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Essay

Suffering without Remedy: The Medically Unexplained Symptoms of Fibromyalgia Syndrome and Long COVID

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Abstract: The term "Medically Unexplained Symptoms" (MUS) describes chronic symptoms for which medical investigations fail to reveal a specific pathology or biomarker. Even as MUS are among the most prevalent chronic health problems in the global north, patients who experience them reside in a nebulous space. Such nebulousness is heightened for women patients. Moreover, women report MUS at higher rates than men. In this review essay, we analyze the medicalization and feminization processes vis-à-vis MUS by focusing on two particular syndromes: Fibromyalgia (FMS) and Long COVID (LC). FMS and LC present clear parallels that allow us to trace an unhappy marriage of women and MUS. We demonstrate how the medical constructions of these two syndromes as knowledge categories are representations of medical uncertainty vis-a-vis women patients. We then scrutinize the resulting gendered consequences of these categories for the illness experience. We conclude our review by calling for a cultural reorientation in our thinking about MUS that centers a recognition that the origins and manifestations of a great deal of human suffering reside outside of medicine's ways of knowing. In so doing, we connect to foundational claims in medical anthropology and sociology; namely, that illness is more than disease, and health cannot be achieved primarily via biomedical means.

Keywords: Medically Unexplained Symptoms; Long COVID; fibromyalgia; chronic illness; contested illness; women's suffering; medicalization

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1. Introduction

We begin with an often-overlooked observation concerning contemporary medicine. Many chronic symptoms remain medically unexplained. The term "Medically Unexplained Symptoms" (MUS) is used to describe chronic symptoms for which medical investigations fail to reveal a specific underlying pathology or biomarker (Marks and Hunter 2015; Bransfield and Friedman 2019)[1]. Insofar as medicine's authority is derived from translating patients' subjective symptoms into objective biomedical signs, patients with MUS reside in a nebulous space (Aronowitz 2001). But MUS are ubiquitous (Nettleton 2006; Jadhakhan et al. 2019). As many as 60 percent of visits to primary care clinics and 70 percent to specialty care clinics involve patients with MUS (Jadhakhan et al. 2019; van Ravenzwaaij et al. 2010). Indeed, in light of these facts, an argument can be made that MUS are among the most commonplace chronic health problems in the global north (Nimnuan et al. 2001).

The commonplace character of MUS is especially evident in women. Women report MUS at significant higher rates than do men (Barsky et al. 2001; Claréus and Renström 2019). Moreover, women are significantly more likely than men to be diagnosed with one of several MUS clusters that have morphed into diagnosable syndrome classifications in recent decades (Arout et al. 2018; Lim et al. 2020; Bai et al. 2022). Some of these syndromes include fibromyalgia syndrome (FMS), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic pelvic pain and vulvodynia, chronic Lyme disease, and,

most recently, Long COVID (LC). Collectively, these syndromes are referred to as *contested illnesses*, defined as chronic conditions characterized by debilitating but nonspecific symptoms for which there is "limited or controversial" (Murphy et al. 2016, p. 3) physical evidence. In turn, contested illnesses "are surrounded by polemic debates regarding their etiology, symptomology, treatment, and even their existence" (Groenevelt and de Boer 2023, p. 1). The feminization of these conditions furthers such polemics.

In this contribution to the literature, we explain the medicalization and feminization processes vis-à-vis MUS as found in two particular syndromes—Fibromyalgia Syndrome (FMS) and Long COVID (LC). We examine FMS and LC as diagnostic categories and illness experiences. Our dual focus on diagnosis and illness experience is crucial. As we will demonstrate, they are two sides of the same analytic coin. First, we situate FMS and LC in key background literatures. Then, we scrutinize and distill the peer-reviewed biomedical literature, as well as social science publications related to these diagnostic categories and/or illness experiences.

There are a number of ways in which FMS and LC are meaningfully different. FMS is a disorder of unknown etiology characterized by chronic widespread pain and an extensive list of associated symptoms. The creation of the FMS diagnosis took decades to emerge and originated almost entirely in the US before being exported via the international medical literature. Now, more than thirty years after adoption of formal diagnostic criteria for the condition, FMS lacks the public and medical attention bestowed LC seemingly overnight. LC[2] is one of several terms proposed more or less simultaneously in different national contexts used to describe an array of "nonspecific" symptoms that persist or appear in the wake of a SARS-CoV-2 infection (Kerzhner et al. 2024). Compared to FMS, formal LC diagnostic categories, including Post-COVID-19 Conditions and Post-Acute Sequelae of SARS-CoV-2 Infections, emerged rapidly. The compressed timeline for LC can in part be explained by the "speed, scale, and sheer number of [LC] patients" (Au et al. 2022). Online patient information and traditional media coverage of the mysterious condition were highly visible only months into the pandemic (Callard and Perego 2021). Moreover, the backdrop of a global pandemic generated initial medical and public support for patient's claims of post-viral distress. But LC's accelerated path is nevertheless a contested path (Au et al. 2022).

We document the different players, timeframes, and contexts vis-à-vis the creation of FMS and LC. But we will also demonstrate that, despite the many differences between these disorders, their unfolding and resulting consequences have a number of marked parallels. We demonstrate how both of these diagnoses, as knowledge categories, represent medical doubt and uncertainty vis-a-vis women patients. We then scrutinize the gendered consequences of such doubt and uncertainty for the illness experiences of FMS and LC. Indeed, if, on the one hand, these diagnostic labels aim to contain forms of women's suffering that are difficult to explain within the biomedical paradigm, on the other hand, they remain "empty" categories by providing neither diagnostic authoritativeness nor effective therapeutic pathways. Housed within these diagnostic categories, the suffering of women patients continues to be medically and socially discredited. As shown in the international literature we analyze, marginalization and disparagement characterize the FMS and LC illness experiences across many different national contexts in the global north. We also address emergent research concerning some of the intersectional dynamics of these diagnostic categories and illness experiences. Finally, by evoking Bryan Turner's (1996, p. 1) conception of the *somatic society*, wherein "major political and personal problems are both problematized in the body and expressed through it", we conclude our review by presenting a critical analysis of the medicalization of women's suffering under these diagnostic categories. Our critique calls for a cultural reorientation in our thinking about MUS centered on a recognition that the origins and manifestations of a great deal of human suffering reside outside of medicine's ways of knowing. In so doing, we connect to foundational claims in medical anthropology and sociology; namely, that illness is more

than disease, and health cannot be achieved primarily via biomedical means (Engels 1952; Zola 1966; Kleinman 1986; Charmaz 1991; Turner 1996; Farmer 2004).

Situating Fibromyalgia Syndrome & Long COVID

To situate FMS and LC as gendered biomedical categories and illness experiences, we draw on several relevant literatures. First, we build on a well-established lineage in anthropology and sociology that investigates how medical knowledge and practice, rather than being neutral or objective, are produced within historical contexts and so shaped by social and cultural factors (Freidson 1970; Lock and Gordon 1988; Joyce 2008; Braun 2014). Within this broad conceptual framework, medicine is understood as one particular (albeit powerful) way of knowing, with its own sociocultural rules and practices as well as its corresponding limitations (Lindenbaum and Lock 1993; Good 1994). Medicine, for example, is unable to capture the meaning of the lived experience of *illness*. The experience of illness stands outside of medicine's meaning-making paradigm (Bury 1982; Kleinman 1986; Charmaz 1991; Frank 1995). For this reason, social scientists have studied the subjective illness experience (i.e., first-person accounts of the meaning of suffering) in general and as an especially useful tool in instances where the gap between medical knowledge and the experiences of sufferers is vast (Kleinman 1988; Barker 2005; Moretti 2019).

