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Emily Lim Rogers
Department of American Studies and Program in STS and the Cogut Institute for the Humanities, Brown University (E-mail: emily_rogers@brown.edu)

Recursive Debility: Symptoms, Patient Activism, and the Incomplete Medicalization of ME/CFS

This article examines the contestation of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Lacking consistent diagnostic definitions, agreed-on biological indicators, or approved treatments, ME/CFS is an incompletely medicalized condition. It is defined by intractable and debilitating exhaustion after any form of exertion. Through an ethnographic exploration of an American ME/CFS patient activist group, I develop the concept of "recursive debility." Symptoms form the very basis for disease activist groupings in the absence of biomarkers, but they also present a significant barrier to traditional forms of activism. Ironically, then, debilitation blocks the means through which debilitation might end. Patients contest systems of knowledge but always in bodies that experience exhaustion without end. This article presents a disability studies intervention in suggesting that the recursivity of debility demonstrates the profound interdependence of the bodily aspects of impairment and the sociopolitical aspects of disability. [ME/CFS, chronic illness, medicalization, symptoms, debility]

On a blustery autumn morning in New York City, people braved the cold in sweaters and windbreakers to gather before the New York State Psychiatric Institute. Walking down the steep street that unfolds into a dramatic view of the Hudson River, I saw about 15 people walking with placards in a picket line under the watch of a few police officers. On further inspection, though, this was no ordinary protest. Holding signs that proclaimed that their condition was "NOT psychosomatic," a few protesters were lying down in the grass or sitting in folding chairs; others looked away as the circling picketers began to make them dizzy; and some donned earplugs to reduce sensory overstimulation. As they chanted "Science not stigma!" a hired film crew—who nearly outnumbered the modest group of protesters—was transmitting this scene to thousands of viewers who were streaming the action live from beds and couches across the globe.

The people protesting were part of a patient activist group I studied between 2016 and 2020. The peculiar shape of this protest, complete with its bedbound viewership, typifies the activism surrounding the disease for which they were advocating: chronic fatigue syndrome (CFS) also known as myalgic encephalomyelitis (ME) or ME/CFS. It is a disease whose nearly four-decade history as a diagnostic entity has

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nevertheless yielded no agreed on biomarkers (markers that objectively confirm its biological presence), leading some, like the psychiatrist the activists were protesting, to conclude the condition is psychogenic. But empirically speaking, ME/CFS is profoundly debilitating, rendering around one-quarter of its sufferers home- or bedbound (IOM 2015). Patient activists with ME/CFS face a dual-pronged challenge: They not only confront the stigma caused by its lack of biological verification and societal acceptance, they do so in bodies that are exhausted. After the protest—which required physical activity most would consider minimal—many would be "crashed" in their beds for weeks, as fatigue after any form of exertion is characteristic of the impairment caused by ME/CFS.

This article examines how, although symptoms organize the biosocial world of ME/CFS patient activists, impairment ironically also becomes a barrier to the very biomedical recognition they seek. Impairment structures the forms of activism that can occur in the context of seriously limited energy. This limits advocacy efforts, which recursively sustains the incomplete medicalization of ME/CFS. ME/CFS's governmental funding per disease burden is the lowest of any entity in the United States (Dimmock et al. 2016). It is incompletely medicalized insofar as it lacks approved treatments; remains without scientific consensus on etiology, case definition, or pathophysiology; and is absent from most medical textbooks in the United States. This undermedicalization is striking, given its nearly four decades of existence as a recognized diagnostic category in the United States (CDC 1986), the high socioeconomic status of its diagnosed patients and patient activists, and its estimated prevalence of up to 2 million Americans—more than multiple sclerosis and AIDS combined (Institute of Medicine 2015). While many cases emerge post-infectiously, the exact cause appears heterogeneous, and a precise mechanism is elusive. Moreover, the hallmark symptom is "post-exertional malaise"— most typically, fatigue after any form of energy expenditure, a subjective symptom frequently met with accusations of psychosomatism or malingering. Patient activists are trying to change this. They participate in protests, attend scientific conferences, and lobby state and federal agencies. Yet activist movements also involve *movement*. They take social and cultural resources such as the socioeconomic and educational backgrounds needed to become an "expert patient," but they also take physical ones. In other words, as one activist told me, activism involves *action*, and people with ME/CFS "can't really do that." This points to the problem of what happens when debilitation blocks the means through which debilitation might end.

