleans, Louisiana.

2014	"Acculturation and Violence-Related Attitudes among College Students." Poster presented at the annual Undergraduate Research Colloquium. University of California, Santa Barbara.
2014	"Acculturation and Violence-Related Attitudes among College Students." Poster presented at the annual Stanford Undergraduate Psychology Conference. Stanford University, California.
2014	"Acculturation and Violence-Related Attitudes among College Students." Poster presented at the annual Psychology Undergraduate Research Conference. University of California, Los Angeles
2014	"Acculturation and Violence-Related Attitudes among College Students." Poster presented at the annual L. Starling Reid Undergraduate Psychology Conference. University of Virginia, Charlottesville.

UNIVERSITY AND DEPARTMENTAL SERVICE

2021	Graduate Student Representative, *Undergraduate Curriculum Committee, UC Santa Barbara*
2020	Graduate Student Mentor, *Sociology Undergraduate Honors Program, UC Santa Barbara*
2017	Graduate Student Representative, *Sociology Graduate Student Association, UC Santa Barbara*
2016	Graduate Student Mentor, *ARC Program, UC Santa Barbara Summer Sessions*
2016	Volunteer Staffer, *Shapeshifters Conference, UC Santa Barbara*
2014	President and Founder, *Meditation Station, UC Santa Barbara*
2014	Co-President, *Active Minds, UC Santa Barbara*
2013	Co-Chair and Program Developer, *Freedom4Youth, UC Santa Barbara*

PEDAGOGY AND CERTIFICATIONS

2021	Crafting your Teaching Philosophy Statement, *Instructional Development, UC Santa Barbara*
2020	Summer Teaching Institute for Associates, *Instructional Development, UC Santa Barbara*
2020	Preparing to Teach Online, *Instructional Development, UC Santa Barbara*

2019	Managing Teaching-Related Anxiety, *TA Development Program, UC Santa Barbara*
2016	TA Orientation, *Sociology TA Training Committee, UC Santa Barbara*
2016	Creating Affirming and Inclusive Classroom Environments, *TA Development Program, UC Santa Barbara*
2016	Engaging Students in Section, *Sociology TA Training Committee, UC Santa Barbara*
2015	TA Orientation, *Sociology TA Training Committee, UC Santa Barbara*
2015	TA Orientation, *TA Development Program, UC Santa Barbara*
2014	Mandated Reporter Training, *Teen Court, Santa Barbara, CA*

RESEARCH EXPERIENCE

2018	Research Assistant for Evaluation of Graduate Program Learning Outcomes. Supervisor: G. Reginald Daniel.
2014	Research Assistant for "Understanding How Affirmations Shape Individuals' Narratives Over Time and in Response to Chronic Naturalistic Threats." Supervisors: Kim Hartson and David Sherman.

PROFESSIONAL AFFILIATIONS

American Sociological Association (ASA)

Pacific Sociological Association (PSA)

American Psychological Association (APA)

ABSTRACT

Invisible Illness, Invisible Inequalities: Gender, Race, Class, and Fibromyalgia

by

Sarah A. Devoto

How do Americans with fibromyalgia understand their condition and how do those meanings shape their actions and opportunities? My dissertation, *Invisible Illness, Invisible Inequalities: Gender, Race, Class, and Fibromyalgia,* broadens our understandings about the intersections of gender, race, class, and (dis)ability using multiple theoretical perspectives and research methods. My project also considers status, legitimacy, care work, and the evolving definitions of wellness. I draw on 493 surveys and 30 in-depth interviews with U.S. adults living with fibromyalgia to explore individuals' intersectional understandings of health and wellness while living with chronic pain.

Incorporating sociology, social psychology, and Black feminist theory, I understand fibromyalgia as a social process of self-definition and social identity formation. In Chapter 1, "How Race and Class Structure a Gendered Invisible Illness," I introduce fibromyalgia as a socially-constructed and socially-contested illness. Fibromyalgia is an "invisible" condition of chronic pain and fatigue that affects two to five percent of the U.S. population (ACPA 2020). Interestingly, the diagnostic patterns show a high prevalence of low-income

white women. The meaning-making process of fibromyalgia raises questions about symptom legitimacy, quality of life, agency, and social inequalities.

In Chapter 2 (“Methods and Data”), I detail the multiple methods I incorporated within my research. In the first phase, I designed a twenty-minute online survey which received 493 respondents. They ranged in age from 19 to 85 (*M* = 55.69 years, *SD* = 13.4) and were primarily white (85.1%), women (90.7%), and middle-class (58.8%). In the next phase, I conducted 30 in-depth interviews with fibromyalgia sufferers from three categories: white women, Black women, and men (of all races).

My findings demonstrate how Americans’ ideologies and intersectional identities structure access to an “invisible” diagnosis and opportunities for wellness at the individual, interactional, and structural levels. In Chapter 3, “Framing Fibromyalgia: Managing Symptoms, Maintaining Well-being,” I show that individuals with more privileged social positionings have less symptom severity, stronger sense of self-mastery over fibromyalgia, and less concern about their conditions. However, identities and status are rarely spoken of as a privilege of well-being: rather, individuals credit their own agency, personalities, and resilience for their symptom improvement.

In Chapter 4, “Wellness Work and the Social Responsibility of Care,” I define wellness as a verb: the social process in which individuals actively pursue well-being, rather than viewing it as an objective state (adjective). Individuals immersed in more caring, accommodating contexts (in the areas of medicine, employment, and the family) have more positive experiences in the wellness process. Importantly, Black women emphasized the social barriers to wellness, understandings which fueled a sense of social responsibility in their advocacy for community care and disability justice.

In Chapter 5, “Identity, Ideologies, and Fibromyalgia: Intersectional Experiences of (Dis)Ability,” I articulate how intersectional ideologies and the controlling images (Collins 2000) of (dis)ability expedite or exclude individuals in the fibromyalgia wellness process. By highlighting the ways that gender, race, and class structure the experience of fibromyalgia, I show how this “invisible” diagnosis is simultaneously a privilege and a form of social control.

In this dissertation, I document how cultural ideologies become pervasive within instances of medical illegitimacy and ambiguity. In my conclusion, I apply my sociological research findings on fibromyalgia to the context of mass disability resulting from long COVID, which – in part due to its relatively recency – is a also medically-ambiguous condition of chronic pain and fatigue. Ultimately, I argue that individual wellness relies on community wellness. Further, equalizing access to wellness requires giving extra support, services, love, and care to the communities most chronically marginalized (primarily, low-income, LGBTQ+, and BIPOC communities). Institutionalizing access to care at the community level will encourage individual-level kindness, compassion, and overall well-being.

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Preface

> *"Where we find happiness teaches us what we value rather than simply what is of value."*
>
> – from *The Promise of Happiness* by Sara Ahmed (2010: 21)

They say hindsight is 20/20 and – in looking back – I can more clearly see the connection between my personal identities and experiences that subsequently inspired this critical dissertation research project.

If you'd asked me about my career goals a decade ago, I would have told you that I hoped to become a psychological counselor or therapist, working with youth from marginalized backgrounds. To prepare myself for this career, I did a *lot* of different types of social and volunteer work (paid and unpaid) in my teens and early 20s: working with food banks, mental health centers, substance abuse clinics, and with youth who struggled with mental health and/or substance use. As a young person, I understood these communities as chronically underserved and psychology seemed to provide solutions (or at least bandages) to these social problems…for the individuals who were lucky enough to access them. While it took some time for me to find my academic home in sociology[1], I entered my graduate program with knowledge of the ways that power and forms of social control create unequal access to health and well-being.

The process of writing this dissertation (in a larger, historical context of the COVID-19 pandemic) has required me to understand wellness from new perspectives. Landing on the case of fibromyalgia, however, was no accident: I was diagnosed with it in 2018 after years of persistent symptoms. I also had second-hand experience with the condition in my

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[1] I largely credit my academic shift from psychology to sociology from my exposure to Black Studies (and Racial and Ethnic Studies more broadly) as an undergraduate.

formative years. My mother had been told by doctors that she suffered from it;[2] additionally, my paternal aunt, Sharan, currently accepts fibromyalgia as the accurate diagnosis. In this way, I have privileges, capital, and *health literacy*[3] in confronting fibromyalgia: I have long-term familiarity with the condition, and I was raised in a family that considered chronic pain a legitimate health condition. In terms of my identities and family history, I fit the image of the typical person with fibromyalgia.

As a sufferer of multiple chronic conditions, I participate in wellness within and around medical institutions in an effort to slow down what feels like spiraling symptom severity: the deterioration of my bodymind.[4] Unfortunately, well-being has turned out to cost a lot of time and money. As a low-income person, I am personally familiar with the social factors which prevent people with chronic conditions from living healthier, happer lives. My intimate knowledge of fibromyalgia fueled my research questions and design, incorporating justice-oriented perspectives by centering multiply-marginalized people with fibromyalgia. I began to understand wellness as form of labor which requires feeling, care, planning, and – most importantly – social resources.

Despite my academic interests in the areas of intersectionality and health, I did not anticipate the COVID-19 pandemic, nor how it would alter this project. It was ironic (in the

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[2] She was later told that she was truly suffering from chronic fatigue syndrome.

[3] Health literacy is more commonly used to denote an individual's access, understanding, and implementation of medical information that is necessary to improve one's health. As a sociologist, I also understand health literacy as a form of cultural capital (Bourdieu 1984): an individual's privileges and social networks which allow some groups to maintain their health and well-being, while simultaneously excluding others.

[4] I resist the separation of mind and body, encouraged by the professionalization of psychology and the medical institution, respectively. In this dissertation, I use the term bodymind (Sins Invalid 2019) to emphasize the integration of the physical and psychological – that our bodies and minds are inextricably linked.

worst way) that at the same time I began my doctoral research on being well in spite of illness, my options for wellness became more limited. This first-hand experience seemed to further supported my argument that self-care can only address so much*: community care is necessary for well-being.*

The themes of privilege and inequality, which appear blurrier in the experience of fibromyalgia, have been made more visible in the case of COVID-19. Due to its level of contagion, the severity of illness, and the overwhelming number of people who have lost their lives, Americans have been forced to confront the ways that demographic factors encourage (or protect against) exposure to the virus. In this way, COVID-19 has made Americans come to terms with the fact that only the most privileged people can maintain their health and well-being. In response, Americans must shift our understandings of wellness from self-care to community care. Ultimately, I argue in this research that we cannot have a healthy society (or disability justice[5]) without race, gender, and class justice.

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[5] Disability justice is a social movement and theoretical framework originating from queer, BIPOC disabled communities which understands ableism as connected to other forms of oppression including racism, capitalism, patriarchy, and homophobia.

I. How Race and Class Frame A Gendered Chronic Pain Condition

"To most people, I look like most people…Fibromyalgia may be invisible to others, but my pain is real..." In a 2018 television advertisement for Lyrica – the spark which initially inflamed the work of this dissertation project - the woman on screen pushes for the condition's authenticity as well as its normativity. She is the target of marketing advertisements for fibromyalgia medications: a middle-aged white, seemingly heterosexual, cis-gendered woman, wife, and mother living in a middle-class suburb. All iterations of the advertisement use a similar spokesperson: a solemn, white, middle-class woman (often a wife and mother) who feels misunderstood until finally receiving a prescription for her widespread joint and muscle pain. The neoliberal assumption underlying this marketing campaign is that individuals with fibromyalgia can "do more" as a result of effective medical intervention, equating good health with economic and social productivity. Unfortunately, what is not revealed in the ads is that receiving a diagnosis and effective medical treatment for fibromyalgia is a lengthy uphill battle (Barker 2005; McKiernan 2018; Pryma 2017). What does well-being mean to people with disabilities and/or chronic illnesses, for whom there exists no medical "cure" for their condition(s)?

Sociologists are interested in the ways that power and social factors influence how knowledge is created and used by individuals through interactions. I use a sociological framework to examine how systems of gender, race, and class shape individuals' meanings of and subjective experiences with fibromyalgia. Specifically, this dissertation explores individuals' diagnostic pathways to better understand how people with fibromyalgia make meaning of their conditions. Through qualitative semi-structured video interviews and a quantitative online survey, my research centers on (dis)ability, a critical aspect of intersectionality. I address the overarching question of how systems of gender, race, and class structure individuals' understandings of fibromyalgia, specifically, and disability more broadly. Further, my sociological approach to wellness shows how gender, race, class, and ability – and their corresponding structures of oppression – shape individuals' subjective experiences and overall well-being.

Defining Fibromyalgia

Fibromyalgia is a condition of chronic pain and fatigue that can be traced back to the 1800's in medical literature. It earned its current name and official diagnostic criteria in 1990 in the academic journal, *Arthritis and Rheumatism,* published by the American Arthritis Association. Presently, public health authorities estimate that between two to five percent of the U.S. population, or as many as twelve million people, meet the diagnostic criteria for fibromyalgia (ACPA 2020). These numbers are similar to those in other countries; a meta-analysis conducted in 2017 confirmed that the prevalence rate of fibromyalgia remains consistent across all regions of the World Health Organization (Heidari, Afshari, and Moosazadeh 2017). Fibromyalgia is therefore a global, structural-level problem based on the sheer number of individuals who are affected.

Fibromyalgia is characterized by a long list of symptoms including (but not limited to):

- joint and musculoskeletal pain
- fatigue and tiredness
- cognitive problems with thinking, memory, and concentration ("Fibro fog")
- tender points
- headaches (and migraines)
- digestive problems
- tingling or numbness in the hands and/or feet
- emotional and mental distress.

Sufferers of fibromyalgia experience their symptoms as extremely debilitating, many of which go unaddressed and undiagnosed due to associated stereotypes and stigma (Pryma 2017). Medical researchers agree that biological, psychological, and social factors are involved in developing the syndrome and in some cases external, environmental forces (such as physical injury or trauma) are most important (St. Amand and Marek 2019). Some risk factors include previous infection or disease, genetics, family history, trauma and PTSD, stress, gender (women), and age (middle-age). While researchers in psychology might point to fibromyalgia as an example of a biopsychosocial condition, most of the health research on fibromyalgia focuses on symptoms within the bodymind, which blurs both social causes and social effects of the condition.

There is a distinct tension between medical knowledge about fibromyalgia and laypersons' experiences of its symptoms. This results from the fact that fibromyalgia is a medical mystery of sorts because medical practitioners and researchers cannot fully explain what it is or where it originates. Doctors and medical researchers have the technology and the tools to understand and diagnose a broad range of conditions as long as there are physical, biological indicators to rely on. However, fibromyalgia is considered an "invisible illness" because it lacks a clear cause and biological markers required for an efficient medical diagnosis, making it "less knowable" to the institution of medicine. As a result, fibromyalgia is a diagnosis of exclusion in which rheumatologists (who take professional ownership of the syndrome) examine patient histories, conduct physical examinations, and analyze X-rays and bloodwork to rule out all other related health problems.

In the 30 years since fibromyalgia earned its diagnostic criteria, medical technology has advanced and some aspects of the condition have become more "knowable" to medical researchers. To begin, there is an established connection between PTSD and fibromyalgia. (Cohen et al. 2002), highlighting the influence of social factors on the condition. Another noteworthy and more recent finding in the health literature focuses on differences in brain-wave activity in non-REM sleep (Rizzi et al. 2020). In other words, researchers have discovered that people with fibromyalgia do not experience a restorative feeling after sleeping as a result of differences within the brain. However, these findings do not constitute clear diagnostic criteria as they are present in a wide range of health conditions. Despite these medical advances, fibromyalgia remains – for most Americans - a diagnosis that is not equally embraced by all medical practitioners (McKiernan 2018). This makes fibromyalgia a quintessentially contested illness,[6] and leaves room for subjective interpretations (and inequalities) within the doctor-patient interaction.

Because medical doctors have yet to specify the causes of the condition, they have also not been able to produce many effective remedies. For the most part, fibromyalgia treatment relies on symptom management and individual-level lifestyle changes using the holistic model of health (Liptan 2016). Although medications are sometimes prescribed, other common treatments include: exercise and healthy eating habits, patient education classes, stress management (meditation, yoga, and massage), good sleep hygiene, and cognitive behavioral therapy (CBT). Although the American treatments for fibromyalgia are similar to those offered in other countries, there tends to be greater recognition of the condition by international medical institutions. With a growing acceptance of fibromyalgia, medical skepticism is beginning to wane, and the social meanings of fibromyalgia are beginning to

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[6] Contested illnesses are a category of disorders that many physicians do not recognize or consider as distinctly medical (Conrad and Barker 2010).

shift, honing in on the importance of social causes in developing the condition, social supports required to manage the condition, and the idea that fibromyalgia can occur in any demographic of people and at any age (ENFA 2019).

The Research Puzzle

In the U.S. and abroad, approximately 91 percent of the individuals who receive a formal fibromyalgia diagnosis are women (Queiroz 2013).[7] The diagnostic patterns by race and socioeconomic class is more difficult to find. However, most studies show higher prevalence rates in white Americans (Raphael et al. 2006) who comprise about 75 percent of those diagnosed (Haviland et al. 2010).[8] Further, there is some evidence that fibromyalgia is associated with lower socioeconomic status and lower levels of education. My dissertation uses these diagnostic patterns as the starting place for the meaning-making processes attached to fibromyalgia. How do individuals make sense of an invisible, chronic condition when not all medical practitioners have answers or solutions? Further – when options for symptom management are subpar (and access to them is unequal) - how do understandings and the lived-experience of fibromyalgia encourage (or discourage) individuals to partake in symptom management?

Of the few published sociological studies on fibromyalgia in the U.S., nearly all hone in on the overrepresentation of women among those who are diagnosed, exploring the ways that gender inequality influences the fibromyalgia experience. As a result, my project is

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[7] Because diagnosis relies on access to medical care, and access to quality care is unequal, fibromyalgia prevalence rates might not be reliable or representative, even if they are sociologically-informative.

[8] In contrast, one study found fibromyalgia to be more prevalent in non-white women (Menzies and Sunny 2008).

grounded within gender and feminist scholarship and makes more visible fibromyalgia's relevant connections to race and class. Researchers have made some headway in explaining how fibromyalgia is gendered and feminized, both due to who is diagnosed (primarily women) and the participants who served as the "models" for crafting a fibromyalgia diagnosis (Barker 2005). Kristin Barker (2005) explains that the fibromyalgia diagnostic criteria itself is feminized due to the fact that medical researchers sampled women with general somatic distress to form the diagnosis. This resulted in a diagnostic template which captures women's general somaticism, potentially leaving room for medical subjectivity in the diagnostic process. Although receiving a diagnosis has been shown to ignite an identity transformation (Barker 2005), fibromyalgia operates (in one capacity) as a form of social control by legitimizing the idea of gender inferiority. The medicalization of fibromyalgia places responsibility of knowledge on the institutions of medicine, granting medical practitioners with seemingly-objective authority over women's bodies and well-beings.

In this dissertation, I argue that whiteness works as the un-named, normative, "invisible" social category in the experience of fibromyalgia. This is due to the fact that the diagnostic entrepreneurs[9] were not just women: they were predominantly privileged *white* women with access to medical specialists. Therefore, intersectional inequality operates in the fibromyalgia diagnosis based on the medicalization of white women's somatic distress, where whiteness functions as the neutral, normative referent. Unfortunately, research that engages fibromyalgia prevalence rates by race is sparse, and can be incredibly difficult to locate. One notable sociological study in the U.S. which specifically analyzed race found

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[9] The fibromyalgia diagnostic entrepreneurs were four university-based rheumatologists, each using their own patients to coin the term "fibromyalgia" and craft the first version of standardized fibromyalgia diagnostic criteria (Barker 2005).

that a lack of diagnosis was more than just a problem of access: the racialized boundaries which structure disability politics and the U.S. welfare system shape how white and Black women explained their fibromyalgia symptoms within the doctor-patient interaction (Pryma 2017). Further, medical researchers have found a relationship between perceived discrimination and chronic pain. A recent study showed a positive relationship between lifetime perceived discrimination (based on gender, race, and a number of other demographic variables) and levels of chronic pain (Brown et al. 2018). From these patterns, one might infer that women of color should be overrepresented in fibromyalgia prevalence rates. Research on chronic pain more generally points to evidence that racially-marginalized groups suffer disproportionately from unrelieved symptoms as a result of: unequal access to health care; misperceptions in the severity of pain during the doctor-patient interaction; patient attitudes beliefs, and behaviors; and provider attitudes and beliefs about chronic pain (Shavers, Bakos, and Sheppard 2010). There are potentially thousands of undiagnosed people of color in the U.S. alone.

In a similar manner, there is little sociological research connecting a capitalistic and class structure to the fibromyalgia experience. This gap in knowledge is surprising given the extensive sociological and psychological literature on the connections between class inequality and health (Coburn 2004). What is known about social class and fibromyalgia contradicts research from the sociology of health in that it is working-class women (rather than middle-class) who tend to receive the diagnosis (Fatemeh, Afshari, and Moosazadeh 2017). Additionally, Jane Pryma's (2017) interview study on fibromyalgia uncovered an interesting intersectional dynamic: while the majority of Black women respondents identified as working-class (7 out of 10), nine of them had undergraduate- or graduate-level degrees. This is in stark contrast to the white women, who still primarily identified as working class (7 out of 11), but only five had an undergraduate-level degree or higher.

The high diagnostic rates for working-class white women with fibromyalgia make sense based on who has access to health care (Shavers, Bakos, and Sheppard 2010). For example, research in social psychology shows how people with more privileged identities and social positionings tend to have better access to health care (Schnittker 2013). However, fibromyalgia prevalence rates are puzzling because of established connections between fibromyalgia and trauma, and the relationship between trauma[10] and social positionings: it is women and all people of color who are more likely to experience the gendered and racialized health effects of institutional discrimination, microaggressions, and trauma (Williams and Lewis 2019). As a result, health is shaped by identities, and intersectional ideologies present at both the institutional and interactional levels (Nelson 2015; Shavers, Bakos, and Sheppard 2010). Therefore, I ask: how do structural processes of gender, race, and class shape Americans' ideologies about fibromyalgia (specifically) and (dis)ability (more broadly)? Conversely, how do these systems shape individuals' fibromyalgia experiences?

Literature Review

My multidisciplinary sociological approach to fibromyalgia provides an analytical framework to interrogate a diverse set of social and cultural identity processes alongside institutional criteria for a medical diagnosis. It builds on the idea that wellness is a social process that is defined by individuals and produced through social interaction (Carel 2016).

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[10] Medical researchers have established that fibromyalgia is often brought on by social factors such as trauma (St. Amand and Marek 2019).

Studying fibromyalgia as a social process and as a social product incorporates ideas from a wide range of research areas within the sociological discipline. The primary areas of scholarship which guided this dissertation project include: feminist scholarship and intersectionality, the sociology of health, social psychology, and disability justice.

Feminist Scholarship and Intersectionality

The sociological case of fibromyalgia relates to broader construction of social identities embedded within interlocking systems of inequality: gender, race, class, and (dis)ability. Importantly, while individuals have some agency over their self-definitions (Cast 2003), they make meaning of themselves and others in contexts laden with institutionalized social inequalities. Furthermore, gender scholars have advanced the notion that institutions are embodied: they are comprised of real people (who think, feel, talk, and act) and have material outcomes. Fibromyalgia offers a case to explore the ways that intersecting ideologies[11] from the structural level are negotiated in the wellness process and experienced and embodied by the individuals.

Black feminist scholars and intersectional[12] researchers (Collins 2000; Hamilton 2020; Moore-Berg and Karpinski 2018) have shown that gender is constructed alongside race, class, and other social identities – no identity is created in isolation. Scholars of status characteristics argue that while gender and race are primary cultural frames, social class

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[11] An ideology is "a set of beliefs and values that explains and justifies a society's system of power and privilege" (Marger 2011). Ideologies are collections of thought which help individuals explain social patterns. In this way, they are a body of ideas that reflect the interests of a group of people (Collins 2000).

[12] Intersectionality is social theory originating from Black Feminist Theory which critiques power from places where power collides, interlocks, and intersects (Crenshaw 1991). Individuals with multiple marginalized identities are cumulatively-disadvantaged and have qualitatively-different (and identity-specific) experiences of oppression.

functions to a lesser extent, despite cultural stereotypes linking it with status and competence (Ridgeway and Kricheli-Katz 2013). When these frames consist of ideologies which function as a form of social control, they are known as *controlling images* (Collins 2000). Controlling images become institutionalized and legitimized[13], sustaining status hierarchies and normalizing unequal outcomes. I understand fibromyalgia as framed by gender, race, and class: unequal diagnostic patterns and controlling images both result from and perpetuate ideologies about the "typical" person with fibromyalgia.

While men's bodies have served as the model for many physical illnesses, women have been the primary group of people diagnosed with psychosomatic[14] conditions. As a cause and a consequence of being conceptualized as a "woman's issue," psychosomaticism has been devalued. Fibromyalgia functions similarly to psychosomatic illnesses in terms of broader structural and cultural legitimacy. Taking this a step further, Nelson (2015) argues that women's bodies have been more susceptible to medicalization due to the fact that, historically, men are typically the normative referent in medical research. The consequences of medicalization have been even worse for Black women and other women of color. For example, in *Killing the Black Body,* Roberts (1998) discusses the state violence toward Black slave women which was enacted through forced procreation. Persisting today, the social control over women's bodyminds – especially for women of color – both creates and sustains health inequalities. This dynamic results from and feeds into cultural ideologies about an individual's symptom legitimacy and worthiness of care. My data show that by

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[13] Legitimation is the process through which the dominant ideology becomes "normalized" and viewed as "natural."

[14] Psychosomatic conditions are physical symptoms which commonly lack medical explanation and are believed to originate from psychological, social, and behavior sources.

normalizing the image of fibromyalgia as a “white woman’s problem,” fibromyalgia sufferers from other social categories are discouraged from identifying with this label – they feel like less of a fit with the broader fibromyalgia community.

The concept of hegemonic femininities offers an explanation for the perpetuation of identity-based inequalities in the experience of illness, providing one theoretical explanation for fibromyalgia diagnostic patterns. Black feminist sociologist Patricia Hill Collins (2000) first deployed the term hegemonic femininity by focusing on the reinforcing axes of oppression within the matrix of domination[15] (rather than focusing solely on gender). Hegemonic femininities have since been defined as “the characteristics defined as womanly that establish and legitimate a hierarchical and complementary relationship to hegemonic masculinity and that, by doing so, guarantee the dominant position of men and the subordination of women” (Schippers 2007: 94). Hegemonic femininities vary by historical, social, and cultural contexts; further, gender, race, class, and ability “are always contested, variable, and constitutive of and constituted by the operation of the matrix of domination in a particular context” (Hamilton et al. 2019: 323). In understanding social inequality, it is not enough to study dominant groups over subordinate groups on one axis (i.e. men over women) because there are multiple locations in the matrix where dominance is exercised and inequality is upheld.