We also draw on social scientific theorizing about diagnoses. As a particular type of medical knowledge, diagnoses are social accomplishments. A disease does not exist, so to speak, until it is named by the institution of medicine (Aronowitz 2001; Jutel 2011). A disease is manifested through a process of diagnostic standardization, which includes naming the condition, creating a clinical case definition, formalized nomenclature, and diagnostic criteria and diagnostic codes (Jutel 2011). Classifications organize things (Bowker and Star 2000). Nevertheless, this line of inquiry recognizes that the organization of things is socially contingent. Medicine does not "carve nature at its joints", as Plato is said to have valorized (Stone 2020, p. 504). Instead, medicine carves "nature" as it sees fit (Zerubavel 1996). For this reason, creating a diagnostic classification always involves the messy politics of interpretation (Conrad and Schneider 1992).

The premise that biomedical knowledge is not merely a reflection of nature also intersects with decades of feminist scholarship. As early as the 1970s, feminist scholars turned their attention to the institution of medicine and medical knowledge as contributing to the social construction of gender meanings, experiences, and inequalities (Ehrenreich and English 1973; Scully and Bart 1981). Over the intervening decades, feminist scholars demonstrated myriad ways that science and medicine reflect and generate inequalities via the naturalization of sex differences (Martin 1987; Laqueur 1990; Blum and Stracuzzi 2004). Disability, queer, and intersectional scholars further these claims by explicating how medical meanings of sex, gender, and sexuality simultaneously reflect and generate other inequalities, which medicine likewise naturalizes (e.g., race, disability, sex, sexualities, etc.) (Hankivsky 2012; Eckhert 2016; Sebring 2021). Rooted in a larger context wherein sex and gender are constituted rather than given (Butler 1988; Laqueur 1990), medicine simultaneously naturalizes what are socio-historical categories and obfuscates their complex and intersectional character (Giritli-Nygren and Olofsson 2014; Singer et al. 2017; Wilson et al. 2019).

Feminist scholars have also charged that certain conditions and diagnoses, like postmenstrual syndrome, obesity, and vasomotor syndromes, to name but a few, can *medicalize* women's bodies, minds, and experiences (Markens 1996; Riska 2003; Boero 2012). Bracketing some of the complexities of medicalization and biomedicalization (i.e., the technoscientific intensification and transformation of the process of medicalization) (Clarke et al. 2003)[3], in simple terms, medicalization involves defining ever more aspects of the human experience in medical terms (Conrad 2005). Gendering the medicalization thesis emphasizes how and with what consequences aspects of women's lives have come to be seen through a medical lens. Even as feminists have demonstrated how women's lives have been especially prone to medicalization, including women's routine embodiment (e.g.,

menstruation, pregnancy, menopause) (Markens 1996; Waggoner 2017), they also challenge simplistic medicalization claims. Women, for example, have rarely been passive recipients of medicalization. Instead, they strategically resist, seek out, and otherwise adapt medicalization (Blum and Stracuzzi 2004; Brubaker 2007; Bacigalupe et al. 2022). There is also a robust body of scholarship explicating how (bio)medicalization is stratified in ways that intersect with other systems of inequalities, sometimes providing resources and sometimes providing surveillance (or both) to women of privilege and/or those on the margins (Fox and Worts 1999; Eckhert 2016; Fernandes de Medeiros et al. 2021; Thornton and Reich 2022; Mann and Bertotti 2024). When examining the relationship between women and medicalization, it is thus necessary to analytically complicate "women" as a category.

Despite all of these complexities and accepting that medicalization can provide useful cultural and material resources, there are important reasons for concern. When the varied distresses of women patients come to be defined as biomedical problems residing within women's bodies and minds[4], the social factors underlying those distresses are obscured (Fernandes de Medeiros et al. 2021; Bacigalupe et al. 2022). Medicine looks for solutions in women's individual bodies and minds and not in the broad gendered malaise of the social body (Richie 2019). Medicalization can provide "biological justification for social circumstances" (Sebring 2021, p. 1958) and, importantly, give "credence to the fallacy that societal problems having to do with health, primarily require health care solutions" (Lantz 2019, p. 37). The medicalization of women's social circumstances and oppressions under the diagnostic label of *hysteria* is an early case in point.

The 19th century diagnosis of hysteria pulls together the above noted literatures in ways that are relevant to FMS and LC. Hysteria was a feminized condition dating back many centuries. Despite the changes in medical interpretation and explanations, hysteria has referred, century after century, not only to conditions specifically experienced by women, but also to specific conceptions about women's bodies and women's proper place in society. For example, the 19th century diagnostic category of hysteria provided naturalistic veneer to cultural anxieties vis-à-vis white bourgeois women in the context of myriad social change (Showalter 1997). In this sense, physicians considered the hysteric to be a woman plagued by a wide range of somatic complaints of psychoneurotic origin (Micale 1995; Showalter 1997). The medicalization of these sociocultural anxieties and malaise failed to translate into meaningful remedies. Not only was the 19th century hysteric poorly understood, but she was treated with a range of ineffective and often iatrogenic therapeutics (Tasca et al. 2012).

With different emphases, the medical and social science literatures alike describe how the 19th century diagnosis of hysteria has found its way into contemporary contested illness diagnoses (Showalter 1997; Barsky and Borus 1999; Aronowitz 2001; Wessely and White 2004; Kempner 2014; Teive et al. 2015). The clinical similarities between hysteria and FMS, ME/CFS, chronic Lyme disease, irritable bowel syndrome, tension type headache, temporomandibular disorder, functional neurological disorder, and LC are unmistakable (Shorter 1992; Showalter 1997; Kirmayer et al. 2004; Seulin 2004; Cathébras 2006; Brigo 2014; Joffe and Elliott 2023). Some of the many symptom overlaps include fatigue, pain, weakness, headaches, cognitive and mood impairments, dizziness, limited motor skills, sensory loss, restless leg, upper respiratory symptoms, and sleep and bowel irregularities. The lack of medical evidence regarding underlying pathology is also shared across these disorders, as is their feminization (Arout et al. 2018; Lim et al. 2020; Bai et al. 2022). Some clinician researchers conceptualize these many disorders as stand-alone entities, but others pull them back together again under the umbrella label *functional disorders,* suggesting that the array of novel diagnostic terms are akin to putting "old wine in new bottles" (Barsky and Borus 1999; Wessely and White 2004; Joffe and Elliott 2023). Just as the lack of medical evidence for the existence of these discrete disorders threatens their diagnostic validity, merging them under the umbrella term operates as a form of diagnostic invalidation (Wolfe and Rasker 2021). And, just as there is contestation concerning these diagnoses, there is contestation about if and how these disorders are related to one another (Mariette 2024).

With regard to hysteria, FMS, and LC, their similarities as categories of medical knowledge and patient experience are considerable. Among other similarities, the emergence of each of these diagnoses involves a feminized patient population presenting commonplace, distressing and ill-defined symptoms and physicians using their available medical knowledge and techniques to offer their women patients imperfect explanations of, and even more imperfect remedies for, their distress. These diagnoses thus demarcate a more than one-hundred-year period during which women patients sought medical explanations for distressing symptoms only to find their suffering marginalized in conventional medical terms. From hysteria to a long list of syndrome clusters, the MUS of women patients have been pressed into diagnostic categories thought to be fully or partially psychosomatic. Thus, women patients have historically occupied the ranks of contested diagnoses that grant them neither the full legitimacy of disease nor meaningful therapeutic remedies. This has been a long and unhappy marriage. But while overt sexism of the 19th century allowed physicians to assert that the hysteric was merely the problematic essence of womanhood itself (Showalter 1997; Tasca et al. 2012), contemporary medicine remains effectively silent about the feminization of contested illnesses beyond recognizing being "female" as a risk factor (Barker 2005; Moretti 2019; Barker et al. 2022).