Disability studies has historically distinguished between impairment, or the bodily obstacles a disabled person experiences, and disability, or the social and political aspects of disability (Clare 1999). These distinctions—laying parallel to medical anthropology's differentiation of disease and illness (Eisenberg 1977; Kleinman 1988)—have been key conceptual terms empirically explored in the anthropology of disability (Ginsburg and Rapp 2013; Hartblay 2020; Ingstad and Whyte 2007). These works have built on disability studies' "social model of disability," which holds that it is the surrounding environment, and not something inherently wrong with disabled people, that creates disability. The social model has been presented in contrast to the medical model, which focuses on impairment and emerges from the province of medical authority. In a paradigmatic text, disability studies scholar and activist Eli Clare acknowledges that disabled people might need particular medical

treatments but asserts that this fact "differs from labeling a person with multiple sclerosis as sick, or thinking of quadriplegia as a disease" (Clare 1999: 105–6).

Chronic illness has sat alongside, but typically struggled to be fully integrated within, disability studies' frameworks for understanding bodily disablement: What about bodies that *are* sick (Wendell 2001), or of ME/CFS activists who *want* to be recognized as having a disease? Because the social model of disability maintains that it is ableism—not bodies—that needs intervention, chronic illness and the activism that accompanies it may strain its political visions. Linton has written of the social model's struggle to discuss the vulnerability of bodily experience (Linton 1998: 529). Disability theorist Alison Kafer has called forth fatigue in particular, writing, "[S]ocial and structural changes will do little to make one's joints stop aching or to alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue" (Kafer 2013: 7). But others emphasize that the social and bodily life of disability are not always distinct. The term "debility" has been proposed as a means of encompassing both "impairment" and "disability per se" (Livingston 2006; Puar 2017).

In the case of ME/CFS and other contested illnesses, the struggle to gain medical legitimation of bodily experience is precisely a political one. Bodies are "divided" (Dumes 2020) insofar as the patient's experience of suffering exists even when it cannot be verified by biomedicine, leaving patients to "fight to get" their diagnoses (Dumit 2006). Scholars have frequently focused on epistemic battles between patients and experts that emerge from this division of bodies, wherein the production of scientific facts becomes a key front in the battle for legitimacy (Dumit 2006). Kroll-Smith and Floyd explore practices of knowledge-making among chronically ill communities as localized "practical epistemologies" that develop when illness exists outside of institutional moorings (Kroll-Smith and Floyd 1997). ME/CFS in particular has been considered as an instance of the social construction of illness (Ware 1992), as a biopolitical phenomenon (Karfakis 2018), as an online social world (Best and Butler 2015), or as an unfortunate example of the medicalization of everyday problems (Shorter 1993).

In this article, I highlight a second valence of "fighting" for illness. The fight between institutional authority and patients takes place at the level of knowledge production, but also at the level of a bodily experience defined by exhaustion. In the case of ME/CFS, whose hallmark symptom is post-exertional malaise, impairment shapes the kinds of activist movements that may take place, and compounds the iatrogenic effects of the privatized, bureaucratic health care system of the United States, where, as one interlocutor put it, "being a patient is a full-time job." This shapes both the struggle to achieve a diagnosis from a doctor and the socialities that form once diagnosis is achieved, where symptoms become the ties that bind, and create impairment that structures both activist worlds and participation in social life. Such a context points to the importance of symptoms and their accompanying impairment as social technologies (Biehl and Moran-Thomas 2009), which acquire special meaning when a disease lacks biomarkers and is shrouded in doubt. Attending to the fight for ME/CFS's legitimacy on different scales reveals that the fraught process of transforming symptoms into disease (Aronowitz 2001) and bodily experience into politics is not linear, but rather, recursively shaped by the nature of debility.

This article leverages the term "recursive debility" to describe the cyclic relationship between the politics of disability and the impairment of bodies. I use the term "debility" as Livingston (2006) and Puar (2017) have done, to hold the social aspects of disability and bodily phenomenon of impairment together. I also build on Manderson and Warren's (2016) concept of "recursive cascades," who use the term recursion to point out how co-morbid chronic conditions overlap to multiply increasing ill health. They borrow the term from information technology, where it describes the ways that "newly derived information works to impact on stored processes to continually change the programmatic output" (p. 491). Rather than describing a cascade, I envision the recursivity of debility as a knot that ties disability and impairment together and *sustains* the present status of ME/CFS as a contested biomedical issue that, at present, lacks political urgency. Recursive debility means that the need for political action and the reality of profound exhaustion—and by extension the social aspects of disability and the medical aspects of impairment—fall back on each other. This maintains both scientific uncertainty and its ramifications for those who live it out in exhausted bodies Recursive debility is a tightly bound knot that is difficult to untie, a cycle that is hard to break—and moreover, to do so would require energy, the precise thing that people with ME/CFS lack.