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[15] The matrix of domination critiques the way that power reappears in different and intersecting forms of oppression. Collins (2000) defines as the ways that intersectional axes of power are organized into one integrated matrix, and how they work together to produce injustice.

An underlying assumption of all hegemonic femininities is that some forms of femininity have power over others. This project specifically names whiteness[16] as a critical factor in both the production of hegemonic femininities and within the fibromyalgia experience. Hegemonic femininities are promoted by the dominant culture in order to encourage the superiority of able-bodied, white women.[17] Racialized stereotypes about health, (dis)ability, and physical-fitness are central to this dynamic, such as the notions that people of color are physically superior (Hawkins 2010), the image of Black women as "welfare queens" (Roberts 2014), and the popular notions that women of color are hypersexual (Benard 2016) and simultaneously "less feminine" (Hamilton et al. 2019). Not naming whiteness in gender research and allowing it to remain invisible results in the complicit perpetuation of racial inequality (Hamilton et al. 2019).

As scholars of critical whiteness studies[18] have argued, whiteness can be a complicated variable to conceptualize in research due to its masked, colorblind nature. Whiteness often functions as the normal or neutral category which allows for (white) individuals to explain unfairness as result of other "natural," inevitable factors (Lipsitz 2018). For example, Valeria Ribierio Corossacz (2018) studied racism using a sample of white, middle-class men to better understand white masculinity as the *normative referent,* or the representation of

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[16] Whiteness is the taken-for-granted privileges associated with white identity, "the taken-for-granted privileges that white people enjoy daily because of their race" (Lipsitz 2018: 111).

[17] *Marginalized femininities*, then, are "those cultural ideals of womanhood that sit just below hegemonic femininities and sometimes even benefit from hegemonic femininities, while subordinated femininities (e.g., those that reflect Blackness and poverty) hold the bottom" (Hamilton et al. 2019: 322).

[18] Research from critical whiteness studies "carefully explore[s] how whites produce, translate, and negotiate whiteness in their everyday private and public lives" (Twine and Gallagher 2008: 12).

"the most fully realized social expression of [the] normative character" of men. When asking her participants about what constituted "whiteness," Corossacz most commonly observed a communicative gap, or instances of silence and non-communication, coupled with "awkward" psychological reactions (2018: 39). Whiteness was construed as related to class and defined in terms of negation (i.e. as being not-Black; Corossacz 2018). In this way, the things that white people *don't say* about whiteness can be more informative about its nature than the things they are able to articulate. Importantly, France Winddance Twine (1996) shows that even though whiteness often goes un-named, the formation of whiteness is an interactional process that begins in childhood and persists through the lifetime. In this sense, white identity has the privilege of normalcy while Black identity is categorized as "other."

This dissertation expands theoretical conceptions of intersectionality by exploring the social and cultural meanings of wellness and its relevant connections to gender, race, class, and (dis)ability and social positioning. I examine how hegemonic femininity works as the normative referent in the construction and experience of fibromyalgia. In doing so, I address questions such as, "do white women have greater access to a fibromyalgia diagnosis?" and "how does the fibromyalgia experience differ for people who are not white women?" The answers broaden sociological understandings of intersectionality as generating qualitatively different experiences of health, wellness, and disability.

Sociology of Health

As noted previously, there have been decades of intersectional feminist research and activism critiquing the ways that patriarchy frames the institution of medicine. Despite advances in social understandings of this problem, intersectional health inequalities persist

(Nelson 2015). This dynamic provides sociologists with avenues to explore intersectional health inequalities (Carel 2016). Drawing on key insights from the sociology of health and disability studies more broadly, I show that the significant overrepresentation of white, working-class women with fibromyalgia is a key factor preventing full social and medical recognition of the legitimacy of the condition.

In the eyes of most of our societal institutions, a formal medical diagnosis is essential to prove the legitimacy of an illness because it can lead to treatment and potential disability accommodations. This partially explains the ways that a fibromyalgia diagnosis is simultaneously a privilege and a form of social control. Receiving a diagnosis not only legitimizes clients' subjective experiences with daily pain and fatigue, but also presents new opportunities for symptom management and the ability to secure financial resources, such as Social Security benefits. Because of the diagnostic uncertainty and ineffective treatment options for fibromyalgia, less-privileged individuals who suffer from the condition are often forced to look outside the medical community in order to manage their symptoms (Sallinen et al. 2011). This potentially contributes to the wellness gap between individuals who are medically-diagnosed and self-diagnosed with the disorder. My results show a wide variety of experiences with fibromyalgia that are contingent on individuals' social identities and interactional experiences.

The social model of disability explains that while the body has an impairment (a physical attribute), society creates the disability (the social meanings and experiences associated with impairment) (Oliver 1996). Because disability is a social process, what is categorized as "disability" varies by context. Disability becomes politicized when individuals do not conform to "medically-determined standards of 'normality'" (Conrad and

Barker 2010: 570). In the United States, the institution of medicine is the gatekeeper of medical expertise, which allows it to remain hegemonic in defining normality. However, fibromyalgia remains a diagnosis that is not equally applied by all rheumatologists. Medical practitioners, in their role as knowledge-producers and decision-makers about health conditions, have played a pivotal position in the devaluation of gendered illnesses. For fibromyalgia specifically, doctors serve as influential gatekeepers because they create and enforce the diagnostic criteria as well as prescribe options for treatment. Access to wellness, then, is shaped by individuals' social positionings and by larger social and cultural contexts. Further, an individual's sense of *bodily doubt*[19] in the illness experience tests their taken-for-granted assumptions about the abilities of one's bodymind, and shifts their understandings of wellness, quality of life, and future goals (Carel 2016).

Social Psychology

Social psychology is the sub-field of sociology which explores concepts such as identity, status, and the self. Social psychology offers frameworks to explore how individuals understand their fibromyalgia and how this understanding shapes their attitudes about themselves. Symbolic interactionists in social psychology argue that shared cultural meanings (defined as norms, values, beliefs, and roles) are accessible to individuals in the social process and are used as cognitive resources within interaction (Stryker 1990:22). Similarly, social identity[20] theory argues that individuals' thoughts, feelings, and behaviors

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[19] Bodily doubt is the "loss of continuity, loss of transparency, and loss of faith in one's body" that results from illness and/or disability (Carel 2013: 178).

[20] A social identity is an individual's sense of who they are based on their membership in a group or social category (Turner and Onorato 1999). In other words, social identity is the internalization of shared, collective understandings of in-group members, often based on

are often a result of their identification with groups, categories, organizations, and cultures (Owens 2003).

Social identity theorists seek to understand how social structure and group membership influence an individual's life outcomes (Stets 2006). Social identity theory is grounded in the assumption that people share similar mental representations (i.e. social and cultural meanings) of their identities as a result of social structure (Jenkins 2014). Therefore, societal structures and group memberships guide a large portion of human behavior. An individual's location in the social structure and the specific roles an individual assumes shape how they see themselves, how they behave, and how their interactions with other people and with social institutions proceed (Burke and Stets 2009). Social positionings and roles are associated with prestige and relative standing which are quite possibly the most important influences on an individual's journey toward well-being. This is because status determines access to resources which allow individuals to more easily navigate the social world and institution of medicine (Schnittker 2013).

Status affects the way that individuals derive cultural meanings from specific identities. Importantly, status characteristics theory shows that members in society share similar mental representations about identities (Ridgeway 2008). Individuals often buy into these status beliefs even if they disadvantage themselves personally. For example, McKiernan (2018) showed that women who suffer from fibromyalgia feel forced to describe their pain using language that promotes ideas of male superiority (including metaphors of severe weakness and susceptibility to violence) in order to effectively convey their symptoms to medical

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cultural stereotypes (Jenkins 2014: 114). There is both external ascription and internal affiliation at work in social identities.

professionals. Further, status beliefs act as frames for a situation which allow individuals to anticipate how people from a certain social category will act. Social psychologist Cecilia Ridgeway (2008, 2011) argues that gender and race[21] function as primary cultural frames which allow individuals to interpret, categorize, and define social situations. When formed under inequitable social circumstances, these frames pose negative consequences. Therefore, status beliefs often legitimate inequality, creating a "hierarchy of esteem and deference between individuals" (Ridgeway 2006: 301). For example, stereotypes about people with marginalized identities (most specifically, LGBTQ+ -identifying individuals), and the status beliefs associated with these identities, played a primary role in the mass media coverage of the HIV/Aids epidemic of the 1970's and 1980's. While there is much less mainstream attention for the fibromyalgia diagnosis, the way it is discussed in popular culture – and the predominantly white women spokespeople for it – alter individuals' perceptions of it. In the case of fibromyalgia, there is research evidence for status processes occurring within the case of fibromyalgia as women of color are required to do more emotional labor to legitimize their pain to family, friends, and medical practitioners (Pryma 2017).

Social psychologists offer theories to explain how individuals might form a fibromyalgia social identity in spite of the ambiguous, seemingly-inconsistent character of the condition. A *fibromyalgia social identity* is a group-based identity created on the basis of similar bodymind experiences and shared journeys toward wellness within and beyond the self-help community. Developing a strong fibromyalgia social identity allows individuals to classify their symptoms as "real" while exhibiting agency within the processes of defining

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[21] Class was also shown to be an important frame, although to a lesser extent (Ridgeway and Kricheli-Katz 2013)

fibromyalgia (Barker 2005). Schwalbe and Mason-Schrock (1996) argue that although individuals have more agency in the social construction of an ambiguous identity, they often turn to others when an identity is ill-defined. In this dissertation, I understand fibromyalgia as a social identity that is negotiated within individuals' social networks in pursuit of well-being. I analyze predominant conceptions of the normative fibromyalgia experience, documenting how shared cultural ideologies shape individuals' understandings of their experiences.

Disability Justice

To explore my research questions, I implement a disability justice framework to elaborate on (dis)ability as a social process and an identity intersection. The disability justice movement uses advocacy and research to draw scholarly attention to the social constructions and definitions of ability as an additional dimension of inequality. Predominant cultural understandings of disability rely more heavily on the legal definition of disability as "a person who has a physical or mental impairment that substantially limits one or more major life activity" (ADA 2022). I prefer the broader, empowerment-based definition of disability as provided by the disability justice collective, *Sins Invalid.* Disability – a term which "has been reclaimed by individuals whose bodyminds have been medicalized and pathologized" – is a social identity (and an associated power structure) shared by people with "common, overlapping related experiences of oppression based in navigating a world designed and defined by able-bodied people" (Sins Invalid 2019: 153).

Contested illnesses provide sociologists with case studies to explore the boundary-making process of (dis)ability. Considered by many as "medically suspect," individuals with contested illnesses often have to "fight to get" a diagnosis (Dumit 2006). Fibromyalgia is contested in part because of its invisible nature, but perhaps even more so because of who is diagnosed (white, working-class women). This sense of medical illegitimacy starkly contrasts with sufferers' daily experiences of pain and fatigue, often forcing them to look outside of the medical community in order to make sense of and legitimize their condition. Social mobilizing and advocacy work conducted by individuals (primarily women) with the condition has resulted in increased cultural awareness. For example, the singer, actress, and pop culture icon Lady Gaga has been very outspoken about having fibromyalgia, which has generated more public discussions of the condition. While there is now a plethora of treatment options, support groups, and self-help resources, there are still few to no effective remedies. When no treatment options provide symptom relief, sufferers begin to internalize the stereotypes and stigma surrounding fibromyalgia, doing more work to process common understandings of the syndrome with their daily experiences.

Importantly, some medical conditions are more stigmatized than others because of who is diagnosed with them. Feminist and intersectional scholars have shown that the medical profession is shaped by gender (Nelson 2015) and racial (King 2008) ideologies with consequences appearing at the interactional and individual levels. As previously noted, women have historically comprised the majority of psychosomatic diagnoses (Kempner 2014), claims which have generated skepticism from the medical community (Werner, Isaksen, and Malterud 2004). Complaints of pain, fatigue, and psychological distress are deemed lower status, less important, and/or dismissed by medical professionals because they are the most common ailments within the general public (Kempner 2014). One historical example is that of hysteria, which allowed medical practitioners to diagnose and incarcerate nearly any woman who displayed typical symptoms of female sexuality. Because the medical tools of the 21st century cannot capture the source of these types of conditions (because they are invisible, lacking any biological markers), there becomes more room for doubt, which leaves more room for subjective interpretation of symptom legitimacy. While some of this medical skepticism results from lack of clear diagnostic criteria, patriarchal stereotypes of women as hypochondriacs and complainers also affect the doctor-patient interaction (Kempner 2014). This diagnostic uncertainty leads "[p]hysicians, the public, and sometimes even the sufferers themselves [to] question the authenticity of the symptoms and the mental stability of the sufferer" (Conrad and Barker 2010: 570).

While it has been established that the medical institution is responsible for perpetuating health-related gendered and racial stereotypes, scholars observe see these same stereotypes infused within popular culture and the mainstream media. The mainstream media run reports about women pretending to be sick or disabled (Clare 2017), portraying women with chronic pain as liars and attention-seekers. This is important because in instances of ambiguity, individuals must turn to others to make sense of their experiences (Schwalbe and Mason-Schrock 1996). Because fibromyalgia is so ambiguous, sufferers turn to external sources (medical practitioners, books, support groups, websites, TV commercials, etc.) in order to better understand themselves, to informational sites which are imbued with many of the same stereotypes.

The cultural meanings surrounding fibromyalgia – that it is an individual's responsibility to participate in self-care and manage one's symptoms – perpetuate inequality in healthcare and evidence how structural racism, sexism, and classism within medical institutions affect individuals' health and well-being. The emphasis on individual responsibility for health lies in the belief in the superiority of some bodyminds over others (Clare 2017). These same beliefs are incorporated into our institutions and cultural ideologies about (dis)ability, which shape opportunities for accommodation. Therefore, understanding the meaning-making process of fibromyalgia raises questions about identity, legitimacy, quality of life, the disabled bodymind, and systems of oppression. In exploring the cultural meanings surrounding fibromyalgia from a disability justice lens, I observe how norms of gender, race, class, and (dis)ability are recreated within the medicalization of fibromyalgia. Ultimately, my research emphasizes how (dis)ability and chronic health conditions are socially-(re)constructed at the individual- and interactional-levels, by medical researchers and practitioners, and by the individuals who experience the condition.

Theoretical Contributions

This study specifically examines how one's experiences with fibromyalgia are related to identities, social positionings, and structural forces of oppression. There are two predominant theoretical contributions of this dissertation. The first is elaboration on the theoretical concept of hegemonic femininity, and utilization of this concept to better understand (dis)ability as an intersection. The second – which I term the *social construction of wellness* – is encouraging a paradigm shift in the way health and disability scholars understand who is responsible for care work. Lakshmi Piepzna-Samarasinha (2018) argues that making communities survive and thrive through accessibility and other measures, is a radical act of solidarity: everyone deserves basic income, care, and access. This paradigm shift focuses radical love, social responsibility, and community care as a right. This reframes cultural ideologies of disabled bodyminds as liabilities to assets. This study emphasizes the importance of accessible community care in equalizing opportunities for wellness in the fibromyalgia experience. Practically, this research has applications in the form of making health care more accessible (broadly) and removing social barriers surrounding fibromyalgia (most specifically).

(Dis)ability and Femininity

The social reality of inequitable institutions creates and constrains interactional negotiations and individual behavior: we can observe this through the social power some actors (i.e. white women) wield over others. Collins (2000) argues that empowerment results when individuals have the power of self-definition over their social identities. In reverse, the people with more privileged identities have a greater ability to define their social situations (Cast 2003). In this data, I show that individuals who most closely embody hegemonic femininities are provided with increased opportunities to develop a strong fibromyalgia social identity. In the case of a fibromyalgia diagnosis, hegemonic femininities structure both 1) shared cultural meanings of health and (dis)ability, in addition to 2) whose invisible conditions are legitimized, diagnosed, and treated.

Intersectional scholars show that identities are created in collaboration with one another (Crenshaw 1991). To fully explain gender, racial, and class inequalities, identities must be understood as “mutually produced” and “simultaneously operative” (Corossacz 2018: x). Identity formation involves a process of social comparison in which individuals must separate “like” from “unlike,” “in-group” versus “out-group.” Hegemonic femininities – in tandem with hegemonic masculinities – reproduce the matrix of domination: those who embody hegemonic femininity but do nothing to critique their privilege are actively complicit in the reproduction of inequality (Hamilton et al. 2019). Further, shared meanings about ability are created alongside meanings about gender, race, and class. This is because the social processes of making meaning from gender, race, and class financial income occur at the site of the body (Ahmed 2002). The configurations and manifestations of identities rely on the social structure. Therefore, both our identities (Cast 2003) as well as our bodily expressions (West and Fenstermaker 1995) reflect larger systems of identity-based inequalities.

Hegemonic femininities (all iterations of which are based on whiteness) show how some women can gain individual benefits even while supporting forms of inequality that disadvantage women overall (Hamilton et al. 2019). One example of how these stereotypes play out within the institution of health is that people of color with chronic pain face more social barriers and challenges in identifying, understanding, and managing their conditions (King 2008). In analyzing the fibromyalgia experience alongside hegemonic femininity, I theorize a diagnosis as both a form of privilege *and* a form of social control. One noteworthy example of this dynamic is Amy McKiernan's (2018) research which showed that women who used metaphors about gender-based violence to express their pain were more likely to have their symptoms acknowledged by medical professionals. This phenomenon disadvantages trauma survivors while simultaneously providing benefits (such as a diagnosis) for women who more closely embody hegemonic femininity (Hamilton et al. 2019).

Ability is another important factor in cultural understandings of femininity, and is a conduit of privilege that functions in a similar manner as whiteness: it often goes un-named, unrecognized and under-critiqued. My data shows that - even within the fibromyalgia community – individuals seek to differentiate the "good" (code for "productive") fibromyalgia-sufferers from the "bad" (or "lazy). Which individuals are classified as good (or bad) is largely subjective, relying heavily on cultural stereotypes of gender and race.

This finding echoes that of Pryma (2017) who found that women of color have to do more moral-boundary work in convincing medical practitioners and support systems that their condition is real. For fibromyalgia specifically, when main symptoms mirror the most common ailments among the general population, how do individuals come to the understanding that their symptoms are worse than what other people are experiencing? How does access to social resources structure how individuals incorporate a fibromyalgia social identity? In this dissertation, I argue that the normative referent of a typical fibromyalgia sufferer is connected to hegemonic femininities. Similarly, those who more closely embody the normative referent are more likely to feel a sense of belonging within the fibromyalgia community, which offers them greater opportunities for both self-definition and symptom management.

The Social Construction of Wellness

The World Health Organization defines *health* as “a state of *complete* physical, mental and social well-being and not merely the absence of disease and infirmity” (WHO 2022). In health, an individual can rely on *bodily certainty*: they can trust their bodies to perform in a certain way (Clare 2017). Bodily certainty, therefore, is an important privilege in that it is often invisible, taken-for-granted, and unacknowledged until illness or disability occurs. For example, although everyone is vulnerable to experiencing pain, those who do not experience chronic pain probably do not think about it very regularly. My findings show that fibromyalgia is consistently inconsistent (see Chapter 3), and that this bodily doubt prevents fibromyalgia sufferers from having *full* health.

While full health requires well-being, individuals can have well-being without full health. Therefore, the theoretical distinction between health, well-being, and wellness is critical for sociologists and disability scholars alike. I define *well-being*[22] as a state of wholeness or completeness within the bodymind. Well-being is physical, psychological, social, and spiritual. It is a temporary state which can vary on a daily, monthly, or even yearly basis. There is qualitative evidence that even in illness and disability, individuals can sustain well-being (Wong 2020). Disability justice advocates like *Sins Invalid*[23] bring attention to this idea by focusing on the humanity of disabled people *in spite of* and *because of* their impairments. For fibromyalgia specifically, well-being is most commonly presented as a state of symptom relief. Further, there is some research which shows that receiving a medical diagnosis of fibromyalgia is beneficial to well-being (Chen 2016; Pryma 2017) and initiates processes of self-definition (Barker 2005).

Participating in wellness can enhance both health and well-being. *Wellness*[24] is the *social process* through which individuals engage in practical, purposeful labor with the goal of achieving and/or maintaining well-being. It is a social and community-based process facilitated by individuals' bodyminds in conversation with institutions of medicine, alternative health providers (the wellness industry), the disability community, and larger social-cultural ideologies. Notions of wellness, which are often blended with ideals about

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[22] Merriam-Webster (2022a) defines well-being as "the state of being happy, healthy, or prosperous."

[23] Sins Invalid is a BIPOC- and LGBTQ-centered disability justice collective which uses education and performance to challenge taken-for-granted understandings of disability. Sins Invalid emphasizes intersectionality, interdependence, and the ways that disability and humanity coincide: how creativity and disability culture can thrive in a culture of community care. Through cross-movement solidarity, Sins Invalid strives for collective access and collective liberation by highlighting the intersections between disability and other forms of oppression.

[24] Culturally, wellness is often considered "the quality or state of being in good health" (Merriam-Webster 2022b) and as the opposite of illness. I emphasize the part which understands it as an actively sought or pursued goal.

the healthy, abled-body, are socially-constructed by individual actors within their cultural contexts. In this dissertation, I hone in on the ways that social processes of power and privilege shape cultural meanings of and participation in wellness. I explore the ways that identities – and their associated systems of power – exclude some groups of people from the physical, social, and emotional resources required for participation in society (Wong 2020). In my definition of wellness, I rely on *healing justice*, a movement and concept which critiques unequal opportunities for healing while simultaneously normalizing and destigmatizing disability (Lakshmi Piepzna-Samarasinha 2018). Created by disabled, working-class, BIPOC, healing justice is a response to burnout, inaccessible medical care, and ableism which reclaims "traditional methods of healing and redefine[s] what healing and health could mean" once structural barriers are removed (Lakshmi Piepzna-Samarasinha 2018: 98). Therefore, in an effort to reframe definitions of wellness, I highlight the importance of social factors in shaping the wellness process.

Centering wellness in this research highlights the agency of individuals with fibromyalgia and encourages the notion that well-being is possible even within illness and disability (Carel 2016). Further, fibromyalgia is an interesting case study for this phenomenon because it is a contested illness, which more strongly encourages the implementation of cultural ideologies in the meaning-making process. At the structural level, individualism[25] promotes the idea that individuals are responsible for managing their own fibromyalgia[26] and well-being. The self-care and lifestyle changes that are prescribed to

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[25] Individualism - a logic of capitalism – is an ideology which encourages individuals to be independent, self-reliant, and in-control of their experiences.

[26] The commodification of wellness which obscures the ways that financially-invested actors recreate social inequalities through promoting the consumption of products ("treatments").

individuals with fibromyalgia further support this idea, which overlooks the persisting structural-level inequalities in health care and society at large. Intersectional stereotypes about (dis)ability - in combination with the stigma and illegitimacy surrounding fibromyalgia - shape how individuals understand their fibromyalgia and interact with the social world. This forces fibromyalgia-sufferers to do work in their process of self-definition and within interaction.[27] As a result, those with more privileged identities experience an expedited wellness process because they have greater access and embodiment of "worthiness."

Placing the Puzzle Pieces

In the chapters of this dissertation, I detail my process for conducting a multidisciplinary, intersectional analysis of fibromyalgia. In Chapter 2, I introduce my three guiding research questions and elaborate on the multiple methods I used to answer these questions. In the next three chapters, I elaborate upon my findings to show how individuals make sense of and experience fibromyalgia at the individual (Chapter 3), interactional (Chapter 4), and structural (Chapter 5) levels. Further, I show how individuals' social positionings – and the socio-cultural ideologies maintaining systems of oppression – shape individuals' opportunities for wellness. In the conclusion (Chapter 6), I situate the condition of fibromyalgia in larger cultural contexts of COVID-19 and the opioid crisis, drawing parallels in the ways that normative understandings about gender, race, class, and (dis)ability shape whose claims of pain are deemed legitimate, and whose bodyminds are worthy of care.

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[27] They must grapple with stigma and societal depictions of ill and disabled people as "broken" (Clare 2017).

II. Methods and Data

Research Questions

- How do Americans with fibromyalgia understand the condition, and how do those meanings shape their actions and experiences?
- How do these socio-cultural meanings vary across social categories?
- How do interpretations of fibromyalgia shape individuals' opportunities for wellness?

To answer the research questions posed above, my dissertation utilizes a multiple method approach to analyze how the socio-cultural meanings surrounding fibromyalgia draw from and perpetuate gender, race, and class inequality. In addition to a quantitative online survey (493 respondents), I also conducted qualitative interviews with 30 individuals with fibromyalgia. This study contributes to the literature on intersectionality by centering an axis that is often underexamined: ability. I sampled individuals with fibromyalgia instead of medical practitioners or researchers in order to center the voices of those living with the condition (Carel 2016). Because this project's goal is to understand bodies, feelings, and the well-being of those with fibromyalgia, it is most appropriate to talk to those who are actually affected by the syndrome.

Online Survey

Before collecting data, I submitted a Human Subjects application to the Institutional Review Board (IRB) at UCSB. I designed a questionnaire using Qualtrics, an online survey-formatting website. Eligible individuals were required to reside in the continental U.S. and be at least 18 years old to complete the survey. Participants were excluded if they did not have fibromyalgia, and those with a medical diagnosis comprised 97.4 percent of the sample. However, as I approach fibromyalgia as a condition that is chronically underdiagnosed, I also include respondents who claim they have fibromyalgia but do not have a formal medical diagnosis (2.6 percent of sample).

Recruitment and Respondents

Data collection began in Fall 2020 with a quantitative online survey. Data from the online survey provides a descriptive picture of the fibromyalgia experience and a greater ability to generalize my results to a larger population of fibromyalgia sufferers. I recruited participants in the following ways, indicating early on in the recruitment process that I have a fibromyalgia diagnosis:

1) With support of the National Fibromyalgia Association (NFA), I shared a call for research participants which was posted on their social media pages as well as their email newsletter. This allowed me to connect with the bulk of my survey respondents.
2) I posted a call for participants on all relevant social media pages (my personal pages included Instagram and Twitter).
3) Finally, snowball sampling also played a part, as I asked respondents and social media users to share my call for research participants on their own social media pages.