The arch from hysteria to FMS to LC transcends distinct historical periods, including different configurations in sex/gender systems and varied orientations and practices in medicine. What we emphasize, however, is that despite these differences, hysteria and contemporary contested illnesses reveal medicine's tendency to create diagnostic categories for women patients with MUS. We point to several key observations. Women report higher rates of sickness, pain, and dysfunction than men (Rieker and Bird 2005; Crimmins et al. 2019; Homan 2019; Short and Zacher 2022). Women are more likely than men to perceive themselves as ill, evaluate their illness as serious, and seek health care in response (Verbrugge 1985; Barsky et al. 2001; Thompson et al. 2016). These patterns are complex, unyielding to scientific certainty, and open to interpretation (Barker 2005; Keogh 2022). As they have been topics of intense debate for millennia, we shall not seek to declare the truth about these observations. What we can say is that the prevalence of MUS among women patients underlies our discussion of FMS and LC. And yet, neither women's MUS nor their clinical interpretations can be understood in essentialist terms. Pain and sickness reflect intersecting systems of inequality, as do clinical encounters. Past and present, certain women have had more access to and greater visibility within the social field of biomedicine, and these intersectional dynamics are also written into the context of FMS and LC (Anderson et al. 2009; Ezenwa and Fleming 2012; Pryma 2017a; Cousin et al. 2022).

In what follows, we approach FMS and LC as socially constructed diagnostic categories of medically unexplained symptoms and illness experiences. This position should not be seen as a statement that pain only affects the female population (Keogh 2022) nor be interpreted as dismissive of the real suffering of those with these diagnoses or an accusation of medical malfeasance. The socially constructed meanings that mediate our experience can be imperfect, but that does not mean that the symptoms that comprise these disorders have no biological basis, or that they would not exist in the absence of the specific diagnostic categories (Barker 2005). It is clear to us that the suffering of FMS and LC are *real* (i.e., material). Our ontological position assumes that a thing can be both real and socially constructed (Brown 1995; Young 1997). In particular, our analytic approach foregrounds gendered social processes and social conditions that interact to promote the organization of certain experiences into FMS and LC as categories of biomedical knowledge and frameworks of meaning and identity, as well as some of the consequences therein for the illness experience of FMS and LC.

2. Diagnostic Categories and Illness Experiences

2.1. Fibromyalgia Syndrome as Diagnosis

Fibromyalgia Syndrome (FMS) is a chronic disorder characterized by widespread pain, fatigue, sleep disturbances, cognitive and mood irregularities, and an array of associated

symptoms (Wolfe et al. 2016). FMS is said to affect between 2 and 5 percent of the global population, of which 80 to 90 percent are women (Salaffi et al. 2020; Ruschak et al. 2023). Even as FMS is commonplace, it is shrouded in medical uncertainty. Tentatively framed as a disorder of central sensitization with neurobiological underpinnings[5], the etiopathology of FMS is unknown (Galvez-Sánchez and Reyes del Paso 2020). FMS is not detectable via routine imaging techniques (x-rays, MRI, etc.) or blood or other laboratory tests. The condition is diagnosed based on clinical observations and patients' reports of symptoms for which other explanations have been ruled out (Wolfe et al. 2016). We have already addressed the tendency for medicine to consider that which it cannot comprehend on its own terms as attributable to psychogenesis (Aronowitz 2001; Nettleton 2006; Byrne 2022). Even as FMS is now widely diagnosed and medically managed, many providers question its legitimacy as a *real* (i.e., physical) disease (Barker 2005; Moretti 2013; Album et al. 2017; Moretti 2019).

We focus on the process by which FMS was created as a diagnostic category and the consequences therein. The diagnosis emerged over a several-decade period, forged by the coming together of a large number of women patients and rheumatologists mainly based in the United States (Barker 2005). In the 1970s and 1980s, a handful of rheumatologists began studying a persistent patient population routinely seen in their clinics—patients with chronic pain and many other distressing symptoms for whom imaging and laboratory results were "unremarkable" (e.g., no biomedical evidence of pathology). For many decades, the diagnosis of *fibrositis*, which was considered a form of *psychogenic rheumatism*, had been applied to such patients. But this new wave of rheumatologists began testing various diagnostic criteria to see if a subset of patients could be distinguished from the larger diagnostic category of psychogenic rheumatism. Picking up an old thread in the rheumatological literature, the examination of places on the body called "tender points" were deemed the key criteria for identifying a subset of patients with otherwise unexplained symptomology. This ongoing research eventually culminated in the 1990 American College of Rheumatology (ACR) diagnostic criteria for FMS, which included a patient's report of widespread pain for at least three months and the presence of pain in at least 11 of 18 defined tender points upon physical examination, for which other explanations have been ruled out (Wolfe et al. 1990). Once established, these criteria were widely adopted by the international biomedical community.

The 1990 ACR criteria brought official recognition to FMS, but the diagnostic classification was and remains riddled with problems. For example, the original criteria were widely critiqued for relying too heavily on tender points at the expense of recognizing the common cluster of symptoms associated with the disorder. Moreover, there was tremendous variability in how tender point examinations were conducted, and, even more problematic, tender points themselves are a dubious concept. For these and other reasons, the 1990 criteria were revised in 2010. The 2010[6] criteria (Wolfe et al. 2010) rely on two scales: one assessing patients' report of pain in 19 bodily regions (e.g., neck, lower leg, shoulder), and the other assessing symptom severity in three core dimensions (fatigue, unrefreshing sleep, and cognitive symptoms), as well as the self-reported impact of 41 other symptoms ranging from headache and constipation to hair loss and dry eyes (Wolfe et al. 2010; Bhargava and Hurley 2024). In 2011 and 2016, additional modifications to the 2010 criteria were made with the goals of better capturing widespread rather than regional pain and assessing levels of symptom severity (see Wolfe and Rasker 2021). New FMS diagnostic modifications continue to be proposed and robustly debated (Arnold et al. 2019; Wolfe 2019). Meanwhile, real-world diagnostic practices are highly idiosyncratic. Rather than hewing closely to official criteria when diagnosing FMS, "many physicians, including physician-experts, still hew to the idea of 'I know it when I see it'" (Wolfe and Rasker 2021, p. 1). There is, in effect, "no clear consensus regarding the concept and diagnosis of FMS among medical professionals" (Galvez-Sánchez and Reyes del Paso 2020).

Notwithstanding all of the diagnostic proposals, revisions, iterations, and debates, FMS continues to stand for a collection of distressing symptoms that are common in

women patients but cannot otherwise be explained. FMS is a messy intellectual concept, with women patients at the center of its messiness. Early studies leading up to the 1990 criteria included mostly, and in some cases only, women. From the outset, working with an almost exclusively women patient population, clinician researchers conceptually organized unexplained, nonspecific symptoms commonly reported by women into the diagnostic criteria themselves. First tender points, and now a collection of symptomatic distress, the criteria represent highly feminized idioms of distress (Wolfe et al. 2018). The feminization of the disorder was and remains baked into the criteria themselves.

Additional feminizing tendencies unfold clinically[7]. Rank and file clinicians work with an established *profile* of the fibromyalgia patient as a woman patient, further skewing clinical encounters toward diagnosing women and not men (Katz et al. 2010; Wolfe et al. 2019). For example, in an ethnographic study conducted in a fibromyalgia clinic in an Italian public hospital (Moretti 2019), clinicians would bend the FMS criteria to diagnose women but uphold the criteria to exclude men in otherwise very similar clinical cases. When interviewed, the Italian clinicians explained that the FMS criteria should be used with some degree of flexibility since the condition varies considerably across patients. But clinical observations revealed a gendered pattern of diagnostic flexibility vis-à-vis women, with diagnostic rigidity vis-à-vis men. In consequence, despite the similarities in clinical pictures and symptomatology, the diagnosis of fibromyalgia was only confirmed in the case of female patients, while male patients received referrals in order to investigate more "plausible" diagnoses. Beyond this single Italian clinic, similar gendered diagnostic practices have been found across many different clinical contexts. Providers know FMS *when they see it* (Wolfe and Rasker 2021), and they see it in women patients (Wolfe et al. 2019). Being a woman is nearly necessary, although not sufficient, to be diagnosed with FMS. Clinical dynamics that lead providers to *see* FMS in women and not in men are likely at play in providers *seeing* FMS more readily in white rather than racial-ethnic minority women, as is the case with other pain disorders (Adams et al. 2024). Racial and ethnic minority patients have largely been excluded from FMS clinical research from the onset, thus racializing the diagnosis itself and the resulting clinical dynamics (Barker 2005; Kempner 2017; Pryma 2017b; De León-Menjivar 2022; Henley et al. 2023).