Methods

This article is based on four years of fieldwork that took place within an ME/CFS patient community in New York City and with an associated national patient organization, ME Progress (a pseudonym), from 2016 to 2020. In addition to observing patient advocacy efforts such as rallies, protests, and educational events in New York City, I also observed support groups in the San Francisco Bay Area and major ME/CFS scientific conferences across the globe. I conducted semi-structured interviews with 50 patients, primarily over videoconference or telephone, and formal and informal interviews with five researchers and clinicians. My focus on patients came with the specific aim of looking from the patients' perspective up (Nader 1972) to the relatively small community of sympathetic clinicians and invested researchers with whom they are networked, rather than looking from within the clinic downward. I chose this strategy because I sought to understand how illness is enacted both inside and outside the clinic (Brown et al. 2012; Packard et al. 2004), and to follow the object (Marcus 1995) of ME/CFS through the multiple sites and scales in which it is experienced and contested. As anthropologists working at the intersection of science studies and feminist anthropology have noted, the "problem of studying a new object" presents ethnographic challenges (Rapp 2000), in which an approach that is not simply multi-sited, but also polymorphous (Gusterson 1997), has proven illuminating (Martin 1994).

Conducting ethnography with a group that is largely homebound presented practical challenges. Some of the richness of in-person ethnography cannot be achieved when studying a community that may leave their homes only once or twice per month. I witnessed the few situations in which people with ME/CFS used their limited energy to interact in person, such as major scientific conferences, protests and rallies, and support groups. But an important part of my fieldwork strategy was virtual ethnography (Boellstorff 2012). I conducted some of my observations of

support groups and planning calls, and most of my interviews, virtually. (All the major conferences and protests I directly observed were in-person, in part because they were some of the few ways I could organically connect with new contacts, and in part because I could watch virtual conference talks asynchronously via recordings.) In this sense, fieldwork was not only polymorphous but also "quantum" (Dumes 2020), taking place simultaneously in virtual and physical space—events streamed to online sites I would later view, conference calls that took place from my home in Brooklyn and beamed me to people in Silicon Valley. As Ginsburg (2012) writes, virtual ethnography is particularly important in chronically ill and disabled communities, as technologies create "network[s] of like-minded people despite the fact that a disability [renders them] homebound" (p. 110). Virtual ethnography has reached new prominence due to the COVID-19 pandemic. Recent projects have brought to light the long history of digital world-making and remote access for disabled people (Critical Design Lab 2021). Building on this research, rather than viewing these virtually mediated social worlds as inferior proxies for embodied ones, I decided to take up this fragmented sociality as part and parcel of the object under investigation. Online interaction, though disembodied, reflected both the tenuous access to biomedicine and to one another.

This fieldwork also presented specific ethical challenges. ME/CFS is defined by post-exertional malaise that may occur through physical exertion, but also through cognitive and emotional activity. Many of my interviewees told me that after our interview, they would "crash" and be forced to rest for the rest of the day, and possibly into the next one. One interlocutor recounted to me how he found that refraining from eating was the only strategy that alleviated his symptoms. "I haven't eaten in three days," he told me, "That's the only reason I'm able to talk to you right now." Nonetheless, many of my interlocutors described it as "worth it" to participate in the project. Even though it was not clinical research, the ethnographic investigation became, in their view, part of a larger project of producing knowledge about ME/CFS that would—hopefully, eventually—lead to greater understanding of their condition. These interactions were, in retrospect, examples of recursive debility, as participation in a project that might end debilitation was itself debilitating.

Reflecting on my own status as a researcher yielded rich ethnographic findings. As a 20-something person of color, I did not fit the profile of a typical ME/CFS patient, and I was rarely assumed to be someone with ME/CFS. In nearly every interview, my interlocutors inquired about my relationship to ME/CFS. Many wanted to know my motivations in studying this understudied topic. Whether I was viewed as a totally naïve outsider, a knowledgeable ally, or someone with ME/CFS herself, changed the ways my interlocutors answered my questions. The genres ranged from informational, to shop talk, to commiseration. Usually, I was viewed as a sympathetic outsider. Midway through my fieldwork, though, I got diagnosed with a chronic illness, one adjacent to ME/CFS and frequently co-morbid with it. Several of my interlocutors were fascinated. Patients would recommend care plans for me—a tilt table test, bloodwork, homeopathy, supplements. My diagnosis eventually gave me access to field sites I otherwise would not have access to, and one interlocutor told me I was "one of [them] now." This was fortuitous for my fieldwork, but at times I felt the conversation strayed, forcing me to strike a balance between sharing mutual experiences and keeping the focus on the interviewee. These gradations of

assumptions about my position revealed the crucial role of trust in discussing a condition shrouded in doubt.