Survey respondents consisted of 804 total individuals, 502 for whom complete data were available. However, based on low sample sizes for Asians (1 respondent) and “some other race” (8 respondents), the results presented here are based on the remaining 493 respondents. The racial distribution was 86.2 percent White (439 respondents), 3.7 percent Latino/Hispanic (19 respondents), 3.5 percent Multiracial (18 respondents), and 3.3 percent Black (17 respondents). The sample was a little on the older side (age had a *M* = 56.0 years, *SD* = 13.0, range 19 to 85). Gender was written as an open-ended question (“How do you currently describe your gender?”), and was then coded for quantitative analysis (woman, man, and gender fluid/non-conforming). It was comprised overwhelmingly of women (90.8%), with smaller numbers identifying as man (7.0%) or gender non-conforming (0.8%).

Table 2.1
Descriptive statistics of composite variables.

	N	*Mean*	*SD*
Fibromyalgia Severity (0 – 27)	493	16.55	3.97
Fibromyalgia Personal Stigma (0 – 20)	493	9.80	4.73
Fibromyalgia Perceived Stigma (0 – 16)	493	9.29	3.27
Fibromyalgia Self-Mastery (0 – 24)	493	10.14	4.60
Fibromyalgia Social Identity (1 – 24)	493	14.90	4.47
Social Identity Salience (0 – 42)	493	21.52	7.95
Personal Identity Salience (0 – 48)	493	28.25	9.01
General Well-Being (0 – 18)	493	5.56	3.93
Masculine Personality (3 - 24)	493	14.45	3.67
Feminine Personality (0 – 28)	493	21.70	4.99
Feminine Performance (0 – 18)	493	13.48	4.39
Masculine Performance (0 – 18)	493	3.64	4.60

The majority of respondents considered themselves middle class (60.1%); only a small percentage identified as affluent (5.7%), with larger numbers identifying as working-class (24.1%) and lower-class/poor (6.3%). Importantly, only 38.7 percent of respondents are currently working for pay, but most have some type of health insurance. An overwhelming 95.9 percent of survey respondents reported having health insurance coverage, whether through their employer or as a dependent on another person's insurance plan. It is worth noting that the state with the largest percentage of respondents was California (13.3%).

In terms of relationship status, 71.8 percent of survey respondents reported being in a romantic relationship with someone while the other 28.2 percent did not currently have a romantic partner. Importantly, only 16.7 percent of people in the survey sample were married, although many were cohabitating (45%). Of my survey sample, about one quarter (25.6%) of respondents reported having children at home. The majority of respondents identified as heterosexual or straight (88.5%), with smaller percentages identifying as bisexual (3.8%) and gay or lesbian (2.2%).

Measures

The consent form, the first page of the questionnaire, explained the study in general terms, outlined associated risks and procedures, explained confidentiality, and provided my contact information in case respondents had follow-up questions or concerns.

The questionnaire measured the following concepts (see Table 2.1 for descriptive statistics):

Symptoms and Severity. I assessed participants' experiences with the condition's primary symptoms by adapting 11 items from the Fibromyalgia Symptom Questionnaire (FSQ; Hauser et al. 2012). The FSQ includes an item to ensure that the participant has experienced symptoms for at least three months. On a four-point scale (with 0 indicating "no problem" and 3 indicating "severe, continuous, life-disturbing problems"), the FSQ asked participants to rank the incidence and severity of nine predominant symptoms and whether their health status has improved since receiving their diagnosis. Before summation, the items in the scale were factor analyzed (see Table 2.2). Using items 3 through 11, I created a composite sum variable ($\alpha = .74$) with higher scores indicating greater current symptom severity.

Table 2.2

Factor analysis of composite fibromyalgia symptom severity variable (N = 493).

Fibromyalgia Symptom Severity	Factor loading
Joint and/or Muscle Pain	0.60
Fatigue	0.71
Trouble thinking or remembering	0.62
Waking up tired	0.67
Digestive issues	0.54
Pain or cramps in the abdomen	0.48
Depression	0.55
Headaches	0.44
Pain in tender points	0.64
Reliability (α)	0.74

Symptom Improvement. I included two items to establish a baseline for symptom severity and to assess current symptom severity. On a 7-point scale (with 0 indicating "no symptoms" and 6 indicating "very severe symptoms"), participants were asked "How severe were your overall fibromyalgia symptoms when you discovered you had fibromyalgia?" and "How severe are your overall fibromyalgia symptoms now?"

Treatment Effectiveness. The next few items asked participants to indicate which methods of treatment they use to manage their fibromyalgia symptoms, from the following list:

- Medication (prescription)
- Medication (over-the-counter)
- Marijuana/CBD
- Alternative/Holistic therapy (such as acupuncture and massage)
- Yoga/Stretching
- Meditation
- Fibromyalgia Coaching
- Psychological counseling / therapy
- Exercise
- Diet / healthy eating habits
- Other (please specify):
- I do not use any treatments for my fibromyalgia symptoms

For the treatments they selected, respondents were asked to rate the effectiveness of these treatments on a 7-point scale (with 0 indicating no effectiveness and 6 indicating incredible effectiveness).

Financial Cost. Two items in this section asked participants to describe how financial cost affects their ability to manage their symptoms. The first was an open-ended question which asked "In an average month, approximately how much money ($) do you spend managing your fibromyalgia?" The second question asked (yes/no) "Have you ever gone without treatment for your fibromyalgia because of cost?"

Fibromyalgia Sources. In 9 items using a 7-point scale (with 0 responding to "very unlikely" to and 6 responding to "very likely"), participants are asked how likely they are to utilize the following resources to manage their fibromyalgia: doctors/medical practitioners; alternative medicines/holistic treatments; medical websites (such as WebMD); online fibromyalgia message boards; fibromyalgia coaches; fibromyalgia support groups; books and/or other printed materials; social media; and Google searches.

Illness Perceptions. I adapted several items from the Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al. 2006). The first asks participants to list the three most important factors which caused their fibromyalgia. The four remaining items include the degree to which fibromyalgia prevents participants from engaging in pleasurable activities, whether they think treatment helps, their concern about fibromyalgia, and how well they feel they understand their disorder. The 5-point scale ranged from 0 ("strongly disagree") to 4 ("strongly agree). These items were created into a composite sum score, but due to low reliability ($\alpha = .42$), it could not be included in analysis. Instead, items in the scale were analyzed individually.

Fibromyalgia Stigma. Carel (2016) shows that individuals with stigmatized illnesses often have lower well-being. I adapted the ten items from the Depression Stigma Scale (Griffiths, Christensen, and Jorm 2008) which asked participants to assess fibromyalgia-related stigma on a five-point scale (with 0 corresponding to "strongly disagree" and 4 corresponding to "strongly agree"). I created two composite sum variables from this scale: fibromyalgia personal stigma ($\alpha = .86$; with higher scores indicating personal stigma toward fibromyalgia), and fibromyalgia perceived stigma ($\alpha = .72$; with higher scores indicating greater perceived stigma against fibromyalgia). One item was removed from each subscale

Table 2.3

Factor analysis of composite variables for fibromyalgia stigma and self-mastery (N = 493).

Fibromyalgia Personal Stigma	Factor Loading
Most people with fibromyalgia could snap out of it	0.88
Fibromyalgia is a sign of personal weakness	0.92
Fibromyalgia is not a medical illness	0.90
Fibromyalgia is a sign of personal failure	0.76
Reliability (α)	0.86
Fibromyalgia Perceived Stigma	
People with fibromyalgia are unpredictable	0.62
Most people wouldn't tell anyone about their fibromyalgia	0.49
Most employers don't want to hire people with fibromyalgia	0.73
Most people wouldn't elect a politician with fibromyalgia	0.79
People are reluctant to date someone with fibromyalgia	0.80
Reliability (α)	0.72

due to a low factor loading. The remaining items (and their factor loadings) used to create these measures can be found in Table 2.3.

Fibromyalgia Self-Mastery. Participants were also asked about their perceptions of control over their fibromyalgia with seven items adapted from the Self-Mastery Scale (Pearlin and Schooler 1978). Respondents responded using a five-point scale with 0 corresponding to “strongly disagree” and 4 corresponding to “strongly agree”. A composite sum score of all items was calculated (α = .82) with higher scores indicating greater mastery over their fibromyalgia condition (see Table 2.4 for items and factor loadings).

Support Groups. Two items gathered information on respondents’ involvement in support groups. The first asked whether participants were in any support groups (online, in-person, both, or neither). The second was an open-ended question which asked how many hours in an average week that participants engaged with their support groups.

Table 2.4

Factor analysis of fibromyalgia self-mastery and social identity composite variables (N = 493).

Fibromyalgia Self-mastery	Factor Loading
There is no way I can manage my fibromyalgia symptoms	0.74
My fibromyalgia has taken control of my life	0.68
I have little control over my fibromyalgia	0.82
I can manage my fibromyalgia if I set my mind to it	0.64
I often feel helpless in dealing with my fibromyalgia	0.78
There is little I can do to change my fibromyalgia	0.68
Reliability (α)	0.82
Fibromyalgia Social Identity	**Factor Loading**
I identify with people in the fibromyalgia community	0.85
I feel committed to the fibromyalgia community	0.85
I am glad to be in the fibromyalgia community	0.72
My experience is similar to others' in the fibromyalgia community	0.64
Reliability (α)	0.76

Fibromyalgia Social Identity. In order to gather information about a potential social identity, I used a four-item social identification measure originally created by Doosje, Ellemers, and Spears (1995) to analyze the conceptualization of fibromyalgia as a social identity. These items used a 7-point scale (with 0 responding to "strongly disagree" to and 6 responding to "strongly agree"), One item was removed from the perceived variable score due to a low factor loading. I included one additional item to ask participants whether their experience is consistent with others in the fibromyalgia community (see Table 2.4 for survey items and factor loadings). I created a composite sum score (α = .76) with higher scores indicating a stronger fibromyalgia social identity.

Identity Salience. I adapted the 16-item Social and Personal Identities Scale (SIPI; Nario-Redmond et al. 2004) to understand the importance that people ascribe to their social and group identities (See Table 2.5 for items and factor loadings). On a scale of 0 ("not at all important to who I am") to 6 ("extremely important to who I am"), respondents were asked

Table 2.5

Factor analysis of identity salience composite variables (N = 493).

Social Identity Salience	Factor Loading
My family nationality or nationalities	0.58
The memberships I have in various social groups	0.59
The places where I have lived	0.63
My sense of belonging to my own racial group	0.71
My gender group	0.73
My socioeconomic class	0.65
My educational background	0.71
Reliability (α)	0.78
Personal Identity Salience	
My rebelliousness	0.57
My need to be completely distinct and unique from everyone else	0.72
My creativity	0.49
My sense of being different from others	0.75
My complete individuality	0.74
My boldness	0.71
My nonconformity	0.76
My sense of independence from others	0.68
Reliability (α)	0.83

how important their identities (including race, class, and gender) are to their overall sense of self. This scale resulted in two composite sum scores: one for social identity salience (α = .78; with higher scores indicating a stronger social identities), and another for personal identity salience (α = .83; with higher scores indicating stronger personal identity salience). I added one item which asked individuals how important their fibromyalgia was to their sense of self, which I analyzed on its own.

General Well-Being. One of the primary theoretical contributions of this project is understanding whether wellness varies across social categories. I measured participants' well-being by adapting six items from the General Well-Being Scale (Dupuy 1977) which ask participants to assess their levels of happiness and quality of life. The index uses a five-point scale, from 0 ("very dissatisfied") to 4 ("extremely happy and satisfied"). The items in

Table 2.6

Factor analysis of general well-being composite variable (N = 493).

General Well-Being	Factor Loading
Feeling in general	0.81
Satisfied or pleased with life in general	0.83
Satisfied or pleased with close, personal relationships	0.71
Daily life has been full of things that are interesting?	0.77
Feeling emotionally stable and sure of self	0.76
Reliability (α)	0.83

the scale were factor analyzed (see Table 2.6), and I created a composite sum score of all items (α = .83) with higher scores indicating greater well-being. One item was removed from the perceived variable score due to a low factor loading.

Gender. Femininity is both an identification (individual) and a performance (interactional). Therefore, I used two measures to gather data on this concept. First, I the Personality Attributes Questionnaire (Spence, Helmreich, and Stapp 1973), a five-point (0-4) semantic differential with contrasting personality attributes, was used to measure gender identity. This scale results in two subscales: masculine personality (α = .68) and feminine personality (α = .85). The items and factor loadings for the two resulting scales can be found in Table 2.7.

Next, I used six items originally created by Steele et al. (2019) which asks participants to assess their gender performance. These items use a seven-point scale, with 0 indicating “not at all like me” and 6 indicating “extremely like me” I created two composite sum scores from these questions (see Table 2.7 for items and factor loadings), one for feminine performance (α = .94) and one for masculine performance (α = .92).

Demographics. The questionnaire concluded with a section with a variety of demographic questions to gather data on gender and race identity, income and socioeconomic class, education level, sexuality, location, relationship status, and children.

Table 2.7
Factor analysis of gender composite variables (N = 493).

Masculine Personality	Factor Loading
Independence	0.52
Active	0.57
Competitive	0.49
Never gives up	0.65
Self-confident	0.79
Feels very superior	0.72
Reliability (α)	0.68
Feminine Personality	
Devoted to others	0.52
Gentle	0.68
Helpful	0.77
Kind	0.84
Aware of others' feelings	0.78
Understanding	0.84
Warm	0.71
Reliability (α)	0.85
Feminine Performance	
My personality is feminine	0.94
I act, appear, and come across to others as feminine	0.96
I think of myself as feminine	0.94
Reliability (α)	0.94
Masculine Performance	
My personality is masculine	0.91
I act, appear, and come across to others as masculine	0.94
I think of myself as masculine	0.94
Reliability (α)	0.92

At the end of the questionnaire, participants had the option of providing their email should they want a short summary of findings once my writing had been completed. Additionally, the debriefing page (the final page of the online questionnaire) gave a more thorough description of my study, provided contact information to crisis lines and the National Fibromyalgia Association (NFA), and provided my contact information once again.

Interviews

Data was also gathered through in-depth, semi-structured interviews, which I conducted in Winter 2021. Interviews allowed participants to present their understandings and experiences in their own words rather than requiring them to fit their knowledge into pre-formulated categories. This flexibility was particularly important in the design of this research project, which focuses on how participants understand the social and cultural meanings surrounding fibromyalgia. The meaning they ascribe to their subjective experience of their conditions would not be adequately captured using solely quantitative methods. Further, my positionality as a working-class woman with fibromyalgia generated a connection between us, affording me personal insight into our shared experiences of health and (dis)ability. These shared experiences transformed the power structure within our interviews, resulting in a more egalitarian dialogue between two people who struggled in multiple capacities to manage the same health condition.

Recruitment and Respondents

I interviewed 30 individuals, 10 from each of three primary social categories: white women, Black women, and men of all races (see Appendix A for demographic information about the interviewees). In understanding white women as the "normative referent," I chose to interview men (to compare gender differences) and Black women (to compare racial differences). It was also important sample Black women as this dissertation incorporated Black feminist theory in its research design. I recruited interview participants through two primary methods. My initial plan was to recruit individuals directly through my quantitative survey; at the end of the online survey, participants were asked if they would be interested in a one-on-one video or phone interview. From this list of interested individuals, I quota sampled by race, gender, and class in order to better understand how identities intersect and interact within the experience of fibromyalgia.

Through the survey, I was not able to reach my goal sample of 10 Black women, which lead me to my second method of recruitment: social media. Just as I posted a call for survey research participants, I posted subsequent calls for interview participants in the same manner. Twitter was particularly helpful in this case as I was able to better reach my sampling frame by utilizing hashtags (#BlackTwitter, #BlackHealth, #BlackWomensHealth). I offered my interview respondents the opportunity to create their own pseudonym, and personally chose pseudonyms for those remaining by scrolling through "Top Womens' [or Mens'] Names Lists on Google.

Procedure

After establishing a diverse sample of participants, I gathered qualitative, contextual data about individuals' identities and their experiences with fibromyalgia. I conducted one-hour interviews with 30 participants to more fully understand individuals' subjective experiences with fibromyalgia, identity formation, and hegemonic femininity (see Appendix A for interview protocol). Interviews took place over zoom or by telephone, depending on the interviewee's preference, and in both formats I captured audio recordings. My primary goal in this phase was to understand how individuals translate socio-cultural narratives about fibromyalgia into attitudes about the self. I anticipated that both the 1) gendered and racialized discourse surrounding health, ability, pain, and distress, and 2) an individual's social positioning would shape the way participants perceive their fibromyalgia experience. Interviews lasted from one hour to one and a half hours.

Data Analysis

In order to code and analyze data produced from my online survey, I used SPSS, a quantitative statistical-analysis software.

To analyze the qualitative data produced from my interviews, I first used Temi, an online automatic transcription service, to transcribe all interview audio. I stored these anonymized interview transcripts and research memos as word documents on my personal computer. Then, using the qualitative analytic software program, NVivo, I identified and coded emergent themes related to health, identity, and emotional labor.

I used colored markers on printed transcripts as a preliminary stage of open coding, which helped me determine exploratory codes and major themes. I focused on individuals' explanations (i.e. their understandings) of fibromyalgia: the metaphors they used to describe their feelings, the constraints they faced in maintaining and/or reaching wellness, and the privileges and support systems that improved the interviewee's quality of life. Within NVivo, I conducted a second round of coding for sub themes, paying particular attention to individuals' narratives about the self, competing or complementary conceptions of fibromyalgia, and their agency and ability to manage their symptoms. Drawing from both survey and interview data, I systematically compared how social positioning shapes individuals' perceptions of fibromyalgia.

III. Framing Fibromyalgia: Managing Symptoms, Maintaining Well-being

Jade (middle-class, Black, woman) called it "perpetual pain."

Heather (affluent, white, woman) described it as "non-specific, squishy symptoms" that are "just a pile of shit."

Sarai (low-income, Black, woman) explained, "It's just been a nightmare."

This chapter looks at the ways individuals' understood and made meaning of their fibromyalgia. While the origins of fibromyalgia varied among individuals, there were many commonalities in the ways that my respondents framed their condition. The current chapter explores patterns of how individuals make sense of their fibromyalgia experience, and how their understandings of fibromyalgia shape their self-concepts. Firstly, participants emphasized the legitimacy of their conditions and the social consequences of the diagnosis. In my data, it became clear that individuals' narratives of fibromyalgia relied on bodymind experiences and relied heavily on medical rhetoric. Individualism was a persistent theme throughout the respondents' narratives; well-being was viewed as within one's own control, a product of the amount of self-care an individual participated in. Finally, most of my respondents spoke of fibromyalgia as a disability (entailing social barriers which prevented full participation in society) without directly identifying as disabled.

Fibromyalgia is…

I approach the meaning-making of fibromyalgia from two angles: quantitative survey data and qualitative interview data. The metaphors my interviewees used to describe fibromyalgia provide a helpful starting place to begin to visualize the experience of fibromyalgia. Most respondents' metaphors centered on the visualization of pain. Shanice (low-income, Black, woman) explained "It feels like you're in a tunnel. Feeling like, um, everything is squeezing you, right. You're close, a hug, an uncomfortable squeeze." Similarly, Bill (low-income, white, man) honed in on the perception of pain but emphasized, "Pain is a big deal. You sense pain a lot throughout your entire body, not just one spot: it moves around." Not only did participants feel that the pain "moved," but some – like Dory (low-income, white, woman) – argued that "there were so many types of pain all at once."

Importantly, not all people with fibromyalgia described pain as their most severe symptom. David (low-income, Asian, man) explained, "For me, I think the fatigue is probably the most debilitating, more so than the pain." For Stan (low-income, multiracial, man), "brain fog," or a lack of mental clarity, was a more prominent symptom. He used an analogy to explain his experience of brain fog:

> if I have a filing cabinet and it's gotten drawers and then inside, it's got files with labels on it. The kind of memory issues I have is - I know everything that's in that file cabinet but I have trouble remembering what's on the folder label, and that's, that's like a person's name, but as soon as you help me remember the name on the folder, I can tell you everything that's in the folder in detail.

Additionally, understandings of fibromyalgia are also tied to other symptoms and comorbidities. Stan argued, "anytime I talk about pain management and, um, and the symptoms of fibromyalgia, they're very closely linked to my spinal problems." Importantly, an overwhelming 92.3% of survey respondents reported having another diagnosable condition, with those most common being depression (55.4%), anxiety (47.2%), and chronic fatigue (29.1%).

My survey participants were asked to list in rank order the top three most important factors which they believed caused their fibromyalgia. The most common responses were stress, trauma and abuse, other physical health conditions, and genetics / heredity. In trying to manage their fibromyalgia, survey respondents were most likely to use the following resources: doctors ($M = 4.66$, $SD = 1.72$), alternative medicines and holistic treatments ($M = 3.88$, $SD = 1.74$), and Google searches ($M = 3.56$, $SD = 1.82$).

In both my survey and interview data, age proved to be an important variable in the understanding and experience of fibromyalgia. Within the survey data, age of diagnosis had an average of 39.9 ($SD = 10.7$). Within my interview data, age was incorporated into individuals' descriptions of fibromyalgia, comparing the condition to the aches and pains people experience as a senior adult. For example, Ken (low-income, multiracial, man) used age as a metaphor to explain his condition: "And so I'm constantly like, how am I, how am I feeling this way already? Aren't I too young to be feeling this way?... I still feel young, but my body is just like done." Therefore, I utilized my survey data to determine whether there was a relationship between fibromyalgia symptom severity and age. Results showed that fibromyalgia symptom severity was negatively related to age of diagnosis ($r = -0.25$, $p < 0.01$). In other words: in this sample, as age increases, fibromyalgia symptom severity tends to decrease. There has been growing medical attention to the experience of fibromyalgia in young people, however (Coles and Uziel 2021). This is something Heather (affluent, white, woman) elaborated on: "So it's a little different, and from my understanding, is sometimes you get whacked more than somebody who developed it older. Or if you get it younger, it tends to be a little more severe." This idea was actually supported in my survey data as those who were diagnosed at younger ages reported higher current symptom severity ($r = -0.24$, $p < 0.01$). Over time, individuals' expectations of what it means to feel well changed.

The above findings begin to point to the idea that age is related to the fibromyalgia experience: interviewees compared the experience of old age to fibromyalgia. Do older individuals feel that they more strongly understand fibromyalgia? I used a multiple regression to explore individuals' understandings of fibromyalgia (see Table 3.1). In model 1, I regress age, race (white vs. non-white), gender (woman vs. non-woman), and socioeconomic class on understanding of fibromyalgia to understand the effect of social positioning alone. Results show a significant positive relationship between age and fibromyalgia understanding ($\beta = 0.03$, $p < 0.001$): as age increases, understanding of fibromyalgia tends to increase. This promotes the idea from my interviews that the experience of fibromyalgia is similar to old age. However, it might actually reflect that individuals' gain a stronger sense of understanding when they've experienced it for a longer amount of time. Another important finding here is the significant negative relationship between race and fibromyalgia understanding ($\beta = -0.59$, $p < 0.01$), pointing my attention to the ways that ideologies of whiteness might be infused within fibromyalgia understandings.

In model 2, I incorporate fibromyalgia symptom severity into the model. Do individuals embodied experiences with fibromyalgia mediate these demographic patterns? While the effects for age and race remain significant, there is no relationship between fibromyalgia symptom severity and understanding of fibromyalgia in this model. Therefore, I add fibromyalgia self-mastery (model 3) to determine whether individuals' sense of control over their condition is related to their understanding of it. Once again, the effects for age and race remain significant. Furthermore, not only is there a positive, significant effect between fibromyalgia self-mastery and understanding of fibromyalgia, the effect for fibromyalgia symptom severity and understanding of fibromyalgia becomes significant ($\beta = 0.09$, $p <$

Table 3.1

Effects of age, race, gender, class, symptom severity, fibromyalgia self-mastery, and fibromyalgia social identity on understanding of fibromyalgia (N = 488).

	Model 1	Model 2	Model 3	Model 4
	β *(SE)*	*Β* *(SE)*	*β* *(SE)*	*β* *(SE)*
Age	0.03*** (0.01)	0.03*** (0.01)	0.03*** (0.01)	0.03*** (0.01)
White	-0.59** (0.22)	-0.61** (0.22)	-0.46* (0.21)	-0.40 (0.21)
Woman	-0.16 (0.23)	-0.19 (0.23)	-0.22 (0.23)	-0.24 (0.22)
Class	-0.03 (0.08)	-0.01 (0.08)	-0.04 (0.09)	0.00 (0.09)
Fibromyalgia Symptom Severity	---	0.03 (0.02)	0.09*** (0.02)	0.06** (0.02)
Fibromyalgia Self-Mastery	---	---	0.08*** (0.02)	-0.08*** (0.02)
Fibromyalgia Social Identity	---	---	---	0.06*** (0.02)
Constant	3.37*** (0.38)	2.86*** (0.51)	1.44** (0.58)	0.61 (0.60)

Notes: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

0.001). Finally, in model 4, I incorporate fibromyalgia social identity, as I suspect an individuals' group affiliation might enhance their understandings of their condition. This effect is shown to be positive and significant ($\beta = 0.06$, $p < 0.001$). Further, of the previously-significant effects, only the effect for race became insignificant ($\beta = -0.4$, $p = 0.06$), which raises questions about the connections between whiteness and a fibromyalgia social identity.