Other consequences of the conceptual messiness of FMS involve its diagnostic generosity regarding women and resulting clinical heterogeneity. Because there are no clear boundaries between FMS and not-FMS (Wolfe and Rasker 2021), there are lots of ways for the distress of women patients to find residence within the FMS diagnosis. Conversely, that the distress is "not otherwise explained" means that diagnostic exclusion can be difficult (Qureshi et al. 2021). In fact, in terms of clinical care, "[f]ibromyalgia is a rule in (not rule out) diagnosis" (Gota 2021). Lots of different things come to be defined as FMS. As noted by the leading author in the research establishing each of the ACR criteria studies: rather than being a "natural kind" of thing, FMS "represents the opinion of a committee" (Wolfe and Rasker 2021, p. 3). Whereas some FMS researchers continue to foreground the heterogeneity in the clinical manifestations of the disorder (Wolfe 2019; Martínez et al. 2021), it is more commonly reified as a discrete thing[8]. When this is done, medical research and treatment advances become something of a fool's errand. Medicine's struggle to provide unified etiological or therapeutic answers for the broad category of FMS is overdetermined.

In the absence of clear *objective* biomedical evidence or intelligible etiology, FMS represents and generates medical uncertainty and skepticism about many women patients. And, when medicine cannot explain what is wrong with women, it becomes suspicious that what is wrong is not *real* (i.e., is psychogenic). As we show in the following section, the suffering that is frequently diagnosed as FMS is very real indeed.

2.2. FMS as Illness Experience

The collective experiences of women living with FMS in the global north can aptly be designated as different but similar. In dozens of qualitative studies, the particular constellation of FMS symptoms, as well as their specific onset and trajectory, are wide-

ranging (Barker 2005; Sim and Madden 2008; Moretti 2013; Mengshoel et al. 2018; Boulton 2019; Moretti 2019; Paxman 2021). Women's illness narratives include both rapid and slow onset of symptoms, sometimes following accidents or injuries, illnesses, menopause, difficult surgeries, physical and sexual trauma, the death of loved ones, the coming together of many of these hardships back to back, or simply appearing out of the blue. Some describe pain as their chief burden, but for many others, the pain pales in comparison to the impacts of fatigue, depression, cognitive malaise ("fibro fog"), sleep or digestive problems, headaches, and/or some combination of these symptoms (Barker 2005; Moretti 2013; Taylor et al. 2016; Hamama and Itzhaki 2023). The official medical literature and popular self-help resources alike suggest that there are nearly as many distinct expressions of FMS as there are those who suffer from FMS (Raspe and Croft 1995; Starlanyl and Copeland 2001). But the experience of FMS coalesces around common features. We focus on four shared features of the FMS illness experience: the envelopment of symptoms and erosion of self, the search for diagnosis and diagnostic transformations, medical disparagement pre- and post-diagnosis, and illness affiliation and identity.

One need only speak to a handful of women with FMS to appreciate the condition's often devastating impacts. In the face of an onslaught of perplexing symptoms, tasks that were once effortless and routine become unimaginably difficult or impossible. Plans and dreams are abandoned as everyday life becomes a set of restrictions geared at managing the collective impacts of FMS symptoms. Relationships become strained. One's sense of self erodes. Understandably, despair sets in. This shared thread of symptom envelopment, social isolation, and self-loss is evident in our research into the FMS illness experience and is also well-documented in the literature broadly (Barker 2005, 2008; Moretti 2013; Mengshoel et al. 2018; Cipolletta et al. 2020).

Dealing with medical uncertainty is also a core feature of the FMS illness experience. When patients originally experience unrelenting symptoms, they seek medical care. So begins a protracted nightmare. Despite innumerable tests and procedures, doctor after doctor can find "nothing wrong". The gap between normal medical examinations and the certainty of their own felt distress leads many women to grapple with epistemic instability. They question their own sanity. This self-doubt often intersects with actual or implied suggestions from providers that their condition might be psychogenic. Prescriptions for psycho-pharmaceuticals and mental health referrals pile up. Medical disbelief spills into disbelief by family, friends, employers, and the public at large. Feelings of isolation and darkness of mood intensify. Patients are left to reconcile how it is possible that nothing is wrong when so many things are so very wrong indeed (Barker 2005, 2008; Wuytack and Miller 2011; Moretti 2013; Taylor et al. 2016; Armentor 2017; Moretti 2019).

In the above section, we emphasized the conceptual ease with which many women patients can be diagnosed with FMS. Even so, the road to diagnosis is generally long and arduous, often taking many years (Barker 2005; Moretti 2013; Pryma 2017a; Mengshoel et al. 2018). In addition to lacking objective biomedical indicators, the symptoms of FMS are commonplace and associated with many different health conditions. This makes clinically sorting it out difficult but also reflects why many providers are skeptical of FMS diagnosis and prefer not to diagnose or treat FMS patients at all (Wolfe and Rasker 2021). The availability of digital health information has increased the likelihood that individuals learn about FMS on their own, and some self-diagnose. Even as self-diagnosis can be affirming, it is no substitute for an official diagnosis. Whether found in a self-help book, on a website, or discovered for the first time in a medical consultation, the FMS diagnosis comes as an intense relief. Being diagnosed can be transformative (Barker 2005, 2008; Moretti 2013, 2019).

Research clearly demonstrates how the FMS diagnosis brings meaning and coherence to a long stretch of doubt and confusion (Sim and Madden 2008; Undeland and Malterud 2007; Mengshoel et al. 2018). Their illness has a name, and it is real. At last, there is some tempering of the self-doubt that characterizes the protracted search for an answer. The phenomenological consequences of the diagnosis are profound. The idea of FMS comes

to shape the experience of self and sickness. This is especially salient in that the women's illnesses and self-hoods have been suspect. The diagnosis confirms women's sense of reality and brings order and meaning to otherwise chaotic and pointless suffering. An intellectual construct developed by rheumatologists—the idea of FMS—reifies and is reified by experience itself (Barker 2005; Moretti 2013).

The moment of diagnostic relief, however, is short lived. After the long diagnostic journey, women patients quickly learn that, as a set of resources, FMS is limited. It remains a medically invisible and thus contested illness. Consequently, medical marginalization and disparagement are core features of the FMS illness experience. A recent meta-analysis found that medical systems are fundamentally unable to support or treat FMS patients (Mengshoel et al. 2018). Patient's accusations of medical invalidation are seen across many different nation-state contexts. This is unsurprising, given that "physicians have grave concerns about the nature and legitimacy of the disorder" (Wolfe and Rasker 2021, p. 12) and consider FMS patients to be difficult, time consuming, and frustrating (Goutte and Cathébras 2021). Some patients do find "fibro-friendly" providers, but most do not. Instead, they describe ongoing medical encounters infused with doubt about whether FMS is a *real* disease and provider innuendos that their problems are psychological (Galvez-Sánchez and Reyes del Paso 2020). Even greater burdens of medical skepticism and invalidation are described by women of color and women who are economically marginalized (Pryma 2017a; Schaefer 2005).