In my survey data, I was surprised to find an insignificant relationship between how concerned individuals felt about their fibromyalgia and how strongly they felt they understood their condition. I had previously assumed that individuals who more strongly understood their fibromyalgia would also report less concern about it. Therefore, I conducted a second multiple regression model to better understand the contributing factors to individuals' levels of concern (see Table 3.2). In model 1, I regress age, race (white vs. non-white), gender (woman vs. non-woman), and socioeconomic class on understanding of fibromyalgia. In this model, the only significant effect was for class ($\beta = -0.36$, $p < 0.001$): individuals with privileged socioeconomic status tended to report less concern about their fibromyalgia. In model 2, I incorporate fibromyalgia symptom severity, as severe bodymind experiences might shape how concerned individuals feel about their fibromyalgia. This showed a significant positive effect ($\beta = 0.13$, $p < 0.001$): as fibromyalgia symptoms worsen, individuals tend to report greater concern. In model 3, I add fibromyalgia self-mastery to determine whether individuals' sense of control over their condition is related to their concern. Results show a significant, negative relationship ($\beta = -0.09$, $p < 0.001$): as individuals feel more in control, they tend to feel less concerned about their fibromyalgia. In models 4 and 5, I add fibromyalgia social identity and social identity salience, respectively. I suspected that individuals who knew others with fibromyalgia – and who had incorporated fibromyalgia into their self-concepts - would feel less concerned about their conditions. I added these separately as I anticipated the effects for each would vary demographically. While the effect for social identity salience was insignificant, results showed a significant, positive relationship for fibromyalgia social identity ($\beta = 0.04$, $p = 0.001$). In other words, individuals with a fibromyalgia social identity tended to report greater concern about their condition, but it didn't matter how salient their fibromyalgia was.

The findings from my survey data show that understanding fibromyalgia – and incorporating it into one's self-concept – can be both positive and negative. This idea was also reflected in my interviews. Dory (low-income, white, woman) argued that "It's been a double-edged sword on that one – it's a blessing and a curse all at the same time." Many of

Table 3.2

Effects of age, race, gender, class, symptom severity, fibromyalgia self-mastery, fibromyalgia social identity, and social identity salience on concern about fibromyalgia (N = 488).

	Model 1	Model 2	Model 3	Model 4	Model 5
	β	*β*	*β*	*β*	*β*
	(SE)	*(SE)*	*(SE)*	*(SE)*	*(SE)*
Age	-0.07	0.00	0.01	0.01	0.01
	(0.01)	(0.01)	(0.01)	(0.01)	(0.01)
White	-0.21	-0.28	-0.44	-0.39	-0.34
	(0.21)	(0.20)	(0.19)	(0.19)	(0.19)
Woman	0.12	-0.06	-0.04	-0.05	-0.07
	(0.22)	(0.21)	(0.20)	(0.20)	(0.20)
Class	-0.36***	-0.25**	-0.21**	-0.18*	-0.19*
	(0.08)	(0.08)	(0.08)	(0.08)	(0.08)
Fibromyalgia Symptom Severity	---	0.13***	0.09***	0.09***	0.09***
		(0.02)	(0.02)	(0.02)	(0.02)
Fibromyalgia Self-Mastery	---	---	-0.09***	-0.08***	0.04***
			(0.01)	(0.01)	(0.01)
Fibromyalgia Social Identity	---	---	---	0.04***	0.04***
				(0.01)	(0.01)
Social Identity Salience					0.01
					(0.01)
Constant	5.57***	2.96***	4.48***	3.84***	3.61***
	(0.27)	(0.46)	(0.51)	(0.54)	(0.57)

Notes: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

my interviewees focused on the negatives, like Brian who claimed fibromyalgia "is a challenge that I live with," and Kathryn (affluent, white, woman) who related functioning with fibromyalgia as living like a "zombie." In contrast, Bill (low-income, white, man), who perhaps had more optimism with his faith-based lifestyle, argued, "It's something people have to come to terms with, that it changes your life. But you can cope with it." Whether focusing on the downsides or trying to remain optimistic, fibromyalgia was framed as life-changing.

Most of my interviewees who spoke about their fibromyalgia symptoms improving credited it to their own personalities and perseverance rather than their relatively privileged social positionings. This finding is unsurprising for a culture shaped by individualism which encourages individuals to be independent and self-reliant. In one example, Stan (low-income, multiracial, man) explained that he was diagnosed relatively quickly "probably because of the strength of character and the advocacy that I do, because I wouldn't have, I wouldn't have accepted that." Later, he recounted successfully resisting the stigma of fibromyalgia: "I never saw myself as like damaged goods or anything like that, because I've always had a very strong sense of self, and a good outlook." Stan did not acknowledge, and perhaps wasn't even aware of, his relatively privileged identities or social positioning for these positive outcomes, but relied on his own personality to explain successful management of his fibromyalgia symptoms.

In many cases, including Natalie's (affluent, Black, woman), participants argued that fibromyalgia "made me change my life for the better," but again, crediting their individual lifestyle choices and agency rather than their structural advantages. Similarly, Michelle (affluent, white, woman) explained, "I just decided that I needed to be strong and everyone can go shove it, and I'm going to take care of it myself. And that's what I did." Some interviewees, however, most commonly those with at least one marginalized identity, talked about being f*orced* to manage their conditions at the individual level due to a lack of support at the institutional level. Twinkle (affluent, Black, woman) explained,

> You're just by yourself, trying to figure out something that you feel like people should be helping you with. Because if you do the research, you'll find out it's a recognized disorder, you know. So why are we out here floundering around like fish out of water, trying to figure out what to do?

Marie (affluent, white, woman) argued that individuals bear the brunt of fibromyalgia responsibility because the condition is "less-knowable" to medical professionals. She explained,

> There's not the consensus of what causes it, so then you don't know how to fix it. So it sort of throws it back on you to figure out, "Okay, these are my symptoms," - cause everybody's a little different – "and which is the most important for me to treat," …So it kind of throws your care back on you, and it's a lot of experimentation.

This experimentation period and unreliability of effective treatments might have contributed to individuals' interpretations of fibromyalgia (and fibromyalgia treatment options) as consistently inconsistent (a theme discussed later in this chapter).

Because my interview data showed a link between identity, ideologies, and individuals' sense of responsibility for improving their fibromyalgia, I composed a regression model to determine the relationship between fibromyalgia self-mastery, demographics, symptom severity, and gendered personality (See Table 3.3). In model 1, I regress age, race (white vs. non-white), gender (woman vs. non-woman), and socioeconomic class on fibromyalgia self-mastery. Interestingly, gender was the only variable that showed an insignificant effect in this model. In model 2, I incorporated fibromyalgia symptom severity, as there was shown to be a relationship between symptom severity and self-mastery in previous regression. Fibromyalgia symptom severity showed a significant, negative relationship to fibromyalgia self-mastery ($\beta = -0.48$, $p < 0.001$), in that those with greater fibromyalgia symptoms also felt less in-control of managing them. Further, including fibromyalgia symptom severity made the effects for age and class insignificant. In models 3 and 4, I add masculine and feminine personality, respectively. I anticipated that gender performance might affect the wellness process, and that those who more closely embodied hegemonic femininity might achieve well-being more easily. My findings showed the opposite: there was a significant positive effect between masculine

more closely embodied hegemonic femininity might achieve well-being more easily. My

Table 3.3

Effects of age, race, class, symptom severity, and masculine/feminine personality on fibromyalgia self-mastery (N = 488).

	Model 1	Model 2	Model 3	Model 4
	β	*β*	*β*	*β*
	(SE)	*(SE)*	*(SE)*	*(SE)*
Age	0.04*	0.91	0.01	0.01
	(0.02)	(0.02)	(0.02)	(0.02)
White	-2.05**	-1.81**	-1.56*	-1.16**
	(0.67)	(0.61)	(0.61)	(0.61)
Woman	-0.33	0.28	0.27	0.14
	(0.71)	(0.65)	(0.65)	(0.66)
Class	0.87***	0.48	0.35	0.35
	(0.27)	(0.25)	(0.25)	(0.25)
Fibromyalgia Symptom Severity	---	-0.48***	-0.47***	-0.47***
		(0.05)	(0.05)	(0.05)
Masculine Personality	---	---	0.15***	0.13**
			(0.05)	(0.06)
Feminine Personality	---	---	---	0.04
				(0.04)
Constant	8.60***	17.95***	15.77***	15.14***
	(1.18)	(1.45)	(1.62)	(1.71)

Notes: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

more closely embodied hegemonic femininity might achieve well-being more easily. My findings showed the opposite: there was a significant positive effect between masculine personality and fibromyalgia self-mastery ($\beta = 0.13$, $p < 0.01$). In other words, individuals who reported a more masculine personality tended to report a stronger sense of control over their fibromyalgia, which relates to notions about masculinity and exerted agency.

Bodymind

Despite fibromyalgia having ambiguous biological causes, most interview participants relied on biological and/or medical causes for fibromyalgia. However – just as there is a debate within the medical community about whether the condition is neurological, auto-immune, or a joint disorder - my interview participants provided conflicting reports for fibromyalgia's origin. Heather (affluent, white, woman), a nurse, succinctly described that "it can be either physical or psychological insults that, to me, alter that pain pathway." Michelle (affluent, white, woman), who was one the more clinically-qualified of my interviewees in her role as a practicing psychology professor, described fibromyalgia as "a generalized pain syndrome. Primarily I think it is because it is an absence of substance P in the spinal cord." Michelle did not consider fibromyalgia a disease or disorder; rather, she explained that

> it's a constellation of symptoms that get under the umbrella of fibromyalgia…but it's neuromuscular, it doesn't involve your bones. It doesn't involve your joints. And it involves pain perception and the relay of pain, which is why there are certain medications that are very effective. Um, such as Cymbalta, which I take.

Perhaps coming from a shift in the medical literature, neurologists are beginning to document differences in pain perception, which also makes them responsible for professional meanings of fibromyalgia (Murke et al. 2022). Bill (low-income, white, man), a theologian and former social sciences professor, also emphasized that fibromyalgia is "a condition of your neurological system that causes you to be more sensitive to pain, and there's many facets to it... So it's a *neurological* disease, many ramifications."

Despite Michelle's (affluent, white, woman) strong argument above emphasizing that fibromyalgia is not a joint disorder, many respondents reported joint pain and continued to understand fibromyalgia as related to joint disorders. Emma (low-income, Black, woman) explained that fibromyalgia "seems to manifest in your muscles near the joints where it can be sometimes mistaken for arthritis." Similarly, Olivia (affluent, white, woman) explained "And so it builds up in the muscles and gives you these like lumps and pain."

Importantly, although some respondents pointed to joints as the place in the body which fibromyalgia affected, the uncomfortable sensation which they pointed to is generalized pain. Prof. Z. (middle-class, white, man) explained, “fibromyalgia is pain all over - for me - pain all over, a pain that doesn't stop, and a pain that only goes away with either alcohol or marijuana.” Prof. Z. relied on fibromyalgia as a problem with pain processing, which also allowed him to understand fibromyalgia by the remedies which alleviated his pain. Many relied on the idea that fibromyalgia results from heightened pain sensitivity or intolerance. Stan (low-income, multiracial, man) explained,

> it is a syndrome, um, a pain syndrome in the body that also affects, the immune system where the body stops its ability to regulate and manage pain. And even small amounts of pain get regulated into larger pain in the body. And it affects a bunch of other systems and in nerves throughout the body and can affect your digestive system and a host of other parts of the body.

A white man and patient advocate, well-versed in the language needed to navigate medical institutions, was able to talk about the specific bodily processes which are affected by fibromyalgia but honed in on the framing of fibromyalgia as a pain processing problem. The usage of *hypersensitivity* came up several times as well, including Viola (middle-class, Black, woman) who explained, “we figured out that what it is, is my body is very hypersensitive... [fibromyalgia] is going to shut your body down.”

Survey respondents were most likely to report using the following options to manage their symptoms: prescription medication (79.6%), over-the-counter medication (54.6%), diet (50.1%), exercise (43.8%), yoga (38.9%), marijuana and CBD (32%), meditation (29.9%), and counseling (22.6%). However, one of the founding premises of this project is that access to fibromyalgia treatments is unequal. Therefore, I ran a two-way ANOVA to understand the effects of gender, race, and class on initial symptoms and symptoms since diagnosis. While none of the variables predicted symptom severity at time of diagnosis, there was an almost significant effect for class that was related to symptoms now ($F(4)= 2.35$, $p = 0.051$) with an observable class relationship between symptoms reported by poor people ($M = 3.75$, $SD = 0.22$) working-class ($M = 3.21$, $SD = 0.13$), middle-class ($M = 3.16$, $SD = 0.12$), and affluent ($M = 2.92$, $SD = 0.24$) people. This finding highlights the importance of socioeconomic status as a privilege of well-being.

As a result of unequal access, I also hypothesized that individuals' ratings of treatment satisfaction (How much do you think your treatment helps your fibromyalgia?) would vary demographically. I ran a two-way ANOVA to explore whether gender, race, and class were related to how satisfied individuals were with treatment. Although the effect for gender was insignificant, race ($F(1) = 4.60$, $p < 0.05$) and class ($F(4) = 5.01$, $p = 0.001$) were significant. Surprisingly, non-white ($M = 3.46$, $SD = 0.22$) people reported greater satisfaction with treatment compared to white people ($M = 3.04$, $SD = 0.14$). Additionally, post-hoc Tukey tests showed that middle-class ($M = 3.52$, $SD = 0.14$) ($t = -1.04$, $p < 0.001$), and affluent ($M = 3.55$, $SD = 0.29$) ($t = -1.07$, $p < 0.01$) individuals reported greater satisfaction with treatment compared to lower class people ($M = 2.49$, $SD = 0.27$). I ran this analysis again incorporating an interaction effect for race and class, but the interaction effect was insignificant.

Throughout my interviews, respondents also pointed to psychological and emotional sources of their condition. Natalie (affluent, Black, woman) related fibromyalgia (and chronic pain more generally) to personal childhood trauma, "Cause what happens is that childhood trauma, your mind may not remember, but the energy gets stuck in your body and that expresses itself as fibromyalgia." This understanding reflects the argument in *The Body*

Keeps the Score, in which Bessel van der Kolk (2015) presents advances in medical literature that show the ways trauma alters individuals' embodied experiences. In a similar vein, Emma (low-income, Black, woman) explained: "We know that the root cause to fibromyalgia is trauma. Some type of trauma, whether physical or emotional, that there's some type of trauma. The root cause for me, it was emotional trauma."

Fibromyalgia "also affects your mental person and the fact that you can be mentally-foggy, forgetful, not clear mentally," Bill (low-income, white, man) explained. Many of my interviewees mentioned the emotional and psychological effects of the condition. Michelle (affluent, white, woman) was one of the few to mention the bodymind connection. "It affects your body and mind." Avery (middle-class, Black, woman) stated, "it has a lot of psychosocial implications and it affects many different systems in one person's body." Natalie (affluent, Black, woman) articulated how fibromyalgia exacerbated her emotional distress: "I think the days that you're in the heaviest pain are really depressing and it's really isolating, you know?" Echoing feelings of isolation and the connection between physical symptoms, psychological distress, and social support, Stan (low-income, multiracial, man) explained, "I think that a lot of people go through a period of time where their symptoms are so bad that they become misunderstood by the people around them."

Others pointed to mental health as a mirror image of the social perceptions of fibromyalgia. Brian explained, "I also have, you know, persistent mental health stuff, which gets treated almost exactly the same way." Importantly, this similarity was viewed as negative, in that both mental health and chronic pain were understood as stigmatized and minimalized. Claire (affluent, white, woman) worried, "I don't want to be labeled as anybody with psychosomatic or hypochondriac, kind of thinking." Additionally, Molly (low-income, white, woman) reiterated an instance where she felt her pain was being minimized and treated as merely a psychological condition:

> My GP sent me to a rheumatologist and he, of course, couldn't find any inflammation, right. And he sent me to a shrink. And of course that infuriated me back at that time, because I felt like he was just dismissing it, the whole situation, even though he said it would help me learn to cope with it. And that did not sit well. Uh, I needed physical help. I didn't have time to spend on coping with this when I was, you know, in a new blended family at that point in my life.

Finally, some wondered whether fibromyalgia was related to a personality type. For example, one theme that arose in several instances was that fibromyalgia is associated with people who are overachievers. "The person that can't say no, basically," Fang (low-income, white, man) explained. Molly (low-income, white, woman) described fibromyalgia sufferers as "people who are achievers. They want to be doing something. They have goals that they're proud of….but I would also describe them as persistent and stubborn. They just don't want to be defeated." And finally, Natalie (affluent, Black, woman) argued, "But there's a couple of celebrities that I figured out had it. And the thing I noticed is, it's real high-performing people." Individualism – which also encouraged individuals to understand their fibromyalgia as a personal responsibility – facilitated a connection between fibromyalgia as a type of burnout resulting from over-productivity.

Disability

In my interview data, there were complicated understandings of fibromyalgia as a disability. While all individuals spoke of fibromyalgia as a disability according to the definitions previously provided (even those individuals who were currently experiencing a period of relative comfort or remission), the vast majority did not self-identify as disabled. Rather, individuals used phrases like debilitating, limiting, and interfering in place of the word “disabling.” The few who did identify as disabled did not talk about it negatively, but rather as an informative tool for determining their levels of ability. Brian explained that, before fibromyalgia, he didn’t know what his limits were: “So sometimes I’d decide to do something and forget I’m disabled, and I get partway through it and go, ‘Oh, fuck, I can’t do this.’” In contrast, one man (Luke; middle-class, white, man) reacted defensively when I self-identified as disabled in our debrief:

> So I’m going to say this with as much respect as possible. But me, right now, disability is a very limiting word and it’s not a word that I want to apply to myself because it’s going to stop me from pursuing the best op-, the best outcome I can have. It’s not- I don’t want to go there.

Several participants talked about fibromyalgia in terms of bodily awareness. Some spoke about fibromyalgia as providing them with a fuller picture of bodily certainty, like Edith (low-income, Black, woman) who emphasized, “I know what I can handle and what my body can handle.” Bill (low-income, white, man) spoke about fibromyalgia as bittersweet when he explained, “I guess it’s kind of humbling because there’s things I would say I would do, and just can’t do it. You know? So you become a little bit humbled by it, that you are a limited person.” Incorporating some self-compassion, Bill spoke of fibromyalgia as limiting but informative: “You have to be willing to recognize too that you’ve got some limitations. There’s some things you can’t do. You’re going to be, kind of have to accept where you’re at.” The majority, however, focused on the experience of bodily doubt. For example, Prof. Z. (middle-class, white, man) argued that fibromyalgia forces sufferers to be more aware of the things that they can no longer do. When talking about the best and worst aspects of being diagnosed with the condition, Prof. Z. explained, “it's been, uh, it's been a rough road to hoe and I guess, if anything, it's just made me more aware physically of what my body is doing and the limitations that I have.”

Although many participants shared their understandings which reflected internalized ableism (see next section), many also attempted to counteract it with individual-level responses of reasoning, therapy, and self-compassion. Sadly, Edith (low-income, Black, woman) noted, "I just think that so many women are being told we're crazy, and we're not crazy." Emma (low-income, Black, woman) wanted other people with invisible illnesses to remind themselves that "you're not just being lazy." Others used humor to combat the stigma they perceived, like Prof. Z. (middle-class, white, man) who noted, "It's not just in my head, in others' heads. No – it's all over."

The only person to raise the concept of disability justice specifically (and to place responsibility for fibromyalgia improvement on society as a whole) was Sarai (low-income, Black, woman), a college student with several other chronic conditions and who self-identified as disabled. Sarai talked about institutional barriers, stigma, and internalized ableism as a barrier to self-identifying as disabled:

> It's been a lot to ask for accommodations and just be able to really begin to accept myself as a person with a disability…And recently, with disability advocacy and watching *Crip Camp* and learning about the disability community, it really inspired me to see the positives of identifying as a disabled person, not as like a student who may live with one or more disabling conditions….It's like, nobody's gonna call me a student with variable levels of blackness!

Through reflection, Sarai talked about becoming a disability advocate in part through her personal struggle to obtain disability accommodations at school. In this way, she connected her own experience to a broader struggle of intersectional social justice. Importantly, the interview respondents most likely to talk about social or collective responses to disability and chronic pain were Black women. For example, Twinkle (affluent, Black, woman) understood the larger community (and access to social services) as being responsible for continued suffering: “If you don’t have any access to the things that are going to help you, then you are going to be, you know, laid out somewhere.”

Twinkle (affluent, Black, woman) argued that - as a result of medical and social illegitimacy – fibromyalgia negatively affected the way she was perceived: “I think I’m perceived as somebody that thinks she’s got something that other people have, and she really doesn’t have it, you know? ‘It’s just all in her mind.’” Utilizing my survey data, I performed a two-way ANOVA to analyze the effects of gender, race, and class on an individual’s personal stigma score, or whether individuals stigmatized themselves. Only the effect for class was significant ($F(4) = 3.75$, $p < 0.01$). However, post-hoc Tukey tests showed no significant differences between classes[28]. A similar two-way ANOVA was run to analyze the effects of gender, race, and class on perceived stigma, but the model was not significant. However, perceived stigma was demonstrated in my interviews, including Bill (low-income, white, man) who explained, “It certainly changes how people perceive you.”

Internalized Ableism

Internalized ableism occurs when disabled people discriminate against themselves and/or other disabled people (Bailey and Mobley 2021). Fibromyalgia functioned as a disability in this capacity. “And so I feel like I’m not as good in that way, because I just don’t have the energy or the ability,” Viola (middle-class, Black, woman) reflected. Scholars of status and social positioning (Ridgeway 2008) show that despite an individual’s rank in the social hierarchy, they are aware of which social groups are oppressed. There was a

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[28] Estimated marginal means showed that that with middle class ($M = 8.24$, $SD = 0.44$) and affluent people ($M = 7.87$, $SD = 0.92$) reported significant less personal stigma than poor people ($M = 10.15$, $SD = 0.86$). Additionally, middle-class individuals reported significantly less personal stigma than working-class individuals ($M = 9.54$, $SD = 0.51$).

general tendency within my interviewees to resist the label of disabled. When individuals belong to marginalized groups, they can often internalize their oppression, and begin to discriminate against themselves and or other marginalized people (Bailey and Mobley 2021). Therefore, social positioning shapes which individuals are able to maintain agency over their self-definitions (Collins 2000).

Some examples of internalized ableism are being ashamed of their disability, attempting to "pass" as able-bodied or "hide" their disability, and refusing disability accommodations and support. Each of these instances of internalized ableism were recorded in my interview data. Olivia (affluent, white, woman) noted that "There's a certain amount of shame involved in being less than." Similarly, Prof. Z. (middle-class, white, man) talked about viewing himself as a "limited person":

> I try not to look at it that way, look at myself that way, but, uh, every morning when I get ready to get cleaned up and get dressed, I see myself that way. And, yeah, it's not something I like.

In both of these examples, individuals internalized cultural ideologies surrounding fibromyalgia, experiencing shame from stigmatization.

In other cases, respondents projected their shame. Directly-discriminatory ableist attitudes came up within the experience of fibromyalgia. For example, Dory (low-income, white, woman) recounted the ways that people stigmatized her for having fibromyalgia. She explained that when people learn of her diagnosis, they react

> very, very tragic and traumatic…And then talk to me like I was a vegetable in a wheelchair. Oh no, that's irritating, I don't like that. That's usually the reaction I get is, 'oh, you poor thing.' And then they're like afraid.

Dory noticed how being perceived as "other" made her feel less-than, and in the next sentence reduces people using mobility aids to "vegetables."

In a similar example, Michelle (affluent, white, woman) spoke about how her condition prevented her from hiking with her family:

> I don’t understand why I can’t just go exercise and feel better like I used to. Cause I used to. I love to exercise, and I have always been really active. Now when I exercise, which I still like doing, I feel like I have the flu….I’d have to stay in the car and I just have to sit around and walk around the parking lot, maybe walk around the nature trails, like all the decrepit people.

Michelle expressed shame because she could no longer move her body in ways she remembered, and exercise was no longer as restorative as it had been previously. At the same time, she talked down to other disabled (“decrepit”) people who are unable to hike the more advanced trails.

There were many instances in which individuals were encouraged to hide their fibromyalgia, whether it be from family, employers, or acquaintances. Natalie (affluent, Black, woman) spoke about having to power through her symptoms in order to retain her employment: “I was missing for like four weeks, and all the rest of the time I was still showing up in pain. … but I can’t talk about it, and no one can see it. It is crazy-making. You feel nuts.” Although she used all of her energy to show up to work, the invisible nature of fibromyalgia allowed her effectively to “pass” as able-bodied. However, this was accompanied by an emotional toll. In speaking about productivity at her fast-paced tech job, Natalie (affluent, Black, woman) later reflected,

> So it’s like this weird loop of like, I’m functioning really well. I do a lot of stuff, but I have this. But I’m not going to tell anyone I have it. So now I’m just going to internally like stuff it and suffer even more.

Kathryn (affluent, white, woman) also spoke about the emotional labor that accompanied internalized ableism. She noted,

> It’s weird because part of my brain is like, ‘you work hard constantly. This is what you do,’ you know? Boom, boom, boom, boom. And the other side is like, ‘um, you can’t do these things. You can’t do them anymore.’ …But I do feel like I fight it a lot. It’s like an internal battle of myself, right?

In a similar fashion, Michelle (affluent, white, woman) articulated the reasons that depression often accompanies fibromyalgia: “There’s a lot of stigma with the diagnosis. Like, ‘They’re all crazy. These people just whine all the time.’ And that’s sort of hurtful.”

In some cases, individuals attempted to prove their worth by refusing accommodations. For example, Heather (affluent, white, woman) – a housewife and mother of two - spoke about hosting family gatherings, insinuating that “good” disabled people still maintain active social lives and don’t cancel plans. Focusing in on the consequences, Heather explained,

> The big impact was lack of energy. Our house was always – even after diagnosis, and when I was like falling on my face – our house was always the house for every single holiday…So I was bedridden for like two days afterwards. I literally couldn’t move.

At the expense of her health and wellness, Heather indirectly categorizes herself as a good, worthy, and productive disabled person. Later, Heather connected individualism and ableism as she explained her reasoning for adamantly rejecting disability accommodations:

> I was determined that I was not going to go on that path because, I think when you’re diagnosed with, at least in my mind, when you’re diagnosed with fibromyalgia, there are like two forks. You go this way, you go that way. “I am my disease.” Or, you know, that way and say, “no, there’s just something that’s out there that is going to be annoying.” And I chose the path and I went to see the rheumatologist…And she said, “And I can help you if you want to go on disability.” And at the time, I was directing a graduate program and that was just like the most – to me – the most bizarre thing that somebody would even say to me. And she said it with all – I still see her – you know, with all empathy and kindness, because I was really crappy when I saw her. But when she said that, I’m like “Oh, no, no no, not doing that.” But I think that was like pivotal. So that was, that was what I had to make my decision. And I stuck to it.

In Heather's understanding, her own actions – seeing a medical specialist AND refusing to accept disability accommodations or identify as disabled – allowed her fibromyalgia symptoms to continue to improve.