What is more, the diagnosis does not translate into effective therapeutic options. The clinical management of FMS includes nonspecific therapeutics targeting nonspecific symptoms (e.g., sleep medications/sleep problems, pain medications/pain symptoms, etc.) that are, at best, marginally effective (Bhargava and Hurley 2024). When, as is almost inevitable, antidepressants and mental health counseling are recommended once again, patients once again feel invalidated (Barker 2005, 2008; Moretti 2013, 2019). And, when they fail to make significant improvements in response to therapeutic interventions, a new round of accusations from providers and individuals in their inner circle arises: their symptoms are not *real*, or they are not trying hard enough to get better in order to reap secondary gains (Wolfe and Rasker 2021). The spirit of this medical grip is captured in the title of the well-known medical publication, "If You Have to Prove You Are Ill, You Can't Get Well" (Hadler 1996). FMS is seen as an illness, not a disease, and patients suffer without remedy.

The contested status of FMS makes peer-to-peer affiliations with digital illness communities and resources an especially important feature of the FMS illness experience (Barker 2005, 2008; Cipolletta et al. 2020). As with illness affiliation for any chronic illness, participants give and receive practical tips for managing symptoms, navigating treatment options, overcoming losses, and negotiating social relationships (Kingod et al. 2017). In the case of FMS illness affiliation, participants also come together to address the previously described disparagements. For example, participants share details about how to find fibro-friendly providers and effective workarounds for managing providers who are fibro-deniers. FMS illness affiliation also operates to substantiate the very existence and legitimacy of FMS. The striking similarities in their shared experience—the devastating impacts of their illness and medical disparagement—offer compelling evidence of the disorder's authenticity. They are not alone, and their illness is real. Drawing on their shared embodied expertise, participants confirm the medical character of their problem and its remedy, and they empower each other to search for physicians who will recognize and treat their condition accordingly (Barker 2008).

It can be said that women's FMS illness experiences are remarkably similar and yet hardly alike. By and large, the clinical differences in terms of symptoms, illness onset, and illness trajectory are overshadowed by the phenomenological similarities. From a biomedical perspective, the absence of a coherent natural history raises questions about the diagnostic legitimacy of FMS. But, as illnesses experiences, the category of FMS is forcefully confirmed.

2.3. Long COVID as Diagnosis

As many as 17 million Europeans and 16 million Americans report some type of post-COVID-19 related health problem (USA Facts 2023; World Health Organization 2022). As we would expect given medicine's classificatory inclinations, the larger category of all possible health problems caused by SARS-CoV-2 continues to be sorted into subsets. Within these sorting processes, the category Long COVID (LC) emerged. We describe a few key moments and consequences of this sorting, including some of the gendered consequences.

The world watched in almost disbelief as millions of individuals died during the early phases of the COVID pandemic. With some tempered relief, the world also watched as some of the sickest people managed to survive after weeks or months of hospitalization. The earliest published research related to surviving COVID patients recounted severe organ damage caused by the infection and also from prolonged medical interventions characteristic of intensive care (Jin et al. 2020). In medically clear and understandable ways, these patients were ill and would require extensive ongoing medical care.

But another much larger category of patients began flooding clinics in need of care. The illnesses presented by these patients were far less medically clear or understandable. In large numbers, both in clinics and on social media, individuals described debilitating fatigue, shortness of breath, headaches, chronic pain, disrupted sleep, and mood and cognitive issues, as well as other distressing symptoms that persisted or emerged long after the typical acute phase of infection (Soriano et al. 2021; Hereth et al. 2022; Kerzhner et al. 2024). Patient advocates began calling their condition the long tail of COVID, Long Haul COVID, and, now the most common term, LC (Callard and Perego 2021). Medical providers could find "nothing wrong" with them, but in digital spaces, patients collectively validated the veracity of their condition. In turn, patient activists, some of whom were medical researchers and providers, effectively used traditional and social media to raise awareness of LC and demand medical recognition of their illness (Roth and Gadebusch-Bondio 2022).

Facing the demands of these activists and a "tsunami" (Lledó et al. 2022) of patients searching for answers, clinician researchers in different countries began to quickly, and almost simultaneously, attempt to define post-COVID illnesses. Indeed, they could only hope to study and treat LC patients by first defining LC. As listed below, expert panels were quick to propose a number of different definitions and diagnostic labels for what patients called LC:

- Post-COVID-19 Condition, The World Health Organization: Post-COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. (Source: https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition Accessed on 1 August 2024)
- Post-COVID-19 Syndrome, The United Kingdom National Institute for Health and Care Excellence (NICE): Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. (Source: https://www.nice.org.uk/guidance/ng188/chapter/1-Identification#case-definition Accessed on 1 August 2024)
- Post-COVID Conditions, The United States Centers for Disease Control: An infection-associated chronic condition that can occur after SARS-CoV-2 infection, the virus that causes COVID-19, and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ system. (Source: https://www.cdc.gov/covid/long-term-effects/?CDC_AAref_Val = https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/ Accessed on 1 August 2024)
- Post-Acute Sequelae of SARS-CoV-2 Infections, United States National Institutes of Health: Long-term effects of COVID may be different for everyone and they can affect many different parts of the body, such as the brain, heart, and lungs. And people who have PASC, including Long COVID, can have different kinds of effects. These effects

may come and go, and they may last for a few weeks, a few months, or longer. (Source: https://recovercovid.org/long-covid Accessed on 1 August 2024)

These definitions differ in significant ways. The WHO's Post-COVID-19 Conditions and the NICE Post-COVID-19 Syndrome are very similar and are specifically limited to cases of illness that are not otherwise explained. The CDC and NIH definitions are umbrella terms that capture all COVID-related illnesses but also recognize a syndrome subset of not otherwise explained patients[9]. Because none of these definitions have gained universal acceptance, they co-exist with disparate assumptions. In short, there is no agreement on how to define or even what to call the range of illnesses in the wake of COVID-19 illness (The Lancet 2021).

But from the outset, clinician researchers were aware of the gulf between patients with medically visible versus medically invisible post-COVID illnesses. In the media and public imagination, and among patient activists, these distinctions are largely blurred. But this cleavage was noted in the medical literature early in the pandemic (Sivan and Taylor 2020). It is along this divide that post-COVID illnesses have fragmented. Specifically, sequelae for which there is an established explanation have split off from what is understood as LC (Barker et al. 2022). For example, renal or heart diseases in the wake of COVID-19 are not conceptualized as LC. They are diagnosed on their own terms[10]. Through this predictable process, LC has become a category of the medically unknown. It has morphed into a diagnosis of exclusion. This is specifically captured in the NICE and WHO definitions of Post COVID 19 Syndrome and Post COVID Condition, respectively, as "not explained by an alternative diagnosis." With explained post-COVID illness relocating to other nomenclature, these *syndrome* classifications are becoming the clinically dominant framing of LC (Barker et al. 2022; Srikanth et al. 2023).

A particularly challenging conceptual matter facing clinician researchers early in the process of defining the LC syndrome category involved their patients' dramatic clinical heterogeneity. There are a vast number of possible, largely nonspecific symptoms said to be associated with LC. The title of a review article, "More Than 100 Persistent Symptoms of SARS-CoV-2 (Long COVID)" (Hayes et al. 2021), is telling. According to the WHO, "over 200 different symptoms have been reported" (World Health Organization 2021). There is also heterogeneity in illness course. Some patients clinically report acute COVID symptoms that never go away, others report symptoms coming and going, and others still report entirely new symptoms appearing weeks or even months post-infection. It is understood that there is no typical LC patient (Oronsky et al. 2023). In other words, LC is a diagnostic entity lacking a biomarker or unified clinical expression (Barker et al. 2022).

What is assumed to bind otherwise clinically heterogeneous cases together is their causal link to a COVID-19 infection. Even as the public generally assumes that the relationship between COVID-19 and LC is well established, this is not the case. In the midst of a global pandemic, clinician researchers conceptually linked COVID and LC on the assumption that the former is at least a possible cause of the latter. But LC is not characterized by an active virus or antibodies across patients, and, indeed, many patients never had a formal positive COVID-19 test. Patients lacked access to testing early in the pandemic, and testing is now customarily done informally at home. The working definitions of LC thus allow for presumed and/or retrospectively determined COVID infections.