The "Natural" Way

Treating fibromyalgia "naturally" was a common thread within my interviews, fueled by internalized ableism (rejecting disability accommodations) and less-than-ideal medical treatment options for fibromyalgia. When asked about what she's currently using for treatment, Jade explained, "I always said that I was going to go the natural way." Avery (middle-class, Black, woman) reflected ableist attitudes when she spoke about declining medication for her fibromyalgia:

> I would never took medication. I refused. I always said that I was going to go the natural way. You know, like I changed my life. A million times. I can tell you nothing worked, but I always kept pushing and trying to go the natural route.

Avery continued to experiment with non-medical treatment despite being unable to find relief from more "natural" methods. In a similar way, Dory (low-income, white, woman) implied that people who decline alternative treatments for fibromyalgia are looking for a quick-fix. In explaining her preference for holistic treatment options, Dory explained,

> The alternative stuff is much better and more effective, I think. But most people don't want that. They want the easy option, the easy out that takes care of it for them. And if it doesn't work, they just cry that it doesn't work. And that's pretty much exactly what I've seen.

Rather than displaying empathy for fellow fibromyalgia-sufferers, Dory perceived herself as better than her lazy peers as she put in the work to maintain her well-being.

Making healthy lifestyle choices was predominantly understood as an individual's responsibility rather than the responsibility of the larger community. Viola (middle-class, Black, woman) expressed a sense of responsibility over her condition that exceeded those of medical practitioners. She explained,

> So my thing was, if this has anything to do with dedication and mind over matter, I'll be fine, because I'm going to figure this out. If most people probably don't take that much of interest in their own healthcare to kind of just, listening to whatever the doctors say, but I've always been a person who does my own research. So I was like, 'I'm going to find the way. We'll figure this out…and my whole attitude was, 'man, watch me!'

In this statement, Viola positioned herself as a more agentic, active participant in managing her own health. While honing in on a sense of individualism, she credits her own personality as allowing her to manage her condition.

After trying some fibromyalgia medications, Emma (low-income, Black, woman) explained that she "started looking at more natural, holistic ways of dealing with this because I don't like medication and prescriptions, and I prefer more natural ways of doing things." Why are people hesitant to take medication for fibromyalgia? For some, fibromyalgia medications were simply ineffective. Shanice (low-income, Black, woman) reflected a sense of individualism as she described, "I had to encourage myself. I had to – all the medications that came out for fibromyalgia did not help me. I had to encourage myself." Others noted the side effects of medication. Fang (low-income, white, man) explained,

> I don't normally do the medicine, because some of the side effects are worse…And all these medicines interact with other medicines. And have complicating, duplicative, bad symptoms, increasing the effect of one or the other, not making one work, et cetera.

However, even for people who cited side effects as the main barrier to using medication, most provided a vague response that treating fibromyalgia requires natural, healthy living.

Claire (affluent, white, woman) noted this lack of specificity: "And that's where I came to the conclusion that there isn't anything real specific to do other than healthy living, healthy as you can live."

What exactly are "natural" and healthy ways to manage fibromyalgia? Michelle (affluent, white, woman) understood them as exercise and cardio. Others, like Claire (affluent, white, woman), understood it as food intake: "I kind of have the attitude that I don't know that there is anything for me that, you know, getting more knowledge about it might be a little bit helpful, but it really is about trying to live as healthfully as I can. And I still, like, I still eat more sugar than I should." Although she was self-disparaging, Claire understood fibromyalgia treatment as living healthfully. Others understood the "natural way" as lifestyle changes, which many understood as a benefit of receiving a diagnosis. For example, Jade explained that the fibromyalgia diagnosis as a

> journey around figuring out me. And I had to slow down. I had to be like, 'No, that doesn't work for me.' …Remember I said [fibromyalgia] was the worst pain I'd had, and it was also my liberation? And so it made me create a life that works for me.

The majority of solutions the respondents provided were focused on the individual making lifestyle changes, rather than emphasizing structural impediments to accessing care for people with chronic pain.

Legitimate

Perhaps in response to the stigma surrounding fibromyalgia, interviewees honed in on the perceived legitimacy of their conditions. The validation that occurs upon receiving a diagnosis further supports what Barker (2005) coined a diagnostic transformation. Scott (middle-class, white, man) described two important positives which resulted from finally receiving a fibromyalgia diagnosis: “It was uh, one: validation. And secondly, it put me on the path to at least try to get treatment.” Brian also understood a fibromyalgia diagnosis as validation “because you know, before that it had just been this, like, ‘why do I have pain when no one else does’ kind of thing. So that was the positive outcome. It was, it’s nice to have a word for it.”

The data from my survey show how a diagnosis might serve as one method of improving fibromyalgia symptoms. On average, survey respondents reported slight symptom improvement ($r(493) = -0.12$, $p < 0.01$). Compared to first discovering their condition ($M = 3.44$, $SD = 1.33$), symptoms now had a ($M = 3.21$, $SD = 1.13$). However, we cannot account for how much of this improvement results from medical treatments or the social-psychological processes of validation that occur from having a health condition become legitimized.

Many participants argued that receiving a fibromyalgia diagnosis counteracted their feelings of being “crazy.” Layla (low-income, Black, woman) explained that with a diagnosis, she “was able to put a name to what I was feeling, um, and I guess kind of, I don’t know what the word is. I guess it made me not feel like I was crazy. Like it was a real thing.” In this sense, a “real thing” meant that fibromyalgia was a medically-legitimate condition. Importantly, though, several respondents talked about feelings of continued “craziness” despite a diagnosis. Olivia (affluent, white, woman) spoke about the ways in which a diagnosis was bittersweet. She explained, “It’s useful to know that you’re not crazy, although you still feel like you’re crazy” because of the social stigma and cultural stereotypes surrounding fibromyalgia.

Bill (low-income, white, man) articulated some of the positives of a fibromyalgia diagnosis, including that

> it was helpful to talk to somebody to understood what was going on, obviously that that always makes you feel good, that they understand this and, and, you know, they, the encouragement that, you know, it's not going to kill you and there is hope to cope with it and there's methods you can cope with it. So the, the affirmation understanding of what was causing all this, the hopes that I could live with it, the fact that none of these things were going to cause me to die in the next year, those things.

While diagnostic legitimacy was one aspect of the benefits of a diagnosis, Bill also spoke about the peace of mind he received by learning that his condition was not life-threatening. Fear of a life-threatening condition was a common theme among my interview respondents – both before a fibromyalgia diagnosis, as well as after, when participants feared medical practitioners were overlooking something more serious. Because the fibromyalgia diagnosis itself is understood as stigmatized, participants like Shayera (low-income, white, woman) worried that medical practitioners were overlooking something more severe by attributing all health symptoms to fibromyalgia. She explained, "when they [doctors] see fibromyalgia in my, in my file, they're like, 'Oh, that's probably just because of that.'"

The fact that fibromyalgia is still medically-illegitimate was also seen as a social barrier "because even some of these new doctors kind of roll their eyes at this sort of stuff," Anne (low-income, white, woman) argued. Even as a diagnosis served as a positive in some aspects, there were just as many (if not more) negatives, including the understanding that "most doctors won't even take [fibromyalgia] seriously" (Dory; low-income, white, woman). After emphasizing the legitimacy and "realness" of her condition, Dory noted her justifiable anger, "I find it honestly appalling that most doctors will still pretty much laugh in your face over fibromyalgia and treat you like you are making everything up. And it's not a real thing." Respondents talked about making the intentional choice to not-disclose their conditions to medical practitioners as a result of this stigma. Claire (affluent, white, woman) related this sense of (il)legitimacy to her great-niece, who is also a fibromyalgia sufferer: "She accepts that she has fibromyalgia, and she like believes that it's true. But she is frustrated with the fact that she feels like she needs to hide that from healthcare professionals, because as soon as that comes out, that changes the way that they interact with her."

Medical (il)legitimacy encouraged some respondents to defensively police the borders of fibromyalgia. For example, Shayera (low-income, white, woman) stopped me in the middle of relating to her fatigue by saying,

> I'm not going to like put you down or anything, but like when I've been on, been on a fibromyalgia support groups and somebody is like, "my only symptom is fatigue and I was diagnosed with fibromyalgia," I'm like, "then you don't have it."

As medical and social understandings of fibromyalgia were still being constructed, individuals had more wiggle room to draw the line between fibromyalgians and non-fibromyalgians. The fibromyalgia boundaries – whether constructed by medical practitioners or the general public – lead some respondents to feel as though they were being gaslighted. Emma (low-income, Black, woman) argued,

> Whether it's, um, autoimmune or not, they need to get it straight in the medical community that this isn't in our head. Stop all the gaslighting it and just end it. I feel like people, a lot of times, doctors will gaslight when they don't know how to fix something.

Even with the diagnosis, many respondents still experienced an emotional toll resulting from fibromyalgia being medically "less-knowable" than other health conditions.

Consistently Inconsistent

Fibromyalgia was spoken of as the wrench in plans for individuals' futures, which forced them to change their perspectives on what is important for a full, well life. "I pretty much had to revamp my entire life in order to accommodate it," Olivia (affluent, white, woman) reflected. Viola (middle-class, Black, woman) explained that after years of college and hard work climbing the corporate ladder, "I had to put all the foundation down and then my body was like, eh, detour," forcing her to take a step back from her career in order to prioritize her health. Similarly, others spoke of the grief of losing "a life that could have been," which accompanied a worsening condition. Marie (affluent, white, woman) explained,

> I had to go through kind of a period of mourning what I thought my life was gonna look like and, you know, some of the travel and activities and things I wanted to do. Um, and my son's 20 now, but as I was raising him, you know, this was getting worse and worse.

Many individuals with fibromyalgia not only have to deal with the present-day symptoms of their conditions, but also the loss of an ideal future life.

Many of the participants explained that fibromyalgia is consistently inconsistent. Stan (low-income, multiracial, man) explained that fibromyalgia

> at its worse, [is] the inability to plan your life. You know, I'd say to a friend, "Hey, well, my partner and I would love to go to dinner with you on Thursday, but we're going to have to tell you on Thursday morning, whether we're going to be able to go or not, because it all depends on whether I've got the strength and stamina for it."

Although a diagnosis allowed some people to better understand their conditions, most people talked about fibromyalgia symptoms as being variable. In a similar vein, Marie (affluent, white, woman) explained, "So my wellbeing really kind of depends on just the month, you know, it's not predictable. So mentally that can be challenging because you just never know, is today going to be a good day or a bad day?" This inconsistency led to both social and psychological effects, which Shanice (low-income, Black, woman) elaborated on: "It has affected where I can't really plan. I can plan, but I can plan knowing that it may not work out. Or I can start it out, and have to not finish what I started."

Consistent inconsistency was present not only in individuals' symptom severity, but also in their opportunities for treatment and wellness. Scott (middle-class, white, man) argued that treatment unreliability was one of the most difficult parts of managing fibromyalgia: "There's conflicting information out there, and I get everybody's different. It might help one person and be a detriment to another person. But conflicting information out there is a problem too, with fibro." In several cases, respondents articulated how treatment options felt counterintuitive. For example, Dory (low-income, white, woman) stated,

> My doctor kept telling me the best thing for it is exercise, and I'm laying on my couch like, "how could that possible be helpful right now?" …So the more it hurts, the more I'm like, "No, I can do the things. It's fine." Cause in my world, like, it's not like it's an injury. It's not like a sprain. You can't make it worse by continuing to do things through it.

Respondents felt the need to power through their conditions, reflecting again the individual approach they took to manage their symptoms, partly due to the overall inconsistency of the symptoms, as well as a product of individualism. Others honed in on the inconsistency of the treatments themselves – while they might have been helpful initially, they weren't always reliable. Bill (low-income, white, man) argued that the hardest part of fibromyalgia is

> when it hits you that you're not going to fix this, because I was really kind of pumped up and…I did some [physical therapy] and I got a good response. I was doing a lot better for a few months. And then, then, I went into a bad period and, you know, kind of crashed and I was hurting again and stuff. And, you know, the realization: this is not fixed, you're not going to just fix it that easy. You couldn't walk away from it.

As the treatment options were unreliable, individuals understood that managing their fibromyalgia would be one constant in their daily lives.

The inability to plan in advance, in addition to missing out on social engagements and a lessening amount of productivity, led individuals to feel more negatively about themselves, In one example, John (low-income, white, man) described how there were times he still experienced denial about his condition: "I'm just not as much fun as I used to be, not as energetic, but that's how I view myself. Because I used to view myself as very energetic, very outgoing. Um, that's just not there anymore. Not to the same extent." In addition to feeling more poorly about himself, John (low-income, white, man) also reflected how masculinity might play a role in his emotions. John explained,

> Guys are just not willing to accept that they may have a real problem. Cause I didn't for years, you know. I just figured…I just, I beat myself up, you know. I played hard and I worked hard. I just, 'it's my fault,' you know, 'there's not anything wrong with me.

John articulated this complicated dynamic of wanting to accept his fibromyalgia as "true" but not wanting to feel like he was personally flawed.

Conclusion

In this chapter, I discussed individuals' understandings of fibromyalgia, and how these interpretations are related to the self. Individuals tend to define fibromyalgia based on the sensations they experience in their bodyminds. Providing visualizations, interviewees relied heavily on metaphors. While many define fibromyalgia using medical and biological rhetoric, others relied more heavily on psychological and emotional interpretations. Importantly, all individuals spoke about fibromyalgia as a disability, despite the strong preference of interviewees to reject this label. Individuals projected their own internalized ableism, both in the ways they compared fibromyalgia to other conditions and in their fibromyalgia treatment preferences. Despite the vast range of symptoms and treatments, interviewees noted a commonality in fibromyalgia experiences and – as a way of maintaining medical legitimacy - policed the borders of a fibromyalgia diagnosis. Overall, fibromyalgia was seen as coming in waves, creating consistent inconsistency in the experience of symptoms, impeding individuals' capacities for making plans for the future.

The results from my survey data take my interview analyses one step further. While race is related to individuals' understandings of fibromyalgia, class more strongly predicts how concerned individuals feel about their conditions. Both race and class, in addition to masculine personality, tended to predict how in-control individuals felt about their conditions. In the next chapter, I elaborate the interactional understandings of fibromyalgia, honing in on the ways that fibromyalgia wellness affects and is constructed with others.

IV. Wellness Work and the Social Responsibility of Care

In the previous chapter, I discussed how individuals with fibromyalgia come to understand their conditions as individuals. In the present chapter, I expand on the ways that wellness is constructed via interaction. When I first conceptualized this section, I imagined that fibromyalgia sufferers would accumulate a *fibromyalgia wellness identity* by undergoing the process of seeking wellness. While there is some qualitative support for this understanding, my quantitative findings were mixed. However, there was strong support for fibromyalgia *wellness* as a social process in both the survey and interview data. Specifically, individuals' statuses, social positionings, and social networks shaped their opportunities for both wellness and well-being.

Making meaning of and managing fibromyalgia diagnosis depends – in part – on the ways individuals' social networks understand and treat people with fibromyalgia. Interviewees speak about the social consequences of fibromyalgia. In the same way that many of the debilitating aspects of fibromyalgia are social, privilege allows people to manage these social effects more effectively. Throughout my interviews, respondents honed in on three primary interactional instances in which fibromyalgia was constructed: 1) the institutions of medicine; 2) employment; 3) the family and social support systems. In each of these instances, individuals with stronger, positive support systems reported both higher well-being and more opportunities to engage in wellness. Notably, there was a gendered and racialized divide in terms of respondents' beliefs about who was socially-responsible for providing care, at both the personal and community levels.

Medicine, Alternative Treatments, the Commodification of Wellness

Under capitalism, medicine and medical care function as for-profit systems, where health is marketed and sold to individuals as consumer products. The *wellness industry*[29] functions in a similar manner: it assumes achieving well-being is an individual's responsibility (and under and individual's control), and asserts consuming wellness products will help make this possible. In our capitalist society, corporations have commodified the term "wellness" and have disguised its social nature. To capitalists, wellness and well-being are one in the same: an experience that is marketed and sold to consumers in the form of medical and alternative treatments[30]. In other words, buying these items allows individuals to fast track the wellness process and more quickly achieve well-being. However, wellness functioning in a for-profit model means access to well-being is inherently unequal. By shifting wellness responsibility to the individual, the wellness industry both overlooks and exacerbates social inequalities. In the present chapter, I highlight the social aspects of wellness, in which self-care requires community care. Fibromyalgia has both social causes and social costs, and as a result, wellness cannot occur in social isolation.

Due to pre-existing social inequalities in society, individuals with privileged social positionings tend to have more opportunities to engage in the wellness process. For most people with fibromyalgia, the medical institution is one of the first places they search for answers about their conditions. Access to medical practitioners and treatments requires financial capital and – in most instances – health insurance coverage. Those without health

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[29] The medical industry, which is professionalized and standardized, requires health insurance to access. In contrast, the wellness industry is accessible with income alone. It is responsible for so called "alternative therapies" (in this project, most commonly massage, acupuncture, and the usage of life coaches).

insurance coverage were often forced to live with worsening symptoms. Layla (low-income, Black, woman) tearfully described being structurally denied access to well-being (through unemployment and lack of health insurance coverage), which also contributed to a pause in her wellness journey: “I’ve been trying to get on Medicaid, I haven’t been able to yet. So seeing doctors and taking medication and everything is kind of not happening right now.”

Health insurance coverage at least implies that you can get your foot in the door of a doctor’s office. This is a structural level of medical gatekeeping, which assumes you can then access effective medical treatments. For health conditions with more effective and affordable medical treatment options, the wellness process might be a lot simpler (and a lot more equitable) than in the case of fibromyalgia. Unlike health conditions with clear medical causes and effective medical treatments, there are few effective medical treatment options for fibromyalgia. This creates reliance on the wellness industry, and more room for class inequality in the fibromyalgia wellness experience, as those with health insurance but without financial capital were bound to a medical model with limited options for well-being.

Low-income individuals were more strongly bound to the constraints of health insurance coverage, and exhibited a kind of learned helplessness in feeling that there was nothing more they could to do for their fibromyalgia wellness. Fang (low-income, white, man) noted that in his inability to find an effective medical treatment for fibromyalgia, he didn’t need to spend much of his own money managing his condition. “The cost is nothing, really. I mean, I’ve got Medicare, and my insurance pays the copay and Medicare pays the rest. The only thing is insurance doesn’t cover the things that they should cover.” In this instance, I was able to observe the ways that access to wellness varied along class lines.

Despite class background, the idea that insurance does not cover actual effective treatments for fibromyalgia (including psychological counseling, massage, acupuncture) was a common theme throughout my interviews. In contrast to low-income interviewees who exhibited learned helplessness in regard to their wellness, interviewees with more class privilege (although noting the constraints of health insurance coverage) listed various alternative treatment options from within the wellness industry that they had previously tried or planned to utilize in the future. For example, Molly (low-income, white, woman) explained,

> Mostly my insurance has covered it, and I was able to pay the copays. A couple of years ago, I went to one comprehensive rehab thing and they did some of the things they used. Laser treatments were not covered by insurance. So I sprung for the money. Couple of thousand bucks. And, I was so desperate at that point, I was almost to the point that I could not sit up.

Having class privilege meant individuals were more likely to access alternative treatments and a breadth of accessible options, which allowed them the opportunity to be optimistic about the improvement of their well-being. Further, social psychologists have shown the importance of optimism in the progression of illness (Schnittker and McLeod 2005).

The next level of medical gatekeeping – the interactional level – includes the doctor-patient interaction. There are several social factors that can influence the doctor-patient interaction including patient's status, social networks, and health literacy, and doctors' values, understandings, stigmas, and biases. Interviewees had varying connections to medical institutions and medical practitioners themselves, and those with closer social ties to the institution of medicine reported a streamlined fibromyalgia diagnosis. David (low-income, Asian, man) credited two of his nephews who were both medical students (one who was currently in-residency) as originally "diagnosing" him with fibromyalgia. Heather (affluent, white, woman) – a clinical psychologist – was diagnosed by the rheumatologist she had previously worked with. Michelle (affluent, white, woman) was similarly diagnosed by her internist. Avery (middle-class, Black, woman) – who was one of my very few participants who spoke highly of the quality of her health care – was diagnosed by doctors she had previously worked for.[31]

Those who had close ties to medical institutions and professionals relied more heavily on their doctors' explanations. However, the lack of medical consensus around fibromyalgia means its meaning is always in-question. This ambiguity resulted in stigmatization, which was noted by the several medical professionals in my interview sample. Olivia (affluent, white, woman) noted that she had known of fibromyalgia prior to receiving her diagnosis, primarily because of the institutional stigma which surrounded the condition:

> I had heard of it in med school, because it was a wastebasket diagnosis and people were very disparaging of it because everyone felt that it was hysteria and these women who were just complaining. And it was not respectful. And there's overlap with chronic fatigue syndrome, which was also discredited…It's sort of like a mass delusion

Taking it a step further, Heather (affluent, white, woman) argued that the consistent inconsistency in individuals' presentations of fibromyalgia symptoms makes it difficult for medical practitioners to generalize and implement standardized diagnostic criteria. She noted medical stigma as a barrier, however, when she argued "What I do see as a commonality thread is the challenge faced when we see physicians. That seems to be a common experiential thread." In other words, at an interactional level, the medical stigma that is common among medical practitioners prevents equitable interactions between

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[31] Avery had such a close connection with her primary care doctor that she was even able to text her when she had concerns.

fibromyalgia sufferers and the institution of medicine. While the institution of medicine attempts to move toward a model of preventative care[32] for health, their options for fibromyalgia are individual-focused lifestyle changes.

Perhaps unsurprisingly, most people in my study reported negative doctor-patient interactions. The inability to develop strong social ties with medical practitioners shaped individuals' opportunities for wellness. Many interviewees reported medical practitioners who made them feel like hypochondriacs, that their fibromyalgia was "all in their heads." "I think the doctor, he saw me coming and yeah, 'he's always like complaining about this.' So he would kind of blow it off." Bill (low-income, white, man) described. My interviewees perceived a lack of empathy from their medical health providers, which they connected to their distrust of the institution of medicine. Others reported being classified as drug-seekers by their medical providers despite not wanting or mentioning medications. The distrust of medical practitioners discouraged them from accessing care (wellness), and also contributed to a psychological toll (well-being). Edith (low-income, Black, woman) explained how her distrust of doctors led to a worsening of her condition:

> And I didn't go, like I- after each one, I got exhausted from them. Cause they would drain me, and I didn't want to have to keep going back and just them belittle me again. So I would stop. And then when I got- when it gets really bad- I would go back again.

The continuous denial of symptoms by the medical community led Edith to feel more helpless about her symptoms.

Ableism and individualism intersect within the wellness industry to promote the idea that fibromyalgia sufferers with lower levels of well-being are simply "not doing enough."

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[32] measures taken to prevent disease or illness

Rather than a medical or social responsibility, Marie (affluent, white, woman) understood fibromyalgia as something that she was responsible for understanding and overcoming. “That’s kind of what I meant by what you fall back on yourself for, to decide what you want to try next, and what your course of treatment should be, because you almost know more than the supposed experts,” Marie (affluent, white, woman) explained. In this way, health literacy in the fibromyalgia wellness process is really just another type of social capital which first and foremost requires access to doctors themselves and then allows one to sift through alternative treatments promoted by the wellness industry. Encouraging individuals to generate more health literacy is – to a sociologist – the structure’s way of shifting the societal responsibility of health, wellness, and well-being onto the individual. The wellness industry overlooks issues of access, status, and social networks, as well as the cultural capital required to search through relatively unregulated products with varying levels of quality.

Financing Fibromyalgia: Income, (Un)Employment, and Social Security

When well-being is sold (and where health insurance is often dependent on being employed), employment and income become directly tied to individuals’ abilities to participate in wellness. In the United States, living with fibromyalgia (or any health condition, for that matter) is not cheap. As Jade noted, “this self-care is expensive! You cut corners where you can, when you don’t have access to it, but it’s not the same.” My survey respondents spent a monthly average of $290.61 on their fibromyalgia. Fibromyalgia symptoms severity was positively related to average amount of money spent on fibromyalgia ($r = 0.16, p < 0.01$). In other words, individuals with higher fibromyalgia symptom severity tended to spend spent more money managing their condition. I argue that individuals who experience more severe fibromyalgia symptoms are forced to spend more money to achieve well-being. “When money is important, money is very important,” Molly (low-income, white, woman) argued. In other words, money (or lack of it) determines how severe one’s fibromyalgia symptoms will be.

Further, employment and occupation served both as a social cause of fibromyalgia and a consequence of fibromyalgia. In my survey sample, only 38.7 percent of respondents were currently working for pay. Individuals who were employed worked an average of 34.42 hours per week. Generally, individuals who lack access to wealth must spend greater hours in paid employment in order to finance their fibromyalgia treatments and their lives. I performed a two-way ANOVA to analyze the effects of gender, race, and class on number of hours worked. The analysis revealed that there was a statistically significant effect between class ($F(4) = 4.77$, $p = 0.001$) on the number of hours. Tukey’s HSD test for multiple comparisons found that the mean value of hours worked was significantly different ($p < 0.001$) between working class ($M = 38.39$, $SD = 2.17$) and affluent groups ($M = 24.12$, $SD = 3.84$). Additionally, there were significant differences ($p < 0.001$) in hours worked between middle class ($M = 36.99$, $SD = 2.15$). and affluent individuals ($M = 24.12$, $SD = 3.84$). In other words, socioeconomic class is a better predictor of hours worked in paid employment when compared to race or gender. Next, t-tests were used to determine whether there were significant differences in the composite variables based on paid employment. Results showed that employment was associated with lower fibromyalgia symptom severity ($t(457.60) = 2.29$, $p < 0.05$). While some might interpret this finding as employment serving to benefit fibromyalgia well-being, from a structural perspective – combined with results from my interview data - I can infer that higher fibromyalgia symptom severity actually contributes to the likelihood of being unemployed.

Importantly, interviewees who reported higher income, employment in higher-status occupations, and/or received structural/cultural support at work also experienced increased opportunities to engage in wellness. One structural opportunity for wellness in the realm of work was an understanding or caring work culture. Natalie (affluent, Black, woman) talked about how a more casual work culture allowed her greater access to fibromyalgia treatments:

> I was in physical therapy for three years, from 2015 to 2018, for like three days a week, which – shout out to my boss – let me go every morning and like come in a little late to work. The benefits of working in a startup because everyone's late.

Natalie had support from her employers which served as an opportunity to manage her fibromyalgia symptoms.

Others whose employers provided flexible work schedules and remote (at-home) based employment opportunities also experienced increased fibromyalgia wellness. Scott (middle-class, white, man) talked about having the understanding of his employer: "[My boss] is very supportive. Like, 'here, if you need time, take time.' Things like that. So she, she is a great boss. It's just, I think she's of the impression like 'hey, that's not a real thing.'" Having the support of his employer allowed Scott to have more agency over his work schedule which allowed increased opportunities to fibromyalgia wellness. Another common theme which arose from my participants was the shift to remote work during the COVID-19 pandemic, and the benefits that this offered for managing fibromyalgia. Marie (affluent, white, woman) explained how her type of work allowed her to better manage her fibromyalgia:

> So I work from home, which is wonderful. And I work on a computer all day, so yeah, I don't have some of the physical demands of somebody like a hairdresser or, you know, someone that has to be on their feet.

Interview respondents who worked in paid employment often reflected perceived stigma at work, from individuals with similar or higher-status roles within their organizations, primarily due to perceived stigma about their levels of productivity. "It's like – employment. I mean, it goes back to that. Cause you know, it's like, what are you going to tell your boss? 'Oh, I'm in pain all the time'?" Ken (low-income, multiracial, man) pondered rhetorically. In a similar example, Viola (middle-class, Black, woman) disclosed her fears when she explained, "I worked at really high stress jobs and I didn't want everybody to say, 'Oh well, she can't do it anymore.'" In addition to bosses, others talked about how fibromyalgia affected social interactions with peers and colleagues. For this reason, most of my interviewees who spoke about employment felt actively discouraged from talking about their fibromyalgia at work.

Despite the cultural understanding of people with fibromyalgia as unproductive or lazy, all of my interviewees who were forced to leave and/or limit their work reported sadness and a threat to their self-esteem. Olivia (affluent, white, woman) honed in on the negatives of unemployment, both in the way others perceived her and in the ways she perceived herself. Olivia explained that when her fibromyalgia reached its worst,

> I didn't have a job. Luckily my husband didn't leave me, but before, I had this horrible job and I was so sick…I had to leave my job and my profession. And so it really changed my whole self-image, you know, as a person, because I had set out to be a doctor and, you know, I had a practice and I had to terminate all my patients. And it was a very traumatic time.

In Olivia's example, fibromyalgia and her occupation are connected: leaving a career she had spent years developing lead her to consider herself unworthy – as well as justify this same discrimination from her husband. Similarly, Layla (low-income, Black, woman) spoke about unemployment as shifting her understandings of a full life:

> It's [fibromyalgia] completely changed my perspective on life, like completely. Like how, how important things are. I mean, cause I used to complain so much about my job and about having to walk everywhere, but now it's like – I would give anything to take a walk and not feel pain, or work a job.

To Layla (low-income, Black, woman), a full life required being able to work, as work would mean *both* her symptoms were less severe *and* that she would be able to finance fibromyalgia treatments (which she was currently going without).

Some of my interviewees attributed fibromyalgia to a drop in income, both as a result of losing work and from increased spending on fibromyalgia treatments. "If I can't afford a treatment, I just don't get it," Emma explained. The majority of my survey sample (51.0%) reported having gone without fibromyalgia treatment due to cost. In my survey data, there were not significant differences in fibromyalgia symptom severity based on whether individuals had foregone treatment due to cost nor whether they were currently receiving social security income. However, cost as a barrier to wellness and well-being was an idea reflected in my interviews. Jade, articulated the connection between unemployment, lack of income and her condition when she explained,

> There were times when I had to quit jobs because of the pain…and, you know, that's taking thousands of dollars out of my house…And so, when I can't, it is anybody who's ever experienced poverty or just not having money knows how expensive it is to be that. And so, it is hard to manage if you don't have the funds. And that is sad in this country that if you don't have the money to get treatment that you need, you will remain in pain, even down to the foods.

Sarai (low-income, Black, woman) spoke about the emotional toll that low-income had on the ability to finance her condition: “It’s been a nightmare, trying to arrange my care…And if I can’t afford something, I end up just existing in a lot more pain.”

Previous researchers have noted that it is often difficult for individuals to receive social security payments for fibromyalgia: courts must determine the legitimacy of symptoms and judge an individual’s credibility (Le Page, Iverson, and Collins 2008). My interviewees noted that securing disability benefits for fibromyalgia seemed to require a lawyer.[33] My survey data reflected the notion that the majority of people with fibromyalgia – even those who were not currently employed – did not receive social security income. While 31.3 percent of my sample reported receiving social security benefits, only 17.2 percent of these people were receiving benefits specifically for fibromyalgia. Several interview respondents articulated difficulties in accessing social security income, even when they felt their conditions warranted it. Findings from my survey showed that those with higher fibromyalgia symptom severity were more likely to be receiving social security income ($t(491) = 4.67, p < 0.05$). From a structural approach, this would seem to suggest that in order for fibromyalgia to be “legitimized” as a disability by the Social Security Administration, individuals must present more severe fibromyalgia symptoms. Additionally, there were significant class differences in who received social security ($F(4, 478)= 7.11, p < 0.001$). Importantly, disability scholars have also noted the ways that maintaining eligibility for social security income requires perpetual poverty (Weaver 2020), a dynamic which Ken (low-income, multiracial, man) called “a never-ending vicious cycle.” My survey data showed confirmed those who received social security income were significantly more likely

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[33] Hiring a lawyer is contingent on one’s financial resources.

to identify as low-income compared to working-class (t = -1.50, $p < 0.001$), middle-class (t = -1.65, $p < 0.001$), or affluent individuals (t = -1.84, $p < 0.001$).

Interviewees with more privileged identities reflected discriminatory attitudes towards people with fibromyalgia who received social security income. Some of my respondents explained being the target of this discrimination, including Molly (low-income, white, woman), who felt discouraged from disclosing her condition at a previous job:

> And, as a matter of fact, back when I was working another job, like this, it just reinforced my attitude to not tell other people. Another lady where I worked was filing for disability with my company for fibromyalgia, and they treated her terribly.

Within and outside of the fibromyalgia community, individuals perceived people who received social security income as lazier, less agentic, less motivated to take charge of their own health. For example, Anne (white, low-income, woman) explained how helplessness and hopelessness arise once individuals receive disability income:

> There are some people who the fibromyalgia has gotten it to where they're on disability, they can't work, and it takes a lot away from them and they kind of, they kind of get to that point to where they think there's nothing else they can do. This is just the way life is.

Even people with fibromyalgia held the assumption that disability benefits lead individuals' conditions to worsen (rather than fibromyalgia being debilitating enough to allow individuals to receive social security income). One instance in my interview with Michelle (affluent, white, woman), which was caught me off guard, was when she talked about actively discouraging her own patients from attempting to secure disability benefits for fibromyalgia. She argued, "And my thing is – no. 'If I'm working, you're working.' I mean - I don't say that out loud - but clearly that's in the back of my mind. 'You're not going on disability for this.'"

In contrast, other respondents (usually those with one or more marginalized identities) felt that institutions were not doing enough to provide social support to people with fibromyalgia. Emma (low-income, Black, woman) made the connection between disability rights and employment when she argued,

> They need to settle it up and settle it up right, whether it's an autoimmune or not. They need to get it straight in the medical community that this isn't in our head, stop all the gaslighting it…I also think it needs to be nailed down medically because it affects your employment. And, and if they, if it's those ADA's, as far as employment, then when you're tore up one day, because you're in a flare, your employer is better able to deal with that. Because if they dump you off of work, because you're not able to meet the demands that one day, then they can get away with that. But when somebody is listed on that disability list, they will get in trouble for not making the accommodations that you need.

Rather than suggesting that those who received disability payments are lazy, my data suggests that when people with fibromyalgia are provided with accommodations that allow greater agency over their work schedule and environment, they are more productive and, consequently, have greater opportunities to participate in wellness.

Family, Faith, and Fibromyalgia

Many of the most debilitating aspects of fibromyalgia are social, and most interviewees seemed to desire more social support, whether or not they had strong social networks. Interviewees talked about the social isolation they experienced as a result of their condition. Shanice (low-income, Black, woman) explained, "I have not been able to do all the things that I know I'm capable of doing as far as social activities and family activities. So I see myself as not complete." This idea was reflected in my survey data, as respondents who reported higher fibromyalgia symptom severity were more likely to report that fibromyalgia prevents them from engaging in pleasurable activities ($r(506) = 0.42$, $p <$

0.01). Molly (low-income, white, woman) spoke of the emotional toll that resulted from having to miss out on social engagements:

> And I don’t go visit people very much because I can’t work out a time of the day where I can go to their place and then visit and then come back without being in so much pain, then it becomes not worth it. And that’s a hard thing to say, because I want to see these people. So I have people, I have friends sitting on hold.

Fibromyalgia support groups are often encouraged by medical practitioners as a way to learn more about the condition and combat the effects of social isolation. However, only 33.8% of participants reported being involved in one. For interviewees who were, there was a general consensus that the fibromyalgia support and advocacy groups have improved in the last few years, in terms of having more, and more helpful, information. Viola (middle-class, Black, woman) explained that belonging to support groups help her come to understand the condition:

> So, you know, being on those groups and seeing the diversity of the condition has been helpful. And then that allows me to be helpful, too, because like, there’s some people who are like “Hey, I’ve got lupus or fibromyalgia and I’m looking to get disability.”

For some – support groups provided crucial help. The majority of my participants, however, reported actively avoiding support groups. Dory (low-income, white, woman) explained this succinctly: “I also really just am tired of seeing all the complaining. I’ve tried so many like online support groups and I’ve left every single one of them because I can’t take the negativity and the complaints.”

For others, there simply weren’t any local fibromyalgia support groups. Bill (low-income, white, man) explained,

> There are no support groups around, but I do have a support from my church. I’m Christian, and I go to the sermons. And then I have, I meet with some guys for Bible study, even during the pandemic we do

> zooming. So I've got some support groups of friends and people to talk to, and that kind of thing. Those are the things I do to cope with it.

Church groups were the most common alternative to support groups that my interviewees reported. Christianity – and individuals' social networks from church – shaped individuals understandings of fibromyalgia and served as a social support system. For interviewees, church served as a place to meet with people who shared similar conditions. Emma (low-income, Black, woman) explained how one of the members of her church helped her self-diagnose:

> Well, so I was actually working for the church I go to…another lady there had fibromyalgia, but, and – you know- I didn't realize what was going on with me, I was constantly tired, constantly tired…and so finally when I talked to this lady what she said, she had described all these symptoms and I'm thinking to myself, "This sounds like me!"

For others, faith and Christianity served as a source of aspirational capital. Twinkle (affluent, Black, woman) reported relying on her faith when she doesn't have money for treatments: "Well, I just go without and pray over it." Finally, some participants held spiritual explanations for fibromyalgia. For example, Natalie's (affluent, Black, woman) access to spiritual treatments and options lead her to rely on spirituality as a potential origin as well as treatment for fibromyalgia. "This may sound kooky, but I actually met with like a spiritual healer and she told me that fibromyalgia is the healer's disease."

Ultimately, it seemed that the family was the most critical support system. The way an individuals' family understood the condition and treated the person with fibromyalgia affected an individuals' wellness. For example, people who were married reported significantly less fibromyalgia symptom severity[34] ($t(54) = 4.30$, $p < 0.05$). This finding can be attributed to the idea that single people have more individual-responsibility for their own care. Additionally, people with children at home reported significantly higher fibromyalgia symptom severity ($t(346.10) = 5.58$, $p < 0.05$) and more personal stigma ($t(489) = 5.73$, $p < 0.05$). In other words, people who have children at home – as well as people who are not married – tend to experience greater fibromyalgia symptom severity.

Individuals whose families understood fibromyalgia and treated it as legitimate had a greater opportunity to access wellness. Molly (low-income, white, woman) had people driving her to appointments. Heather (affluent, white, woman) argued that her kids would "jump in" to do chores whenever she was experiencing a flare up. Avery (middle-class, Black, woman) spoke of the various forms of emotional labor (researching the condition, using Google whenever she is flaring) her family participated in in order to support her.

People who had family members or close friends with fibromyalgia also reported a more positive experience. Molly (low-income, white, woman) spoke about her ability to be a fibromyalgia advocate within her family:

> I have a great niece who also has this condition. She was diagnosed at 10 and is now 14… she feels like she has an advocate, she has somebody who understands literally, and understands what she's going through. Her mother is very supportive, but they're both happy to know that they have, you know, somebody that just really gets it. And so we were thrilled to have an in-person community, even if it's a very small community.

In a similar vein, Luke (middle-class, white, man) spoke about a family history of fibromyalgia as eliminating his need to legitimize it to his family members. "Within my

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[34] I cannot infer the direction of this effect: whether individuals with lower fibromyalgia symptoms are more likely to find a mate, or whether having social support from a spouse provides an opportunity for wellness.

family, my mom has had this for years, so there was no, ‘Oh my God, what is that?’ My sister has it and actually, you know, among friends, everyone’s been accepting of it.”

In contrast, individuals whose families knew little about fibromyalgia – or who knew about it but did not believe in its legitimacy – had to do more emotional labor within their family networks. Kathryn (affluent, white, woman) explained, “And I mean, I still, to this day, I really don’t think my parents, my brother and my sister, they don’t really understand or kind of even, you know, it’s just not in their world.” The fact that fibromyalgia was “not in their world” meant that Kathryn had to continue to engage in moral boundary work with her family. Similarly, Twinkle (affluent, Black, woman) explained “I think I'm perceived as somebody that thinks she's got something that other people have and she really doesn't have it, you know, it's just all in her mind.” Natalie (affluent, Black, woman) articulated a similar experience in trying to mitigate stigma with her family, “So like, I don't know how to explain that to you because you can't feel it and you can't see it, but take my word for it. This sucks.”

Gendered Care Work

The institution of family illuminated gendered differences in individuals’ access to wellness. The most striking contrast of the gendered division of care was the absence of men’s discussions of the ways that their condition affected their children. While men tended to put their own self-care first – treating their individual symptoms as their main priority – women spoke about putting family care first. There were many mothers in my interview sample, of both races, who felt like they had been neglectful mothers (Shanice - low-income, Black, woman; Michelle - affluent, white, woman) or felt they had directly caused their children problems (Dory - low-income, white, woman). Claire (affluent, white, woman) explained that one of the worst parts of fibromyalgia was "the way my children saw me was as an invalid."

Importantly, when women required support with their children, they tended to turn to other women for support (rather than their intimate partners). Olivia (affluent, white, woman) explains having to give up her job and move closer to her mother for help with child care. She notes, "I'm really lucky my husband stuck with me," before moving back to the impact her fibromyalgia had on her children,

> but it was really terrible, and not being able to play with my kids. Like I couldn't get down on the floor and play with them, or pick up the child. I mean, it was really, couldn't pick up that child, that poor kid. I don't know how he survived, mainly because my mother helped out.

In contrast, a handful of women – usually those with multiple marginalizations - spoke of children and child care responsibilities as a form of salvation. For example, Viola (middle-class, Black, woman) explained that although it required more labor, she has been able to manage her condition alongside the responsibilities that come with raising four young children. Further, she explained the connection between community care and wellness: "I was fortunate because of my children. Like, people always say, 'Oh my God, wasn't it so hard to have children?' I was like, 'Are you crazy? The reason I'm here is because of the kids.'"

The women in my sample did not regularly speak about their intimate partners as playing such an active role in helping them manage their fibromyalgia.[35] Rather, women noted their family responsibilities. Most women explained the ways that their work and

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[35] One woman interviewee who did speak about strong social support from her husband was Edith (low-income, Black, woman), who relied on him for things like texting her to pick her up from work when she is in so much pain, to regular massages, and to just general security and emotional support.

family responsibilities at best, prevented them from adequately managing their condition and, at worst, exacerbated their conditions. In Molly's (low-income, white, woman) case, she was required to work a full-time job while going to college in order to support her family. She explained that

> And so surviving during all those years, it meant that getting to work – because I had to support my family – it means that I had to take a nap in my car in the middle of the day. And, just to recuperate from the pain that had built up. I spent many a day just in tears, sitting in my car, and I would go away from the place where I worked so that no one who knew me would see what was happening. I didn't tell, I didn't know… I didn't tell people that I had it because I didn't think they would understand…It almost killed me, I will admit. It really took the wind out of my sails. But I just, I was so determined, and my family – I did not have any education above high school before that. And my husband was, um, the more and more unable to do anything. He certainly wasn't able to work. And so we needed a better income for my family. So I had lots of reasons to get through [college].

In this more optimistic example, Molly spoke about powering through her symptoms as a form of wellness, in that bettering her family's situation would also benefit her own. However, there were also purely blatant examples of patriarchy and gender roles when it came to the household division of labor.

In contrast, the men with fibromyalgia in my sample were in many cases actively assisted in their self-care by women in their life, and often spoke about having a woman's social and emotional support. For Prof. Z. (middle-class, white, man), this support meant that his wife was often there to "pick up the slack": "A lot of the things that I should have done around the house, I didn't get done. Regular maintenance, things like that." Housework and finances – even the extra financial work that went into planning her husband's medicines - went to his wife. In another example, Bill (low-income, white, man) directly credited his wife for helping him experiment until he found the right balance of diet and lifestyle changes:

> My wife helped me with diet and exercise and I did- we just experimented with things that worked… My wife has been amazing. This is in another year, we'll be married 50 years and all those years she's put up with all this stuff with me. She's done a diet for me, and she's really worked hard on it. So she's been amazing support.

Both men and women reported feeling shame in discussing their struggles with fibromyalgia. Men discussed feeling this shame most directly with romantic partners and within intimate relationships. Scott (middle-class, white, man) incorporated masculinity when he talked about his wife having to do more in order to accommodate his disability,

> So I am married, and it's impacted me. There are days that I can't walk to the dog, for instance, I'm so tired or I can no longer work out the way I used to….so it definitely, and just kind of as a man, there I think there's that typical stereotype where you have to be the provider and somebody who's just doing stuff around the house, things like that, chipping in, just doing your part. And when I'm not able to do that, as a man, it kind of, it's kinda deflating and it makes me feel bad that my wife has to pick up the slack sometimes.

In a similar way, men who did not have a romantic partner often blamed their fibromyalgia. This was a theme touched upon in one of my early interviews that I observed throughout. Even Stan (low-income, multiracial, man) – an active member in a men's fibromyalgia support group on Facebook – noted that one of the most recurring problems he's noticed in his years involved with this group were the ways it affected men's marriages. Soon after Stan's interview, I spoke with Fang (low-income, white, man), who credited a "nasty" divorce to his fibromyalgia and not being able to equally-contribute to his relationship.

Some of the women in my sample, like Emma (low-income, Black, woman), talked about the ways that dating and relationships became more difficult after her fibromyalgia because she was seen as lazy, "frail," and undesirable. Rather than turning the focus of their anger on the patriarchy and the tendency of men to value traditional gender roles in the family (Gerson 2009), women met their partner's lack of support with self-blame. I observed this most articulately in Natalie's (affluent, Black, woman) discussion of the ways that fibromyalgia impacted her mood. When speaking about her husband, she argued,

> So that's a huge amount of guilt of like, this person has to live with me and I'm sick all the time and I don't get to be my best self. And like, I'm probably more irritable and crabby because I don't feel good. So it's like, I'm probably annoying as hell to be with. So it's like, how much patience can one person have, you like, like all of that goes through your head. Meanwhile, you're the one in pain. So it's like this merry-go-round of I'm hurting, but I don't want to affect other people's experience. So I'm trying to like manage, and then when I lose, I feel guilty.

When asked about the negative impacts of fibromyalgia, Marie (affluent, white, woman) explained, "It's definitely affected my family life. And again, you know, my husband will sometimes say, you know, 'I have fibromyalgia, too' because it's, it's changed what we can do as a couple." Although Jade (middle-class, Black, woman) was one respondent to list the ways her husband attempted to accommodate her, most women talked about doing more to make sure they maintained their marriage. In fact, Twinkle (affluent, Black, woman) spoke about the consequences of not being able to do more, and the ways housework responsibilities led to a divorce. She explained,

> My ex could not sometimes understand why I wasn't doing more things around the house. He had been reared to think that, I guess, you know- so women he definitely thought were supposed to clean, and everything was supposed to be spick and span. And I was supposed to take care of my sons, and I was supposed to clean, and I'm supposed to cook, and I'm like working and you're expecting me to do all these things. And he was having a lot of trouble accepting the situation.

Consistent with the extensive literature on gender inequalities in care work (see Hochschild 1983), many of my women respondents did not receive increased social support from their intimate partners; rather, women's partners continued to hold them accountable for conventional gender roles, despite their partners' symptoms.

Wellness as Community Care

So far, this chapter has analyzed the ways that social networks can serve as both sources of privilege but also as forms of oppression. However, there were also intersectional patterns in the ways which my interviewees understood, practiced, and defined "self-care." Individuals with more positional privilege tended to focus on care at the individual level, through medical treatments, lifestyle changes, and interests/hobbies. Other interviewees understood self-care as immersing themselves in outside interests or hobbies. While internet use is oftentimes connected to greater levels of depression, for some of my respondents, the internet and streaming services provided people experiencing social isolation with social-psychological engagement. Avery (middle-class, Black, woman) credited YouTube and stand-up comedy with helping her depression, while Natalie (affluent, Black, woman) watched cat videos for the same reason. Art was another theme that many of my participants touched on, including quilting (Olivia), jewelry-making (Jade), and painting (Dory).

The vast majority, though, understood self-care as something more physical: diet and exercise. Bill (low-income, white, man) attributed a lot of his symptom improvement to exercise and eating more healthily. He explained,

> Diet for me is extremely important. I've cut out– I don't eat anything with added sugar to it, and also found that gluten wheat-refined products caused me a lot of indigestion, irritable bowel. I also avoid stimulants like caffeine or anything like that. And then, the best exercise.

There were respondents who noted the positive effects of exercise and – most specifically – the benefits of swimming and water exercises.

Most of my participants who understood wellness as an individual's responsibility also tended to have more positional privilege and more access to alternative treatments, in addition to the minimum requirements of healthy food, exercise, and access to medical care. Being privileged enough to access these alternative treatments also allowed participants the opportunity to understand their conditions in a more positive light. In one example, Natalie (affluent, Black, woman) explained,

> I think that it [the fibromyalgia diagnosis] was actually the gateway to my wellness journey. So in a really weird way, it's actually life afforded me some of the best healing…I made many changes in my life and that's actually what made me so passionate about coaching and like sharing a lot of this stuff with people because I started to realize like, a) I'm not the only person that has invisible things that you can't figure out; b) like, there's a lot of factors here that doctors aren't going to tell you about such as like sleep, diet, therapy, traumas trapped in the body, energy. Like, there's a bunch of things that like, no one's approaching. And as I started to like dive down the rabbit hole of it, it actually became kind of a blessing that it like forced me to learn all of that stuff.

Although touching on some of the social and institutional barriers that prevent people with fibromyalgia from achieving full well-being, Natalie (affluent, Black, woman) placed the burden of responsibility on herself - the individual - to navigate around these barriers and only then, on her individual responsibility to share her experiences to help others.

Importantly, interviewees who experienced some form of marginalization – and specifically, my Black women respondents - were more likely to talk about the structural and social problems that exacerbate fibromyalgia. Further, these respondents were also more likely to move this knowledge into action through advocacy, volunteer work, and acts of community service. While increasing labor output might seem detrimental to combatting fibromyalgia symptom severity, being able to provide community care was at least in small part self-serving, as it allowed individuals to engage in opportunities for wellness. Including fibromyalgia awareness events (Shayera - low-income, white, woman), mental health counseling (Jade - middle-class, Black, woman), handing out masks at the beginning of the pandemic (Emma - low-income, Black, woman), and patient advocacy (Viola - middle-class, Black, woman), my more marginalized respondents (who also suffered the social causes of fibromyalgia more strongly) also felt a stronger sense of responsibility for community wellness.

Shanice (low-income, Black, woman) - my respondent who was most fully immersed in community activism – also talked about her social responsibilities as enhancing her wellness. In talking about her daughter with multiple sclerosis,

> I have to take care of my daughter, and that – that's the driving force right there. And that's all I can say about having a disabled daughter at this point, it has been a blessing because sometimes I feel like without her and going through this, I would probably be in a nursing home, would have been in a nursing home for a while now.

Shanice explained that – in addition to serving as a caregiver for her daughter – she had moved to rural Arkansas to help people of color. Noting that Black Americans' lack of wealth meant they were forced to work in long hours in paid employment, Shanice explained how this created a racialized barrier to wellness: "we can't stop to pacify too long. We have to suffer in silence because there's nothing else we can do." Although Shanice credited her community activism to her personal wellness, there were instances in which she placed community care above self-care. Shanice related contracting COVID-19 in October of 2020 and – as a result of severe medical complications – being admitted to the emergency room for several nights. She explained,

> Even with all this going on, I even talked to the governor in the hospital because I didn't want to miss the [Autism Speaks] meeting…I didn't want to miss the meetings. That was me. That's how I am. Autism Speaks. Cause my grandson has autism and I had to talk to him about, Autism

> Speaks, about the bill, the house and community bill. So I'm like one of the advocates, a volunteer advocate ambassador….so I have to get it done, even if I'm dying.

In some cases, individuals' placed community needs above their own. In Shanice's case, she articulates her understanding that her wellness and healing are bigger than just treating fibromyalgia specifically.

Conclusion

Overall, this chapter shows how reaching fibromyalgia wellness occurs through interaction, when individuals can both provide and receive social support. Individuals immersed in more accommodating, collective institutions in the areas of medicine, employment, and the family experienced greater opportunities for wellness. Wellness, then, requires both an individual's emotional labor, social positionings, *and* support from their social networks. In this way*, individual wellness relies on community wellness*. Institutions must provide equal access to not just the minimum requirements for wellness, but social services and support for our most marginalized community members. Further, advocates of disability and healing justice must continue to resist the commodification of wellness in order to reclaim this concept in medical practice, legislation, and in the public imagination. In the following chapter, I more thoroughly analyze how systems of gender, race, and class influence individuals' understandings and experiences of fibromyalgia.