The result is a diagnosis with high sensitivity but low specificity (Alwan and Johnson 2021). It is easy to rule a case in as LC, and it is difficult to rule a case out as not Long COVID. For example, a person who never had symptomatic acute COVID-19 illness (and therefore no COVID test) but who reports some of the 100 or 200 highly commonplace symptoms associated with LC three, or eight, or fifteen months after a time when there were high infection rates in their community can retrospectively be diagnosed with possible or probable COVID-19 and thus LC. There are sound reasons for allowing flexibility regarding COVID infection status, but it creates amorphous diagnostic boundaries picking up more and more cases of potentially different sorts of things which may or may not have a causal relationship to COVID-19 (Barker et al. 2022).

When early cases of unexplainable post-COVID symptoms were first reported, many researchers suggested classifying them within pre-existing diagnostic categories. Clinically speaking, LC neatly maps onto Post-Infectious Syndromes (PIS) (Yong 2021). CFS/ME is also a near perfect clinical match with a large subset of LC patients (Wong and Weitzer 2021), and the overlaps with FMS are likewise prominent (Clauw and Calabrese 2024; Goldenberg 2024). Lumping LC patients into one or more of these categories was and remains a classificatory option. But these other conditions remain poorly understood and have long-standing medical marginalization. In the context of the COVID pandemic, urgent clinical demands, and fast-tracked funding opportunities, clinician researchers focused on a novel post-viral illness. There were no clear benefits of looking diagnostically sideways or backwards (Barker et al. 2022).

On one hand, LC patients may benefit from medical and public support not extended to other contested illness patients based on the presumption that their symptoms are attributable to COVID-19 in ways that are not yet understood (Barker et al. 2022). On the other hand, without a biomarker or even a positive test requirement, the LC diagnosis cannot easily garner ontological backing from COVID-19. LC currently resides between an emerging diagnostic entity and a contested illness characterized by MUS considered to be in full or in part psychogenic, and medicine repeatedly points to the mind when it cannot find evidence for disease in the body (Nettleton 2006; Jutel 2011; Pick 2023). But suggestions that LC symptoms are not caused by COVID-19, or that they parallel those of other conditions of unknown and possible psychogenic origins, have met with indignant charges of medical invalidation, newly branded *medical gaslighting* (Au et al. 2022).

Unlike in the case of FMS, where the early research included almost all women, early research related to post-COVID illnesses was less overtly feminized. During the first wave of the pandemic, men were overrepresented among those with severe COVID complications requiring hospitalization (Giacomelli et al. 2021; Fernández-de-las-Peñas et al. 2022). Early research on discharged COVID patients with ongoing health problems skewed male (Jin et al. 2020). As post-COVID illnesses that are medically explainable defect to other diagnostic homes and LC morphs into a diagnosis of exclusion, its feminization comes into focus. LC impacts women at significantly higher rates than men (Nabavi 2020; Phillips and Williams 2021; Ortona and Malorni 2022; Pelà et al. 2022). We anticipate that LC's feminization will become even more pronounced over time. This will happen as those individuals whose symptomology extends for many months post-infection eventually recover, leaving the category occupied by what becomes a long-term chronic illness. What is more, the long-standing mismatch between medical ways of knowing and the commonplace symptoms of women patients are written into the LC diagnosis. As biomedicine moved to create a standardized diagnosis out of a collection of nonspecific symptoms that effectively capture women's commonly reported distress, the diagnosis has transformed into a category that has and will likely continue to disproportionately be applied to women patients, again underrepresenting some women compared to others (Norredam et al. 2022; Khullar et al. 2023).

Like FMS, the diagnostic category of LC is a messy concept that makes a muddle of any research attempting to unveil etiological answers and treatment protocols (Fernández-de-las-Peñas et al. 2021). And, like FMS, it is disproportionately women patients who are left sorting out this mess as part and parcel of their illness experience.

2.4. Long COVID as Illness Experience

Research conducted in different national contexts reveals how the contested status of the LC diagnosis impacts the LC illness experience (Moretti et al. 2022; Wurz et al. 2022; Brehon et al. 2023; Fang et al. 2024). The particular cluster of symptoms experienced and the manner in which they arise in relationship to COVID-19 illness vary considerably across individuals. But from these distinctions a strong likeness is forged. What is shared are the hardships and losses of living with a number of debilitating, unpredictable, and fluctuating symptoms brought on in some fashion or another by a SARS-CoV-2 infection, in

tandem with and exacerbated by medical uncertainty and ineffectualness (Ladds et al. 2020; Spence et al. 2023). The literature points to common features that characterize the LC illness experience: life and self-alterations due to symptomology, the management of medical uncertainty, and the influence of online patient communities on the collective affirmation of LC in the face of medical invalidation.

Patients suffering from LC recall how, not all that long ago, they were in remarkably good health. Then, everything about their lives changed on a dime: they caught COVID (Moretti et al. 2022). In some cases, they experienced a mild or moderate flu-like illness, and in other cases, the suspected COVID was asymptomatic. Following a normal acute phase and a negative COVID test, a number of debilitating symptoms either persisted or arose entirely anew. They describe different combinations of fatigue, pain, headaches, alterations in sleep, tachycardia, shortness of breath, confusion, memory loss, depression, and concentration problems that come together as an overwhelming force (Hayes et al. 2021; Lopez-Leon et al. 2021). When their crushing symptoms persist, they seek medical help. But every bit as troubling as their symptoms is the fact that their medical providers can find "nothing wrong" (Au et al. 2022; Ireson et al. 2022; Owen et al. 2024). In a continued search for answers, patients consult more and more doctors, undergoing more and more examinations. Test after test reveals nothing. These medical encounters are troubling, but they do not take place in a vacuum. Through patient activists' successful "mobilization of subjective evidence" (Roth and Gadebusch-Bondio 2022), the idea of LC circulated widely and well in advance of the first published medical research addressing the condition. Traditional and social media were especially influential. Given the ubiquity of LC as a public narrative, most patients encounter information about LC prior to their official diagnosis. Many find these public narratives to map onto their illness experience (Miyake and Martin 2021; Rushforth et al. 2021; Moretti et al. 2022), but patients need to have their diagnosis confirmed by medical authorities. For most, this was an arduous path (Ladds et al. 2020; Brehon et al. 2023).

Living with a poorly understood condition adds complexity to the illness experience (Jackes et al. 2022). Like other contested illnesses, LC can become a diagnosis you have "to fight to get" (Dumit 2006). As detailed in the previous section, there is no objective indictor of the disorder and no agreed upon diagnostic criteria. Additionally, there is no subfield of medicine that specializes in or oversees LC patients. Even after being formally diagnosed, patients are required to push through endless medical confusion. They report feeling stigmatized by ongoing medical skepticism (Au et al. 2022; Moretti et al. 2022). They feel frustrated, angry, and frightened as they come to realize that providers, by and large, are unable to understand or effectively treat their condition (Kingstone et al. 2020).

Meanwhile, patients' worlds and self-hoods continue to fall apart. They watch their vitality, independence, and autonomy quickly fade from view. They encounter doubt and disbelief not only in medical encounters but also in their encounters with family, friends, and employers (Aghaei et al. 2022; Moretti et al. 2022; Nittas et al. 2022). Support can be hard to come by. They also face the very real threats of losing their relationships, employment, and even their ability to care for themselves. They repeatedly express feeling isolated and abandoned (Wurz et al. 2022; Skilbeck et al. 2023). Although most of the research captures the LC illness experiences of white women, a small handful of studies illustrates that these invalidating burdens, as is the case with the FMS experience, are further amplified for racial and ethnic minority women (Smyth et al. 2022; Bergmans et al. 2024; Cañas et al. 2024).