V. Identity, Ideologies, and Fibromyalgia: Intersectional Experiences of (Dis)Ability

In the previous chapter, I discussed how individuals' social networks and interactions shape their understandings and experiences in the wellness process. In the current chapter, I focus on the fibromyalgia experience as resulting from structural-level norms and ideologies. Specifically, I explore the ways that controlling images of gender, race, and class influence individuals' meanings about fibromyalgia and disability, and I analyze how certain meanings about fibromyalgia become legitimized and institutionalized. My findings show how gender, race, class function both separately and interconnectedly in individuals' experiences and understandings of fibromyalgia. My interview data shows that respondents describe the normative referent for a person with fibromyalgia as a middle-class, white woman. White women tended to dominate fibromyalgia spaces and feel a stronger sense of fibromyalgia community. Importantly, Black women explained qualitatively different experiences with fibromyalgia, in addition to instances of direct racism in the diagnostic process. Although I approached this study from the perspectives of gender and race, class proved to be a critical variable in individuals' understandings and experiences. Analyses from my survey data highlighted the ways that these ideologies were embodied. Results showed identity-based differences in symptom severity, feelings of self-agency, understanding of the condition, and treatment satisfaction.

"The Girl's Club"

As noted previously, predominant conceptions of fibromyalgia as a "woman's problem" strongly shape individuals' understandings of fibromyalgia, and most participants were aware of the gendered diagnostic patterns within fibromyalgia. My interview data highlights these perceived gender differences, as well as in which cases gender becomes most salient. The gendered words used to explain the social experience of fibromyalgia also reflected this idea: Shayera (low-income, white, woman) talked about being branded as a "drama queen" and family members who were constantly questioning what she might be "bitching" about today. Women were often told they just had a low pain threshold, mental health problems, were overweight, or going through menopause. Additionally, when asked what a *typical* fibromyalgia patient might look like, a large number of respondents leaned on the idea that most people with fibromyalgia are women. This idea was reflected in other parts of the interview process, as when most people talked about someone they knew who had fibromyalgia, they referenced a woman: a mother, sister, aunt, niece, or (woman) friend. Some women noted how fibromyalgia served as a threat to their femininity, making them less desirable as sexual partners, and preventing them from feminine gender performances. In one specific example, Jade (middle-class, Black, woman) talked about no longer being able to wear high-heeled shoes, and how she's kept all of them in a visible place in her closet as a reminder -- but also because she can't bear to part with them.

Despite ideas of fibromyalgia as manifesting itself differently based on gender, in running preliminary analyses to explore whether there were significant gender differences in the composite variables from my survey, there were only significant differences in composite variables for both masculine ($t(488) = 11.49$, $p < 0.01$) and feminine ($t(488) = 30.78$, $p < 0.01$) gender performance. This finding was unsurprising as my sample is comprised overwhelmingly of women. This shows us that despite understandings of the condition as being drastically different across genders, the experience of fibromyalgia is fairly similar.

Both men and women used biological and genetic-type rhetoric to explain perceived gendered differences in fibromyalgia. In several cases, individuals relied on the statistics of who is diagnosed (primarily women) to explain fibromyalgia as a woman's problem. Fang (low-income, white, man) very clearly reiterated his gendered and biological understandings when he mentioned toward the end of our interview,

> I wonder if they would check the hormone levels again, like the female hormone. We both have male and female hormones, ok. Everybody has male hormones and the people that have fibro have more of the feminine hormone, greater balance of it than the, you know, testosterone.

Dory (low-income, white, woman) also relied on the idea that each gender has drastically different hormones to connect biology to the gendered diagnostic patterns and to the lack of men's representation within fibromyalgia:

> I'm always fascinated when I see men talking about it, like 'Hey, yeah, probably a whole different world going on.' I was just, I'm curious about that - to like really talk with a man about it more in-depth because women, we have very different hormones than men.

In a similar vein, some participants utilized gendered psychological understandings to make sense of the ways that fibromyalgia might manifest itself differently based on gender. Relying on patriarchal and ableist stereotypes of women as more frail and emotional, Bill (low-income, white, man) argued,

> Well, my sister-in-law, and I know another woman, they have more – for her, just touching her at times, it's very painful. She seems to have more emotional and mental issues…So it seems to be more mental. It seems to be more touchy, emotional-type things.

Relying on a woman with fibromyalgia who he knew personally, Bill generalized his sister-in-law's experience to women's experiences with fibromyalgia, more generally. He later clarified by explaining his feeling that the diagnostic criteria itself were gendered because "early on, they were looking for those about seven or five [tender] points or stuff, and men don't seem to have that. And women do."

A lot of the men also noted a lack of gender representation in medical literature and fibromyalgia resources, especially early on in the creation of the fibromyalgia diagnosis. Some men talked about the understanding of fibromyalgia as a women's problem as impeding their diagnostic process. Bill recounted an early experience in his diagnostic journey where his doctor, a man, told him "You don't have fibromyalgia, but you know, men don't have fibromyalgia." One respondent, Stan (low-income, multiracial, man), even spoke to the lack of diagnosis directly: "…at least it used to be, it was relatively rare to find guys that had fibromyalgia. As it turns out, it's just underreported. That guys have it. We probably have it just as much as everyone else." Many of the men articulated that what they wished most people knew about fibromyalgia was that it doesn't only affect women. Luke (middle-class, white, man) explained,

> I wish there was more awareness that it isn't just an older women's disease because, you know, I saw this about guys, but if you're in your twenties and you're trying to have a family and this is happening and you, even, if you say something to somebody who's got it, they're going to go, 'well, yeah, my grandmother's got that. What's your problem?

Luke contextualized this connection between gender (women), fibromyalgia, and the larger fibromyalgia community when he recounted that he had not felt excluded from support groups for fibromyalgia despite his initial perceptions of them as "the girl's club." "People don't believe it in the beginning, to begin with. And even the people who are familiar with it, it's like 'Dude, guys don't get that.' Well, yeah they do."

Men also spoke about the ways that internalized masculinity affected their acceptance of fibromyalgia. Scott (middle-class, white, man) explained,

> I think as a man…it's really interesting because there's, you know, maybe it's an older mindset, but where a man has to be tough and put on this tough exterior. Because I'm a man, but in being in these groups, you find how vulnerable people are and what they're willing to open up about with complete strangers, as opposed to even their own family. I know there's people who say they don't share things with their own family because they're going to be judged or like, 'it's in your head.'

Here, Scott explains how his masculinity and status as male is threatened by his lessened abilities. Further, he talks about participation in a men's fibromyalgia support group as reframing his understandings of manhood.

Despite gendered barriers in explaining fibromyalgia to family and members of support systems, Prof. Z. (middle-class, white, man) a former professor of sociology, reflexively identified how his gender might have helped him establish legitimacy from his doctor and within his social networks:

> I could see where it would be taken very negatively in certain contexts. I think that if I weren't a white, Anglo-Saxon Protestant, that, you know, it's just the same as anything. A person of color would not, it would be something like, 'well, it's all in your head' and, you know, 'get back to work' … so I think that for women and for persons of color, it could be an entirely different situation and that people could react much differently, but I think that's just part of the flawed mindset of our country.

Brian, a trans man, expanded on these notions of manhood, masculinity, and ability. Brian did not feel that he fit well within the fibromyalgia community, and talked about actively disagreeing with the collective understandings of fibromyalgia. As he actively works to reclaim these meanings within himself, he understood his gender as initially *helpful* (he received his diagnosis of fibromyalgia prior to transitioning). As Brian he "certainly appeared to be a white, middle-class, married woman," he was able to navigate the diagnostic process by more easily matching the typical fibromyalgia patient. However, currently - as a transitioned trans man - he explained how his gender impedes his ability to manage his condition: “These days, they’re mostly distracted by my beard and the general fact that I’m transgender and don’t pass for any gender. So, we don’t talk about my disability that much because we’re busy talking about my gender.”

The singer, actress, and pop icon Lady Gaga has been vocal about her experience with fibromyalgia in the last few years, and this was something that several of my women participants touched upon, as both a pro and a con of fibromyalgia progress. Kathryn (affluent, white, woman) explained,

> So, you know, Lady Gaga came out with her documentary, that was like a game changer at first because everyone saw the documentary and was like, ‘Is that what you have, what Lady Gaga has?’ And I was like, ‘Oh my god, thank God for Lady Gaga.’ It just brought it forward. And now when, if you say fibromyalgia, people will say ‘Oh, like that’s what Lady Gaga has,’ you know? And that was the single biggest change I think that has happened with fibromyalgia in the last decade.

Others noted their frustration that it took a person with such fame and status to begin to legitimize fibromyalgia as a “real” condition. Jade (middle-class, Black, woman) explained,

> I recently saw that Lady Gaga came out about her diagnosis. And I think that it’s important to my earlier point that why is it sensationalized when a famous person gets to say ‘I’m in pain’? But when a regular person says it, and more specifically a Black woman says it, it’s like ‘I don’t believe you.’ And so, I mean, that’s with everything: somebody, a famous person, can come out and say ‘I have depression.’ And it’s like ‘Oh, now we can talk about it.’ And it’s like, you were living in pain all of this time, and because Beyoncé said it, now it’s a real thing. I think that there needs to be more space made for real people with real stories about their experience with this.

Pointing to the ways that high status can make invisible conditions more visible, Jade – a Black woman - introduces a sociological critique at the intersections of gender, race, class, and the ability to live well.

“A **White** *Woman’s Problem”*

Gendered understandings and experiences of fibromyalgia become more complicated when integrating race. White women tend to dominate fibromyalgia spaces. When I asked if there is a specific type of person who is more likely to have fibromyalgia, the second most common answer after “woman” was that it doesn’t discriminate and can affect everyone equally. Emma (low-income, Black, woman) explained,

> I’ve seen mainly women have it…Because the lady who had it, when I figured it out from her symptoms, gave me a clue that something was up. She was young, very thin and white. And then my other friend who has fibromyalgia, she’s older than me, and she’s Latina. And, there’s another lady that one of my friends has, and she’s younger than me and Latina. So, it isn’t any one personality type. It’s not any one ethnicity. But it does seem to be mostly women.

However, there was not one instance of a white woman detailing what this might look like based on race; instead, they focused on gender and class. Anne (low-income, white, woman) explained

> I think it doesn’t, it’s not picky. It’s not choosy. It’ll take whoever because I mean, my one friend, she’s got a $70,000 a year job. She’s got a really nice house. She’s, I mean, she’s doing really good for herself financially, but I mean, it still limits her big time. And then my other friend, she works. I mean, she’s busted her butt. She worked at Casey’s. She didn’t have a glamorous lifestyle, but she still had what she needed, and it still went after her.

Both White and Black women spoke of the fibromyalgia experience as a woman’s experience, using she/her pronouns when talking about a hypothetical fibromyalgia patient, and referencing women and women’s experiences in their answers.

I ran some preliminary analyses to explore whether individuals’ race was related to the composite variables from my survey. I began with t-tests to compare white people to non-white people. Importantly, non-white people reported significantly greater masculine performance ($t(491) = 7.00$, $p < 0.01$). Subsequent t-tests discovered further racial differences.

Compared to non-white people, whites were more likely to use doctors ($t(491) = 5.20$, $p < 0.05$) and fibromyalgia coaches ($t(491) = 6.33$, $p < 0.05$). Whites also reported more hours spent interacting with support groups ($t(491) = 6.00$, $p < 0.01$), and reported fibromyalgia as being more important to them ($t(491) = 4.60$, $p < 0.05$).

Speaking with Black women shed a light on observable, qualitative racial differences in the fibromyalgia experience. Several Black women specifically honed in on racial differences in the diagnosis even if they noted it was mostly women with fibromyalgia. For example, when asked about the typical fibromyalgia patient, Jade (middle-class, Black, woman) explained, “usually what I see is similar to what we see in like, yoga ads: so, it’s usually a white woman.” In fact, most of the Black women participants understood fibromyalgia as a white woman’s problem. Twinkle (affluent, Black, woman) touched on this directly when she explained,

> Well, I think – not from my perspective, but from other people’s perspectives – people of color are not supposed to have this disorder. That’s the way people seem to perceive the situation. Um, whereas I had no, um I guess preconceived notions about it.

And further, “Well I’ll tell you honestly, I think the impression that, uh, you know, my so-called friends, half of them believe is that it’s a disorder of rich Caucasian women.” And David (low-income, Asian, man) reiterated this idea: “And really what I’ve come to understand is that…it is looking to me like…a lot of this disparity is coming from the stereotypes of fibromyalgia as kind of a white woman’s problem.”

Several Black women spoke about how their race affected the doctor-patient interaction and diagnostic process directly. Jade (middle-class, Black, woman) pointed back to the stereotype of the strong Black woman when she explained,

> So, 10 years of you telling me, 'Oh, no, there's nothing wrong.' Um, or you know, 'maybe you just need to take some time off of work,' or 'buck up, it's going to be ok, just be strong, be a strong Black woman, be everything to everybody.' Um, we find so often in the medical care of Black women.

Twinkle (middle-class, Black, woman) reiterated this anger when she explained that the doctors do not want to believe Black women:

> And I truly do believe something needs to be done in terms of the medical profession to help people realize that, you know, we're not all walking around just making up a disease or disorder, whatever you want to call it. You know, this is actually something real, and I did not ask for it, and I didn't ask to bring it upon myself. I didn't realize how mad I was until we started talking.

Additionally, Black women noted direct instances of racism and medical trauma which occurred within their interactions with medical providers. Edith (low-income, Black, woman), an affluent Black woman and celebrity make-up artist, noted an instance of intersectional racism when she explained "I find that the, even the last doctor that I just had, it was to where I don't even want to go to the doctors anymore. He told me, 'why don't you just get your uterus removed?'" When I asked her what his reasoning could have been to recommend such a procedure for chronic pain, she expanded:

> How about the doctor tell you that you don't have a fever, you're African-American, you can't get a fever? You can't burn and guess what? I passed out in his office, Ok. Yeah, so that's a whole 'nother, another thing… 'Oh, no, it's in your head. Nothing's wrong with you.' Ok, OUT.

Edith's (low-income, Black, woman) experiences show us clearly how white privilege functions in the case of fibromyalgia, not only by allowing an easier diagnostic process, but without these racist barriers which serve as roadblocks on one's diagnostic pathway.

Finally, some white participants policed the borders of whiteness when talking about fibromyalgia, most specifically, through stereotypes that masked anti-Asian sentiments relating to alternative therapies and practitioners.[3] When talking about treatment opportunities, Prof. Z. (middle-class, white, man) explained "I don't trust a chiropractor who's going through for acupuncture, unless the chiropractor is Chinese." Heather (affluent, white, woman) once again raised Chinese acupuncture, although her practitioner also performed other kinds of therapy. Heather explained,

> [my mom] had been seeing an acupuncture physician who did traditional Chinese medicine for other stuff. And then he put me on - I couldn't do it. It was all in Chinese. It was probably, like, eye of newt and hair of ass, but he gave me this other thing. They were drops for pain. When I first saw him, my husband thought it was bull shit. 'Oh, come on, acupuncture?' You know, this was in 1997… I don't know what was in it. It could be morphine or cocaine. I don't read Chinese, but I took it. And then within like three days, I had no pain. No pain… so I tried dumb traditional Chinese medicine acupuncture, which was pretty effective.

In both cases, white participants understand Asian people (and Chinese people, specifically) as a racial "other," with better understandings of illness and medicine, tropes which while seemingly complimentary have historical and racist origins. However, this same type of benevolent racism was perpetuated by Avery (middle-class, Black, woman) when she explained, "I get professional massages, when I actually go in the city here, there's like these little booths, like massage parlors, Asian, and they're the bomb. So I have one specific lady who I go to all the time to get me my massages." Although this comment can seem to a form of compliment, it normalizes occupational racial segregation in the service industry.

Although the doctor-patient interaction seemed to vary by identity, so did individuals' abilities to find support within their social networks. Jade (middle-class, Black, woman) explained how pain is normalized within Black communities. She cites her aunt as an example of the way stigma prevents Black women in chronic pain from coming forward.

> Explaining it to my family was difficult, and I have an aunt who has it and she didn't tell anyone until she heard about my diagnosis. And so often in our communities, that stigma is not just with mental health, it's with a lot of things.

> And so, I can remember like kind of shuffling along at an event and they're like, 'Is Jade ok?' And I'm like, 'I'm good,'

The strong Black woman stereotype affected Jade's ability to communicate her condition to her family. She continued by elaborating on the culture of pain that surrounds Blackness.

> And you know, Black women, we live in pain, right? There was nothing for me to say, 'Oh, my back hurts.' And my aunt would say, 'Oh girl, mine too!' Or, you know, for me to be like, 'I just, I don't feel well, I'm tired. I just can't quite put the thoughts together today. What is happening?' And it's like, you just keep pushing through, you gotta be strong.

This statement connects to Twinkle's (affluent, Black, woman) answer about seeing herself within the fibromyalgia community, when she explained "I think that [my experience] is similar to maybe other people of color."

Viola (middle-class, Black, woman) understood fibromyalgia diagnostic patterns as a result of structural barriers to health care. She explained,

> It's mostly white women, it's because they mostly have access to these great doctors. Like, I tell people if I hadn't been in, if I had been in Mississippi, I probably still would've been trying to figure out what was going on.

Unfortunately, lack of racial representation within the fibromyalgia diagnosis had both social and material outcomes. For example, Jade also spoke about the ways that fibromyalgia symptoms had qualitatively different consequences for Black people:

> [Fibromyalgia]'s changed my hair… I've had natural hair since 2005, and I would spend money to get a blowout, right? So, take my curls from tight and curly to straight. I'd go to bed, have one of those night sweats, it's gone! Um, and so money down the drain. And so having to figure out what that looks like. So even a weave didn't work because the, usually this part [pointing to the top segment of her hair, closest to her scalp] of your hair is still left out. If I'm sweating, this is changed, this is still straight: that doesn't work. Um, and I've just landed at locking my hair because it's the most simple thing to do. Um, and easiest... but you know, I've tried it a couple times before, so it's something that I've always liked. Um, but didn't necessarily want to be forced into.

White privilege blinded white people from the racial differences in fibromyalgia experience. Night sweats dramatically affected the way Jade was able to wear and style her hair, which affected her sense of womanhood, and is also something white women don't need to confront. Jade went on to make a connection between lack of racial representation and contradictory understandings of a condition:

> Things like my hair having to change doesn't come up… for me, it goes a little bit further than that because I can't just jump in the shower, rinse my hair, and kind of keep going. If I do that, we have a whole different set of situations. And so I have even in searching the hashtag, I never see myself. I never saw myself in the psoriasis ads. Usually the scales and in those ads and medications and pictures on Google were around plaques that were pink and mine didn't look that way, mine were more gray. And so in the discussion boards, the person is usually a white.

Racial representation is about more than just highlighting different symptoms and coping mechanisms – lack of representation is an additional barrier to medical understandings and diagnostic criteria.

Income and Class: "A cost to my ability to live better"

My data shows the ways that higher socioeconomic status can serve as an opportunity to better cope with fibromyalgia symptoms and maintain general wellness. I used a one-way analysis of variance to compare the means of each socioeconomic class to symptom severity. There were significant differences in fibromyalgia severity ($F(4) = 7.06$, $p < 0.001$), Most generally, people with low-income experience greater fibromyalgia symptoms severity. Therefore, does socioeconomic status also produce (or prevent) general well-being? I ran a one-way ANOVA to compare the means of general well-being by class status. Results showed a positive significant effect ($F(4) = 4.97$, $p = 0.001$). Further, post-hoc Tukey tests showed that working-class ($t = 2.40, p < 0.05$), middle-class ($t = 3.00, p < 0.001$), and affluent people ($t = 3.80, p < 0.01$) reported significantly greater well-being than low-income individuals.

An additional ANOVA showed class differences in age of diagnosis ($F(4, 471) = 2.67$, $p < 0.05$), and Tukey post-hoc tests showed that working-class people were diagnosed younger than middle-class people ($t = -3.41$, $p < 0.05$). This finding could potentially be a result of occupational burnout. Additionally, people in the working-class (who have less autonomy over their labor) might require a diagnosis at earlier ages in order to request disability accommodations.

As there are class-based patterns in fibromyalgia prevalence rates, I ran an ANOVA to determine whether class was related to perceptions of a shared fibromyalgia experience. The effect was significant ($F(4, 486) = 5.13$, $p < 0.001$). Post-hoc Tukey tests showed that low-income ($t = -1.25, p < 0.01$), working-class people ($t = -1.21, p < 0.01$), and middle-class people ($t = -0.86$, $p < 0.05$) are more likely than affluent people to think their experience is similar to the fibromyalgia community.

Through the interview data, we can see the dynamic functions of class. While low-income people felt they were doing all they could to manage their symptoms, people with more wealth and higher levels of income spoke about accessing all different types of expensive treatments, in addition to other treatments/solutions they would like to try. For example, Claire (affluent, white, woman) explained that she was able to be seen by a medical group with doctors who treat the San Francisco 49ers. Claire’s doctor had been so understanding, supportive, and engaged that she continued to be seen by him for 14 years, in addition to using “alternative stuff like acupuncture and massage therapy.” Despite her high-status medical treatment, Claire still noted financial constraints when she explained “you don’t have any insurance to pay for acupuncture or massage or all those other things that actually help you to take good care of your body… it's just not covered." Claire explained that she "would really like to spend more money on maybe creams, ointments, and other things that I found do help, you know, it's expensive… everything is so expensive." Natalie (affluent, Black, woman) also had good insurance coverage but still noted the large sum of money she spends to manage her condition. "Even with insurance, I've paid a lot of money…so, for example, I stopped getting things like cat scans and MRIs because even with insurance, I was coming out of pocket a couple hundred dollars every time."

In contrast, many low-income individuals felt they were already doing all that they could to manage their fibromyalgia and there was nothing else they would like to try. Bill (low-income, white, man) explained, "[cost] hasn't been an issue for me. I've had insurance that covered anything I needed." However, he mentioned some treatments that he had to go without, such as laser treatments, because they were not covered by insurance. People of lower socioeconomic status also talked about the inconsistency in managing their fibromyalgia. Shayera (low-income, white, woman) explained,

> At the time, I didn't have insurance. So, it was like a sliding scale payment thing, or he gave me like free sample things or something, but I couldn't keep going to him because the bills weren't being paid. … going from being on it for a little while and then going off of it, because it wasn't covered.

Shayera explained she receives treatments "not consistently at all," and that she's "not getting a lot of treatment for anything." She noted her disappointment that she had to stop seeing medical providers or using treatments even when they were beneficial because of their cost. She made the connection between income, wellness, and opportunity when she explained "It's not so much cost out of my pocket. It's more of a cost to my ability to live better." Many of the low-income individuals emphasized the constraints they faced due to inadequate health insurance.

Several low-income individuals also spoke about the difficulty and/or inability of receiving financial support or social security income. Stan (low-income, multiracial, man) explained,

> I applied for social security disability and was turned down for a couple of years, several years. And then I used a social security attorney and won my social security disability. So I've been on Medicare, uh, disability. And I use a, um, a Medicare advantage plan. So pretty much everything is covered.

But even then, Stan struggled to afford all that could help him live better:

> The biggest thing would be like, you know, Modafinil is not covered under my plan. Um and I'd have to, you know, that might cost $60 or something like that for a prescription, which I might have to pay for that, you know, and that's not cheap for me on social security.

Some low-income individuals did understand lower class status as preventing them from adequately managing their condition. Ken (low-income, multiracial, man) explained,

> So it actually, before paying out of pocket, going to like Kaiser or something was a little bit more expensive, even though I had platinum, but I mean, it just sucks because the stuff that works for me, you know, like the medical marijuana salves, like the topicals, are so expensive and it's ridiculous that it can't just be, you know, more affordable. Even the CBD stuff in the store.

Not only are low-income people more likely to have less insurance coverage, they are also more likely to have limited access to medical providers. Dory (low-income, white, woman) explained that here state insurance covered only SIU medicine:

> It's just like a student program out here, it's the medical part. You get the medical students. So at first I was just, I bounced, I didn't see a consistent doctor with it and I bounced through like three of them.

Additionally, Dory cited her class status and low-income as preventing her from maintain wellness.

> Some things I've looked at for treatment and management, I have flat out not been able to do or try because of cost. Um, like we talked about before, massage is supposed to be one of the big, helpful things for [fibromyalgia]. That alone is outrageous. I hear that – um, what's it called? The one with all the needles: acupuncture. Yes, I've heard that's supposed to be really helpful. It doesn't really look enjoyable, um, but it's expensive, so I've never tried it.

Michelle (affluent, white, woman), who works for a health insurance company, honed in on the idea that insurance doesn't cover the treatments that are most beneficial for fibromyalgia. She critiqued Covered California when she explained, "Why are we so excited about this, just to say they have insurance? Cause it doesn't cover anything." Similarly, Claire (affluent, white, woman) touched on the fact that the disconnectedness of medical specialties - combined with bureaucratic health insurance coverage - prevent practitioners from understanding and treating fibromyalgia with a "whole-body approach."

Financial privileges are rarely spoken of as an important means for maintaining fibromyalgia, even though most people who experienced lessening symptoms had better financial means. Heather (affluent, white, woman), a professor and psychologist, explained how insurance works when you have the highest-level tier:

> I'm very fortunate that way, because I have really good health insurance. So just a couple of years ago I went onto Medicare, but I still have Blue Cross, Blue Shield PPO, because my husband was with the VA. When he retired, federal Blue Cross is part of his annuity every month. The Blue Cross comes out of it and so we're still covered. Okay, that's great. So, it covers almost everything, really. And I haven't slowed down anymore and you know, up until 2012, I was flying to Minneapolis every other week for a week around the clock, which is pretty darn cold in the winter from South Florida to feel good.

In a contrasting example, Prof. Z. (middle-class, white, man) talked about moving from middle class to lower-middle-class as a result of aging and retirement, and explained "Well, in dealing with it, it's going to continually get more difficult just because the medication and changes in medication, the lack of medication because of insurance and all of those things."

When I asked what more he'd like to do for his fibromyalgia if cost weren't an issue, he explained:

> I never thought of it that way, because cost has always been a factor. I guess then it would be, well, you know, get me back on the extended release Oxy and, uh, then get me back on the extended release Tramadol[36], and uh, I'd be making a lot of trips to Denver.