The role of online patient communities in the unfolding of LC has been much discussed (Callard and Perego 2021; Rushforth et al. 2021; Au et al. 2022). At the start of the pandemic, online patient forums were crucial public spaces for articulating the potential for COVID-19 illnesses to drag on and on. From the outset, patient activists used digital illness forums to define their own conditions. But, as patient experiences continued to meet with medical disbelief, online patient forums further functioned to validate the reality of their shared illness (Callard and Perego 2021; Au et al. 2022; Russell et al. 2022; Hossain et al. 2023).

Sometimes described as an "epiphany" (Ladds et al. 2020), the discovery of online groups helps sufferers cope with ongoing uncertainty. Patients join peer support groups to seek advice on managing symptoms, to identify potential treatments or recovery practices, to find sympathetic specialists or clinics, and to exchange tips for asking family and friends for support. Illness communities provide important self-validation in the context of dismissive health care interactions (Russell et al. 2022; Hossain et al. 2023). The rhetoric of *medical gaslighting* (i.e., medicine's denial of patient's lived realties) circulates widely in and through LC patient communities (Au et al. 2022). Charges of gaslighting challenge medicine's attempt to invalidate patients' experiences and provides "[a] sense-making and identify-forming mechanisms for long-haulers" (Au et al. 2022, p. 9). However, even as the particular features of the LC illness experience have and will continue to change over time, given the messiness of its original diagnostic boundaries, it is unlikely to find its way into medicine's good graces, however forceful the demands of patient activists.

3. Feminization-Medicalization and Suffering without Remedy

FMS and LC are diagnostic categories created at different times, at different paces, by different players, and in different contexts. Nevertheless, they share many similarities. They are both concepts created by the coming together of ill patients and clinician researchers trying to translate their illnesses into biomedical terms. They are characterized by varied combinations of very troubling but commonplace (i.e., nonspecific) symptoms that are especially prevalent among women. The very symptoms that constitute these disorders capture the general observation that, as socially constituted categories themselves, *women* report more pain, fatigue, and disability than *men*. In both FMS and LC, the symptoms remain otherwise medically unexplained. Moreover, neither condition is aligned with effective medical therapeutics. There is ongoing disagreement about how to define these conditions, and there are more questions than answers about their etiologies and pathophysiologies. For all these reasons, FMS and LC are contested illnesses.

As illness experiences, FMS and LC are likewise similar in significant ways. Sufferers, who are disproportionately women, describe lives turned upside down by the collective breadth and intensity of symptoms and a resulting cascade of losses. On top of these often crushing burdens lays the weight of medical disparagement. As experiences, FMS and LC are marked by epistemic injustices (Fricker 2007; Carel and Kidd 2014): sufferers' credibility is repeatedly challenged. The status of FMS and LC as *real* conditions is questioned by many health care professionals, making it difficult for patients to be diagnosed and receive much-needed care. What care is provided falls far short of remedy. And yet, despite widespread medical derision, millions of patients are diagnosed with these conditions. They must cope with their suffering without the cultural support and legitimacy that a diagnosis ordinarily bestows.

Of critical importance, the lived experiences of FMS and LC defy medicine's invalidation. Sufferers thus toggle between confusion and fury at implicit or explicit assessments that their distress is psychosomatic. The ability to counter medicine's disparagement is bolstered through illness affiliation, including connections to digital/online patient communities. Whereas some literature raises questions about the negative consequences of illness affiliation in terms of circulating misinformation, our focus lies elsewhere. Specifically, we draw attention to the social dynamics of illness affiliation through which contested diagnostic categories are reified as distinct disease entities, collective illness identities are forged, and patient demands coalesce around calls for medicine to validate the *real* (i.e., objective biological) nature of their suffering. Even as biomedical science is unable to make FMS or LC visible, from the social fabric of illness forums emerges a powerful sense of shared experience. In the context of medical uncertainty, illness communities simultaneously and paradoxically challenge physicians' expertise and encourage the expansion of medicine's jurisdictional authority.

The similarities between FMS and LC require a gendered analysis. Via different paths, FMS and LC are feminized disorders. FMS was created out of the unexplained

somatic distress of a pool of almost exclusively women patients from the onset (Barker 2005). LC has morphed into a feminized disorder as it has crystallized into a subset of Post-COVID illnesses that are not otherwise explained. Clinician researchers eked out diagnostic definitions and criteria that capture a broad range of MUS commonly reported by women patients. But they are messy categories. Because these are each immense conceptual categories under which many different forms of distress can be housed, the suffering to which each diagnosis is applied comprises many different things. There are several important consequences of this. First, medical research is stymied. Efforts to advance the understanding and treatment of these conditions, which are concepts applied to heterogeneous cases, are muddled, foiled, and disappointing (Galvez-Sánchez and Reyes del Paso 2020; Bhargava and Hurley 2024).

Second, because the boundaries of FMS and LC are generous, they are also porous. When LC appeared, a wave of published research reflected on the many ways that LC overlaps with other contested illnesses, including FMS. Take, for example, a recent journal article entitled "Long COVID: A New Word for Naming Fibromyalgia?" (Mariette 2024). There are many claims regarding diagnostic overlaps, causal links, and redundancies (Ursini et al. 2021; Gavrilova et al. 2022; Haider et al. 2023; Savin et al. 2023), as well as those eschewing both distinct categories, favoring instead their recognition as *functional somatic disorders* (Pick 2023). These various claims offer different interpretations of a similar observation: many patients with FMS meet the LC diagnostic definition/criteria, and vice versa (Clauw and Calabrese 2024). The ease with which these boundaries meld reveals the precarious diagnostic cover either one of them provides patients.

A third consequence of the generous boundaries of FMS and LC relates to the nexus of feminization and medicalization. As we have demonstrated, the very parameters of these categories are constituted using highly feminized MUS. FMS and LC are thus not only immense conceptual categories; they are immense conceptual categories through which a wide range of women's distress can be readily medicalized (i.e., defined in medical terms). But, for the reasons discussed above, these are contested medicalizations. As such, some of the potential resources that can be marshalled by way of medicalization are difficult to secure in general and for racially and economically marginalized women in particular (Pryma 2017a; Devoto 2023).

There are reasons for a critical analysis of the medicalization of women's suffering under the labels of FMS, LC, and other feminized contested illnesses. Medicalization runs the risk of turning the consequences of various inequalities into individual problems residing in individual bodies and requiring techno-medical interventions. When it comes to the problems of medicalization, an upstream versus downstream emphasis is a useful metaphor (Lantz 2019). Medicalization begets health care, but contemporary health care is a downstream affair: it emphasizes rescuing already sick individuals in the downstream waters. Meanwhile, medicalization often diverts our attention from "the upstream forces that are pushing groups of people and their communities into the rivers of health inequality in the first place" (Lantz 2019, p. 39).

What do we gain from an upstream focus? Among other things, it reorients our thinking about MUS. Without denying the biological basis of FMS and LC, we maintain that the complex character of much of women's suffering emerges from their everyday lives. The realities of women's social worlds and lives are "embodied" (Csordas 1990; Turner 1996), and those realities reside within different intersecting social positions (Pryma 2017a). Women's suffering is *real*, albeit its materiality is not exclusively biological. These claims overlap with insights from the vast research into the social determinants or social inequities of health; namely, that well-being is not randomly distributed, but rather falls along the intersection axes of power and inequality. Gender, of course, is a key social determinant of health inequalities (Short and Zacher 2022). When considering gendered health inequalities, it is necessary to consider how sex and gender are themselves fluid, and they are also constituted by other intersecting systems of inequality (Butler 1988; Hankivsky 2012). With these complexities in mind, there is a wealth of evidence demonstrating "the

negative health consequences of gendered material and cultural oppressions" (Syed 2021, p. 1) and/or the "systematic gender inequality in power and resources" (Homan 2019, p. 486).

The following is a short and by no means exhaustive list of gendered matters that have been found to make women sick: poverty, workplace discrimination, sex-segregated labor markets and low-pay/low-status work, workplace policies, welfare-state policies, inadequate daycare, unequal distribution of paid domestic and care work, unequal marital/partner relationships, reproductive injustice, social exclusions, sexual harassment, gender norms and performativity, and gendered violence (Doyal 1995; Homan 2019; Syed 2021; McLoughlin et al. 2023). The impacts of these experiences are often more deleterious as they intersect with "race, class, ability or disability, age, and other social identities" (Syed 2021, p. 5, see also Hankivsky 2012). The two-sided problem with medicalization is that the subordination of women and its resulting impacts on health remain beyond the reach of medicine to identify, explain, or remedy, and the very upstream factors that make women sick in the first place remain unaddressed.

Our critique of medicalization is likely to be heard by FMS and LC patients and advocates as yet another account dismissing women's suffering. For this reason, we want to address our sympathies with and distinctions from other emerging arguments emphasizing women's oppression vis-à-vis contested illness diagnoses. Some researchers, activists, and commenters have expressed the hope that the highly visible, contested illness of LC will be galvanizing; specifically, the prominence of LC and the resources devoted to its study and treatment might finally lead to discoveries regarding the yet unknown objective bases underlying the subjective suffering of LC and other contested illnesses and also transcend the long-standing debates concerning the psychosomatic character of these illnesses (Davidson and Menkes 2021; Newman 2021; Camero 2022). In the process, women's voices should finally be heard, their suffering finally acknowledged and treated, and medicine should finally end its long history of clinically dismissing women's suffering (i.e., gaslighting) (Sebring 2021; McLoughlin et al. 2023). These are truly important concerns. We consider health care to be a human right and the need to address all patients suffering in the here and now a political imperative. Efforts to overcome gender and other clinical biases are also essential. Providing respectful and non-dismissive care should be the norm for all patients. Medical humility is undoubtedly a potent and underdeveloped tool, both within clinical encounters and within medicine as an enterprise.

However, we question ardent demands that medicine finally discover the *real* basis of women's distress as a principal goal. Our concern is not that we think women's suffering has no biological basis, nor are we suggesting that FMS and LC are imaginary or that FMS and LC should be folded into psychiatric nosology. However, it is also clear that demands to take women's suffering seriously, by which some patient advocates emphasize affirming its *real biomedical* basis, are problematic. For one thing, as our analysis has shown, the real suffering of FMS and LC is highly heterogeneous. Neither of these categories are discrete things. There is no unifying biomedical reality to be found. Some FMS and LC cases will likely come to be explained in orthodox biomedical terms, but many will not. Secondly, the feminized MUS housed within these categories have been cobbled together into disparaged medical diagnoses for well over 100 years, at least in part because women's suffering cannot be adequately translated into the world of biomedicine. We maintain that the origins of a great deal of women's suffering, indeed all human suffering, reside outside of biomedicine's ways of knowing.

Finally, demands to medically validate the *real* suffering of FMS and LC fail to incorporate a crucial feminist critique of medicine. The *real* body in biomedicine is a gendered cultural artifact (Martin 1987). Medicine has repeatedly provided accounts of women's suffering that rely on (mis)representations of gender. Feminist and other critical scholars remind us that medicine defines women's bodies and minds in ways that reflect and reproduce inequalities under the guise of objective, natural differences. Curiously, FMS and LC patient advocates have also identified medicine's myopic commitment to objectivism as deeply problematic. There is thus a jarring paradox in the hyper-biologizing demands of

contested-illness patients and advocates (Au et al. 2022). Pinning our hopes on discovering discrete bio-entities misses opportunities to address the inevitable mismatch between the tools of biomedicine and the complex character underlying the suffering of socially situated women. Importantly, demands prioritizing the discovery of the *nature* of contested illnesses are themselves evidence of our residency within medicalized societies.

Here is the dilemma. Historically and contemporarily, women's experiences have been misidentified, mistreated, demeaned, and/or ignored by medicine. These transgressions have been more pronounced for some women than others. These damning charges warrant ongoing critiques and committed reforms. Medicine possesses tremendous cultural authority, and, as such, FMS and LC patients turn to medicine to help them make sense of and mitigate their suffering. Biomedicine is rightly being asked to problematize its gaze by honoring suffering that it cannot fully explain. And yet, as seen with LC and FMS, medicine is being asked to do that which it cannot do effectively. Although part of the solution, a medical response cannot address the upstream factors underlying women's medically difficult-to-explain suffering in the first place. How to thread this needle will be an ongoing feminist scholarly and political project, not just a biomedical one.

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Notes

1 We appreciate the critiques of the term MUS, namely that it can reify the mind/body dualism, privilege medical knowledge over lay knowledge, and give way to dismissal of the patient's lived experience. In fact, it is precisely for these reasons that we foreground "MUS" in our analysis. We do not use the term uncritically, as indicated by our use of quotation marks.

2 In practice—both in medicine and popular discourse—the term "Long Covid (LC)" is used inconsistently. We are likewise guilty. To avoid a tedious level of detail and qualifying statements, we use the term "LC" in two distinct ways. First, to capture all the different labels medicine has proposed to describe the range of health problems with possible links to a SARs-CoV2 infection. Because there are many different labels in play, we adopt "LC" for the sake of readability. We also use "LC" to describe the narrower subcategory of these conditions that includes an array of nonspecific symptoms in the wake of a COVID-19 infection that remain otherwise medically unexplained (Pfaff et al. 2022). We have tried to write around this inconsistency in ways that help the reader know which of these meanings we imply in a given context.

3 As a concept and process, medicalization is complex: There are different degrees and dimensions of medicalization and demedicalization; there are multiple and competing forces (inside and outside the institution of medicine) contributing to and resisting medicalization; some people (and places) experience more medicalization than others (Bell and Figert 2012); and these forces have changed and continue to change over time (Clarke et al. 2003; Conrad 2005). Even in the face of some emerging pockets of resistance and countervailing forces (Light 2001; Conrad 2005), the drive toward medicalization or biomedicalization is a marked feature of life in the global north.

4 Parenthetically, medicine's mind/body dualism is a cultural artifact that our analysis rejects.

5 The role of central sensitization or nociplastic pain in FMS "remains to be elucidated" (Wolfe and Rasker 2021, p. 15).

6 The 2010 revisions eliminated tender point exams and formally recognized FMS as a multi-symptom rather than only a pain disorder.

7 Tender points are far more common in women than men, and, despite removing them from official diagnostic criteria in 2010, they are routinely used for diagnostic purposes by rank-and-file clinicians.

8 Wolfe traces the "idea of fibromyalgia" and notes that "[t]he future of fibromyalgia as a discrete disorder remains uncertain as features of fibromyalgia are increasingly observed in patients with multiple different medical conditions" (Wolfe and Rasker 2021, p. 1).

[9] "Long COVID can sometimes be attributed to organ damage and well-characterized pathophysiology, but more often there is no evidence of organ damage or abnormal biomarkers. This is most evident in patients with mild to moderate initial SARS-CoV-2 infection who were not hospitalized" (Goldenberg 2024).

[10] Without getting into the weeds, these conditions might also, for research purposes, be considered examples of PASC as defined by the NIH. The NIH category of PASC does include what is now understood as LC, as well as post-intensive care illnesses and end-organ diseases. This category is the messiest of those put forth. It is not widely used clinically to diagnose what has emerged as the phenomenon of LC. We imagine a time in the near future when PASC will fall out of favor and/or morph into something in line with the NICE and WHO definitions. Eventually, a single definition and set of criteria will be proposed. But, as the case of FMS suggests, this can be an ongoing process stretching out decades.

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