Finally, Heather (affluent, white, woman) spoke about the increased awareness of fibromyalgia as a result of capitalism and the pharmaceutical industry. She explained,

> I think it's getting more attention because the pharmaceutical companies have been coming up with some things, and they have to be able to label it where it's not off-label…so I think that it's getting more traction because of sales and it's something that can be prescribed. So, the reps can come and say, 'We've got this new thing, doctor.' I think that's why the research is happening: You see dollars that you had, it's not like an orphan disease, like Sjogren's used to be an orphan disease, no money for it. Now there's gobs of money.

Intersectional Analyses

Based on the interview data, we can observe that there are patterns based on race, class, and gender. I ran a two-way ANOVAs to see if these results were replicated within my survey data, and whether social identities might show significant differences in the fibromyalgia experience and in social identity formation.

First, a two-way ANOVA were performed to analyze the effect of gender, race, and class on fibromyalgia symptom severity. The analysis revealed that there were statistically significant effects between gender ($F(1) = 4.84$, $p < 0.05$) and class ($F(4) = 7.14$, $p < 0.001$) on fibromyalgia symptom severity. Results from post-hoc Tukey tests showed that low-income people ($M = 19.21$, $SD = 0.77$) reported greater fibromyalgia symptoms severity compared to working-class ($M = 16.46$, $SD = 0.46$)($t = 2.75$, $p < 0.001$), middle-class ($M =$

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[36] a prescription for pain relief

15.71, $SD = 0.40$))($t = 3.51$, $p < 0.001$), affluent individuals ($M = 14.41$, $SD = 0.83$))($t = 4.81$, $p < 0.001$). Working-class individuals also reported significantly greater fibromyalgia symptom severity compared to affluent people ($t = 2.06$, $p < 0.05$). Next, I ran the same two-way ANOVA but included an interaction effect for gender and class. The interaction effect was shown to be significant, ($F(3) = 2.87$, $p < 0.05$). A Tukey post hoc test showed that lower-class women reported significantly higher fibromyalgia symptom severity than working-class women ($t = 3.38$, $p < 0.001$), middle-class women ($t = 4.28$, $p < 0.001$), and affluent women ($t = 5.50$, $p < 0.001$). Therefore, being a low-income woman is most strongly related to the severity of fibromyalgia symptoms.

Two additional two-way ANOVAs was performed to analyze the effect of gender, race, and class on the age at diagnosis. The analysis showed that there was a statistically significant effect for race ($F(1) = 10.83$, $p < 0.001$) and class ($F(4) = 2.60$, $p < 0.05$) on age of diagnosis. Compared to non-white people ($M = 36.33$, $SD = 1.80$), whites ($M = 41.53$, $SD =1.08$) reported significantly higher age at time of fibromyalgia diagnosis ($t = 2.75$, $p < 0.001$). Additionally, post-hoc Tukey tests showed that working-class individuals ($M = 36.90$, $SD = 1.31$) reported a younger age of diagnosis than middle-class people ($M = 40.26$, $SD = 1.13$))($t = 3.31$, $p < 0.05$). I ran the same two-way ANOVA but included an interaction effect for race and class; however, the interaction effect was insignificant.

The next set of ANOVAs explored the effects of gender, race, and class on social and personal identity salience. The analysis revealed that there were statistically significant effects of race: on personal identity salience ($F(1) = 17.72$, $p < 0.001$) and social identity salience and ($F(1) = 24.93$, $p < 0.001$). White people reported lower personal and social identity salience than non-white people.

I ran an additional ANOVA to explore the effects of gender, race, and class on fibromyalgia as a social identity. Results showed that class ($F(4) = 5.31$, $p < 0.001$) had a statistically significant effect with fibromyalgia social identity. Post-hoc Tukey tests showed that low-income people ($M = 16.59$, $SD = 0.88$) were more likely to report strong fibromyalgia social identities in comparison to middle class ($M = 14.82$, $SD = 0.46$))($t = 1.77$, $p < 0.05$) and affluent individuals ($M = 11.85$, $SD = 0.94$))($t = 4.74$, $p < 0.001$). Additionally, working-class ($M = 15.72$, $SD = 0.52$)($t = 3.87$, $p < 0.001$) and middle-class individuals ($t = 2.97$, $p < 0.001$) reported significantly higher fibromyalgia social identity compared to affluent individuals.

The final two ANOVAs explored whether gender, race, and class predicted how much individuals spent on fibromyalgia and whether they had gone without treatment because of cost. For the amount individuals spent on fibromyalgia, there was a significant effect for gender. Compared to women, men reported spending significantly more money on their fibromyalgia ($F(1) = 4.02$, $p < 0.05$). Additionally, there was a statistically significant effect between class ($F(4) = 5.15$, $p < 0.001$) and whether they had gone without fibromyalgia treatment due to cost. Results from post-hoc Tukey tests showed that low-income people ($M = 0.82$, $SD = 0.10$) were significantly more likely than middle class ($M = 0.50$, $SD = 0.05$)($t = 0.32$, $p < 0.05$) and affluent individuals ($M = 0.36$, $SD = 0.11$)($t = 0.47$, $p < 0.01$) to have gone without treatment. Additionally, working-class people ($M = 0.67$, $SD = 0.06$) were more likely to have gone without treatment than middle-class ($t = 0.17$, $p < 0.05$) and affluent people ($t = 0.32$, $p < 0.05$).

I used a multiple regression model to investigate the relationship between fibromyalgia symptom severity, gender, race, and class (see Table 5.1). Model 1 regresses age, gender,

Table 5.1

Effects of age, gender, whiteness, socioeconomic class, fibromyalgia self-mastery, fibromyalgia social identity, and general well-being on fibromyalgia symptom severity (N = 488).

	Model 1	Model 2	Model 3	Model 4
	β *(SE)*	*β* *(SE)*	*β* *(SE)*	*β* *(SE)*
Age	-0.06***	-0.46***	-0.05***	-0.05***
	(0.01)	(0.01)	(0.11)	(0.01)
Woman	-0.55	-0.50	-0.74	-0.45
	(1.17)	(1.07)	(1.06)	(1.04)
Man	-2.43	-2.21	-2.45*	-2.15
	(1.33)	(1.22)	(1.21)	(1.19)
White	0.47	-0.23	-0.13	-0.13
	(0.56)	(0.52)	(0.52)	(0.51)
Class	-0.84***	-0.54*	-0.48*	-0.35
	(0.23)	(0.21)	(0.21)	(0.21)
Fibro Self-Mastery	---	-0.34***	-0.34***	-0.27***
		(0.04)	(0.04)	(0.04)
Fibro Social Identity	---	---	0.10**	0.11**
			(0.04)	(0.04)
General Well-Being	---	---	---	-0.21***
				(0.04)
Constant	21.57***	24.34***	22.79***	22.81***
	(1.46)	(1.37)	(1.48)	(1.44)

Notes: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

whiteness, and class on fibromyalgia symptom severity. Older individuals ($\beta = -0.06$, $p < 0.001$) and people of lower classes ($\beta = -0.84$, $p < 0.001$) report significant greater fibromyalgia severity. Next, I added fibromyalgia self-mastery (model 2), which showed that individuals who feel more capable in managing their conditions report slightly less fibromyalgia severity ($\beta = -0.34$, $p < 0.001$). In model 3, individuals who have stronger fibromyalgia social identities report more slightly severe fibromyalgia symptoms ($\beta = 0.10$, $p < 0.01$). In model 4, my results show that individuals who report lower general well-being also report greater fibromyalgia symptom severity ($\beta = -0.21$, p < 0.001). Importantly, incorporating general well-being into the model makes the effect for class insignificant. My results show that fibromyalgia severity is mediated by gender and class as well as personal agency, social identity, and general well-being.

Conclusion

The sociological case of fibromyalgia relates to broader construction and negotiation of identities embedded within interlocking systems of social differentiation and oppression: gender, race, class, and ability. My data shows that patriarchy, racism, and capitalism shape the experience of fibromyalgia as well as individuals' understandings of the condition. Gendered and ableist understandings shape the meanings individuals derive from their own experiences, which affects the doctor-patient interaction, social networks, and individuals' support systems. Importantly, racism and white privilege add cumulative affects to these gendered findings, with non-white people experiencing greater fibromyalgia severity and receiving fewer opportunities for symptom management. Finally, lower socioeconomic class serves as a barrier to opportunities for wellness and condition improvement across gender and race backgrounds. These analyses describe how normalizing the image of fibromyalgia as a "white woman's problem" constrains the behavior of individuals from other social categories.

VI. COVID-19 as a Catalyst for Community Care

When people learn that I am a fibromyalgia "expert," I am often asked whether the condition is "real." In all honesty, I have grown fatigued from this question. Focusing on the realness of a condition – instead of simply *believing the person experiencing it* – is an example of ableism: it ignores the ways that social structures both generate medical illegitimacy as well as benefit from it. Because Americans live in an individualist culture, a fibromyalgia diagnosis is a guilty until proven innocent model: each individual with fibromyalgia must effectively prove to their doctors (and their social networks more generally) that they are telling the truth: *their symptoms are real*. Further, a lack of medical evidence – which results from gaps in knowledge at the structural level - encourages greater subjective interpretation at the individual level. In other words, cultural ideologies and stereotypes more strongly influence how individuals determine who *really* has fibromyalgia (and who's "just messing around and faking it"[37]). This requires the average American with fibromyalgia to do more labor in legitimizing their condition (as well as determining how to manage it).

This project is based on the premise that fibromyalgia is a legitimate condition, real in the individuals' bodymind experiences and imbued with tangible social consequences. Cultural beliefs about gender, race, and class (about who is *strong* or *weak, truthful* or *dishonest, worthy* or *disposable)* shape the experience of (dis)ability, generally, and fibromyalgia more specifically. Medical skepticism at the structural level influences both 1) who is diagnosed with the condition and 2) how individuals experience their condition. In consequence, cultural understandings about fibromyalgia's realness originate from and

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[37] from Ken (low-income, multiracial, man)

sustain unequal experiences of (dis)ability. In my research findings, we can see the ways that individuals embody, reinforce, and resist these structural-level ideologies.

Finetuning Fibromyalgia

My findings show that when faced with an ambiguous health condition, individuals rely more heavily on intersectional ideologies to make sense of their lived experiences. Additionally, the controlling images (Collins 2000) which shape Americans' understandings of fibromyalgia originate from and perpetuate inequalities in its diagnosis. In this dissertation, I employed multiple methods to explore the ways that individuals understand fibromyalgia (an ambiguous, contested illness), and how the experience of fibromyalgia is shaped by racial, class, and gender inequality. In analyzing these social understandings, I determined how the fibromyalgia wellness process both encourages and excludes social categories.

People with fibromyalgia tend to approach wellness as something for which they are personally responsible. Unfortunately, this accounting draws attention away from the ways that interactional, institutional, and cultural forces *require* this self-care. Capitalist ideologies of individualism frame cultural understandings of and individual experiences with fibromyalgia. Findings from my survey data show the effects of this individualist narrative on individuals' general well-being. Specifically, those with lower socioeconomic status experienced greater concern about their fibromyalgia. In other words, class privilege affords individuals the peace of mind that comes with feeling in-control of one's well-being. Chen's (2019) study on implementing medical information through lifestyle changes showed that knowledge about one's condition is a critical factor in coming to terms with chronic pain. Further, *acceptance* of this pain was associated with lower pain severity and better overall well-being (Chen 2019). In this way, *knowledge is power.* My survey data confirm this notion: a regression model (see Table 5.1) highlighted the importance of self-mastery in the process of fibromyalgia wellness. In other words, feeling in-control of one's fibromyalgia tends to result in lower levels of concern. Importantly, whites (compared to non-whites) and masculine-performing people tended to feel a stronger sense of fibromyalgia self-mastery. This finding offers an opportunity to explore the ways that ideologies, practices, processes, and structures of whiteness and masculinity are connected with 1) individualism and 2) gendered notions of the responsibility of care (Glenn 2019).

My findings showed patterns in access to quality and effective fibromyalgia treatments on the basis of socioeconomic status. However, high-status class backgrounds (and wealth) were rarely ever spoken of as privileges. Instead, interviewees with low-income focused on the social barriers that impeded their fibromyalgia wellness. My respondents also highlighted the consistent inconsistency[38] (see Chapter 3) of fibromyalgia, which often had social consequences in the forms of not being able to plan in advance and/or missing out on social engagements. Although interviewees' descriptions of their fibromyalgia experience are consistent with social models of disability (as – at least temporarily - limiting their full participation in physical, psychological, and social capacities), as a consequence of internalized ableism, the vast majority did not self-identify as disabled.

The ways that accessibility and community-care were (or were not) institutionalized allowed for (or prevented) individuals' participation in wellness. I observed social patterns across three primary interactional instances: 1) the medical institution; 2) employment and occupation; and 3) the family and other social support systems. Gender ideologies about the

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[38] which resulted in part from interviewees' experiences of bodily doubt

social responsibility of care work (Hochschild 1983) produced intersectional inequalities in these contexts: while men were more strongly encouraged to participate in self-care, they also more readily received social support for fibromyalgia. Conversely, women were often forced to put family responsibilities before their own care, presenting a barrier to fibromyalgia wellness. In this way, they reported more self-reliance. Importantly, Black women spoke about the ways that they resisted these ideologies as a form of wellness, moving their knowledge of health inequalities into wellness through advocacy, volunteer work, and acts of community service. In taking action, Black women embodied collectivism, community care, and resisted structural forces as a radical act of love (Lakshmi Piepzna-Samarasinha 2018). Black women intuitively understand that community wellness results in individual well-being. Among all of my interviewees, even those with strong social networks and support systems reported desiring more community support, compassion, and care. In my interviews, those with intersectional privileges more strongly understood wellness and well-being through the lens of individualism (self-care).

My findings confirm that the cultural understandings of fibromyalgia – that it is a condition of middle-class, white women – are constructed alongside controlling images (Collins 2000) of gender, race, and class. Accountings of fibromyalgia from both Black women and men interview respondents relied on these racialized and gendered narratives. Results from my survey data are consistent with these predominant cultural conceptions: an ANOVA showed that low-income women reported greater fibromyalgia symptom severity. Barker (2005) argues that these patterns originate from the structural level: feminization of fibromyalgia's diagnostic criteria has encouraged a greater "diagnostic fit" with women, and this has resulted in the differential application of diagnosis. Furthermore, my intersectional analysis of fibromyalgia highlights the ways that whiteness functions as the unnamed norm in understandings of the condition. Black women interviewees often discussed white women's domination of fibromyalgia spaces. I observed the effects of this qualitative finding in my survey data, as white respondents more strongly identified with fibromyalgia and were more likely to be involved in fibromyalgia support groups. Furthermore, in addition to direct instances of racism within the doctor-patient interaction, Black women respondents also described qualitative differences in the embodiment of fibromyalgia (such as the effect of night-sweats on textured hair). Respondents also resisted these ideologies by acknowledging the ways that lack of representation within the fibromyalgia wellness process shaped their understandings of themselves and the condition.

Considering Long COVID

As this is a dissertation on making meaning in relation to health, wellness, illness, and (dis)ability, it would be remiss without incorporating an analysis of COVID-19. The COVID-19 pandemic has shed a light on which communities are structurally-exposed to chronic pain, and the ways that structures of power legitimize these inequalities. Further, the pandemic has forced the American public to directly address the ways that systems of power create differential opportunities for health, wellness, and well-being. I strongly encourage the implementation of disability justice frameworks to address directly the social and political factors which prevent individuals from achieving health and well-being.

COVID-19 is the most socially-significant disease of our generation: it has resulted in the death of over one million American lives (CDC 2022) and has caused physical and mental mass disability.[39] Globally, the most marginalized groups (primarily working-class and people of color) have been hit hardest by COVID-19, experiencing far higher illness and death rates (Abedi et al. 2021). Due to structural discrimination and resulting social inequalities in COVID exposure, researchers can also anticipate social patterns in the prevalence rates for long COVID. Long COVID is defined as a range of new, returning, or ongoing health problems lasting four or more weeks after first being infected with COVID-19 (CDC 2021) with predominant symptoms of chronic pain, headaches, fatigue, and difficulty thinking or concentrating ("brain fog"). As a crucial first step in establishing structural and institutional legitimacy,[40] in July 2021, long COVID was first categorized as a disability under Sections 504 and 1557 of the Americans with Disabilities Act (ADA; HHS 2021). If individuals are forced to be responsible for their own care in the management of long COVID – only those with privileged social positionings will be provided opportunities to maintain well-being. Will the COVID-19 pandemic (and the resulting disability from long COVID) initiate a structural shift from sick-care to health-care? Will long COVID be the catalyst for establishing institutional legitimacy for chronic pain?

The social connections between long COVID and fibromyalgia allow sociologists to anticipate how Americans will make meaning of the condition and treat the individuals who are living with it. The ideologies which create and sustain inequalities in the fibromyalgia experience are similar to those for long COVID. There are also overlapping bodymind experiences in long COVID and fibromyalgia. Just like fibromyalgia –long COVID

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[39] Imani Barbarin (a disabled Black woman) is disability justice advocate, author, and educator who argues that COVID-19 is a *mass disabling event* because 31% of American COVID-survivors experience disability from Long COVID (Chen et al. 2022).

[40] Recognition by the ADA presents an opportunity for individuals to receive institutional accommodations.

functions as an invisible illness: although there are biological markers for COVID-19, there currently are no professionalized medical indications for long COVID. Individualism has forced individuals with invisible illnesses to be responsible for *proving their disability* while simultaneously presenting structural barriers to achieve well-being. In fact, we can already observe the ways that individualism has framed Americans' understandings and experiences of COVID through the shift in public health messages about masking: from "wear a mask to protect others," to "wear a mask to protect yourself." Without immediate, community-level accommodations for both COVID-19 and long COVID (and frameworks of disability justice more broadly), I fear this event of mass disability will further exacerbate existing health inequalities. In order to alleviate the most dire consequences of long COVID (and provide the "preventative care" that medical practitioners claim to be working toward), medical researchers, sociologists, and disability scholars must center disabled, working-class BIPOC in research and in response efforts.

My research on the social construction of wellness and intersectional experiences of fibromyalgia can help inform the public health response to long COVID. My intersectional analysis of fibromyalgia allows sociologists to document the ways that some individuals are fast-tracked in the wellness process while others are excluded. When the medical industry offers no effective options, individuals must turn to a wellness industry (if they have enough privilege), which creates greater inequality by gatekeeping access to well-being. My findings show that institutions can open these gates by making wellness more accessible: through increasing community programs and accommodations (especially in the forms of family support and flexible working hours). In caring contexts, individuals become more well. In turn, individual well-being promotes continued community wellness.

Making Wellness Work for Us

This dissertation challenges conceptions of fibromyalgia, (dis)ability, and wellness. Well-being is an achievement that some people can more easily maintain; however, others have to work much harder to access it. Unfortunately, understanding well-being as *solely* an individual achievement gets at the crux of what is currently wrong with commercialized understandings of well-being (and how the wellness process has become a consumer product). The wellness industry tells Americans that the more products we purchase, the better we will feel. However, this notion ignores the social factors that cannot be made well through an individual's consumption. *Drinking celery juice every single morning won't encourage my boss to let me work remotely full-time.* Common understandings of wellness encourage Americans to ignore the structural sources of inequality (gender, race, class, and ability), which profit off of unequal access to well-being.

Ultimately, this research project examines how individuals pursue wellness in the face of structural and social constraints. In doing so, I gathered data which directly challenges cultural stereotypes about (dis)ability, legitimacy, self-care, and wellness. As with any research project, this dissertation comes with its limitations as well as areas for growth. First, I must address the small effect sizes for some of age, race, and class in some of my quantitative findings.[41] While I understand this limitation might point to no meaningful connections between the concepts I explored, part of the premise of this project is that quantitative methods cannot fully capture the embodied experiences of fibromyalgia. Further, most of these quantitative findings were supported with qualitative data.

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[41] see Tables 3.1, 3.2, and 5.1

Another critique of this project is the limited racial diversity in both samples but which can be seen most obviously within my survey data. My interview sample serves as both a limitation and a source for further research. I over-sampled Black women in my interviews for two reasons: they are under-represented in the fibromyalgia diagnosis, and I relied on Black Feminist Theory in my research design. However, there are also indications that Latinas and Native Americans are *over-represented* in the diagnosis, while Asians (both in American and internationally) have low rates of fibromyalgia diagnosis. Examining a greater diversity of fibromyalgia experiences would be culturally-informative, illuminating the ways that ideologies of individualism (with strong ties to capitalism and American nationalism). This might require future fibromyalgia researchers to over-sample from these categories as well. Finally, the lack of investigation surrounding sexuality serves as both a limitation[42] and a future direction for research. My findings showed that family and romantic relationships were a critical site for fibromyalgia wellness. Therefore, scholars should investigate the ways that gender and sexual identities – in tandem with the ideologies stemming from patriarchy and heteronormativity - shape individuals' understandings of and experiences with fibromyalgia, care, and well-being.

My findings point to the notion that when individuals are faced with social barriers that prevent them from achieving well-being, they turn to community care, advocating for healing justice as both a form of wellness and as resistance to the forces in power. Glenn (2019) argues that establishing community-care cannot happen without *implementing policies which make caring an economic, political, and public responsibility.*[43] Additionally,

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[42] I had a very small number of respondents who identified as gender non-conforming.

[43] In other words, rather than making individuals (and their families) responsible for well-being, the government (and society more broadly) must acknowledge individuals'

in order to transition to a more just society, individuals must also become more caring. As individuals become more caring, care-work becomes more valuable at the societal level, equalizing access to well-being. Queer, working-class, BIPOC have spent decades advocating for these structural solutions to care through the creation of collective, community-based care systems. In practice, healing justice is displayed by *Sins Invalid*, who – through cross-movement solidarity – strives for collective access and liberation by highlighting disability, intersectionality, and humanity. This collective exemplifies Lakshmi Piepzna-Samarasinha (2018)'s conception of healing as a form of radical solidarity and community love. While empathy doesn't solve everything, researchers have documented the reciprocal relationship between care, kindness, and justice (Glenn 2019). In order to make wellness work for us, we must value kindness, care, and love: in promoting care, we make well-being a possibility for everyone.

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agency and social interdependence, requiring us to make employment more accessible and the industry of paid care valuable.

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Appendices

Appendix A: Demographic information about interview respondents.

Pseudonym	Gender	Race	Class
Anne	Woman	White	Low-Income
Avery	Woman	Black	Middle Class
Bill	Man	White	Low-income
Brian	(Trans) Man	White	Middle Class
Claire	Woman	White	Affluent
David	Man	Multi-racial	Low-income
Dory	Woman	White	Low-income
Edith	Woman	Black	Low-income
Emma	Woman	Black	Low-income
Fang	Man	White	Low-income
Heather	Woman	White	Affluent
Jade	Woman	Black	Middle Class
John	Man	White	Low-income
Kathryn	Woman	White	Affluent
Ken	Man	Multi-racial	Low-income
Layla	Woman	Black	Low-income
Luke	Man	White	Middle Class
Marie	Woman	White	Affluent
Michelle	Woman	White	Affluent
Molly	Woman	White	Low-income
Natalie	Woman	Black	Affluent
Olivia	Woman	White	Affluent
Prof. Z.	Man	White	Middle Class
Sarai	Woman	Black	Low-income
Scott	Man	White	Middle Class
Shanice	Woman	Black	Low-income
Shayera	Woman	White	Low-income
Stan	Man	Multi-racial	Low-income
Twinkle	Woman	Black	Affluent
Viola	Woman	Black	Middle Class

Appendix B: Interview Protocol[44]

Reference Number:
Date:
Time and Duration:
Respondent:
Contact:

Interviewer: I genuinely appreciate this opportunity to speak with you. As stated previously, this interview should take about one hour and covers 4 main areas. We'll start with some general questions about your experience with fibromyalgia, follow with questions about your diagnostic pathway, talk about treatment options and how you manage your symptoms, and conclude with your thoughts about the larger fibromyalgia community.

Before I begin, I want to make sure it's alright with you if I tape record this interview.

Everything you say will remain confidential: your name and identifying information will not be connected to your answers. Is that okay with you? Please be advised that you can refuse to answer any of my questions, and that you can withdraw from this study at any time.

Do you wish to pick a pseudonym or should I do so?

Do you have any initial questions before we get started?

Interviewer: First, I'm going to ask you a few questions about fibromyalgia in general.
1. In your own words, what is fibromyalgia?
2. Are you familiar with any metaphors used to describe fibromyalgia?
3. How has fibromyalgia affected your daily life?
4. How has fibromyalgia changed the way you see yourself?

Interviewer: Next, I'm going to ask you about your interactions with health care professionals. 1. Please describe the process that you were diagnosed fibromyalgia.

If DIAGNOSED by doctor:

1a. How long did it take to receive a diagnosis? How many doctors did you see before receiving your diagnosis?
1b. What were your motivations for seeking a medical diagnosis?

If SELF-DIAGNOSED:

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[44] Opening format and information adapted from Strolovitch (2007).

1c. How many doctors have you seen for symptoms that are related to your fibromyalgia? How long have you been attempting to receiving a diagnosis?
1d. What were your motivations for seeking a medical diagnosis?
1e. Why do you believe you have not been diagnosed?

2. What are the positive outcomes to receiving a fibromyalgia diagnosis? What are the costs?
3. How has your well-being changed since finding out about your fibromyalgia?

Interviewer: Now, I'm going to ask you some questions about how you manage your fibromyalgia symptoms.
1. What forms of treatment do you use to manage your fibromyalgia symptoms? What encouraged you to start using these things?
2. How does cost of treatment/medication affect your ability to manage your fibromyalgia? What do you do if you can't afford a treatment/medication?
3. When you have questions or concerns about fibromyalgia, where do you go?
4. What more do you wish you could be doing to manage your fibromyalgia?
5. What about your fibromyalgia experience has changed since the COVID-19 pandemic?

Interviewer: In this section, I'm going to ask you some questions about your perceptions of the fibromyalgia community more broadly.
1. Describe the "average" person with fibromyalgia. Is there a specific type of person who is more likely to have the syndrome?
2. How do others react when you tell them about your fibromyalgia?
3. Do you feel like your experience is similar to others who also have fibromyalgia?
4. Fibromyalgia has received increased attention and awareness over the last several decades. As someone with this ambiguous syndrome, what is something that you think is important about fibromyalgia that is not being discussed?

Interviewer: Finally, is there anything else I should know or understand about your experiences with fibromyalgia?

Interviewer: I really appreciate you taking the time to sit down and talk with me. Do you know of any other individuals with fibromyalgia who might be interested in talking to me about these kinds of questions? Would you be willing to connect me?