The (In)Consistency of ME/CFS

"Does the woman in the hut in Africa have ME/CFS, and she just doesn't know it?" Jennifer, a white woman from North Carolina, donning a pink cardigan and pearls, asked me over boxed lunches at a National Institutes of Health conference after I mentioned I was an anthropologist. Profoundly stratified, ME/CFS is rarely diagnosed outside the Global North. We found ourselves at one of its epicenters: the East Coast United States, here at one of the largest ME/CFS conferences in the world. We sat in uncomfortable plastic chairs, surrounded by banners expressing optimism for people with ME/CFS, all wrapped in the rhetoric of scientific progress—research oriented around hope and cure. I mulled over my response for a second, assuming her question was rhetorical, until her expectant expression made me think otherwise. I was only able to nod, acknowledging it was an important question. Her tone and cadence echoed the well-worn conundrum: If a tree falls in a forest and no one is around to hear it, does it make a sound? It also raised the question of how ME/CFS—without consistent definitions or standardized tests—might travel across space and place, and how it is that two different bodies can be said to have the same disease.

The evasiveness of ME/CFS loops back on itself in a system predicated on consistent, objective markers for disease that can, as my interlocutor may have wanted, travel across bodies and place. Lock and Nguyen (2010) note that biomedicine extracts data from bodies to make human disease "everywhere the same" (p. 11), but this apparent axiom of biomedicine was strained by my lunch companion's riddle. The ontology of disease is enacted across various clinical settings, such that the reality of a clinical entity is formed across space (Mol 2003). Mol asks how it is that, across various sites and scales, a disease manages to avoid "clashes and explosive confrontations" (p. 6) to maintain its consistency and shape. Yet, a thing called ME/CFS exists, despite being ripe with clashes and confrontations, with no agreed on biomarkers, no consistent clinical or research case definition, and no standard diagnostic tests. Indeed, over at the next table, patients debated over the defining characteristics of the disease, as if case definitions were small talk. ME/CFS patients came from all over the country to attend this event. In this conference room, disease was enacted through collective practice, but everywhere its consistency threatened to disintegrate.

Without agreed on biomarkers, ME/CFS is a slippery disease category. Without a standardized case definition, consistent studies cannot cohere around it. Because research studies do not cohere, biological proof of ME/CFS is not one discrete test, but rather a hodgepodge of clinical signs that may vary from individual to individual. It could be Epstein-Barr virus antibodies, human herpes virus six, elevated inflammatory markers, or numerous others. ME/CFS may emerge post-infectiously, but several heterogeneous infections may trigger its symptoms, from a common cold to H1N1 to SARS-CoV-2. It is only a critical mass of biological data and clinical symptoms—not to mention an uphill battle of finding the right doctor—that lead to an ME/CFS diagnosis. Because these clinical signs are various and specialists are

few and far between, the condition is surrounded in doubt. Because of this doubt, research is seriously underfunded.

The boundaries between ME/CFS and other diseases had to be continually renewed by both patient activists and sympathetic researchers and clinicians. The task of making disease bona fide through scientific research in the face of already-inconsistent ways of defining it presented a perpetual challenge among the patients, doctors, and researchers I encountered. Studies were not easily comparable, and in the gaps between case definitions, much negotiation ensued as patients discussed the latest research. One study might have used one case definition and found a correlation between ME/CFS and elevated titers for a particular virus. Another might have used a different definition and found no such correlation. Meanwhile, both studies might have suffered from underfunding, with study populations that were too small to make the generalized conclusions that evidence-based medicine demands. In a comment to a meeting of ME/CFS patients and researchers, an official from the NIH stated that they typically reject proposals to investigate ME/CFS because they get so few and the ones they get are low quality. Other researchers countered that out-of-hand rejections discouraged people from the field in the first place. Both funding and interest in conducting the research, then, are recursively linked, sustaining disinterest and uncertainty in the biological basis of ME/CFS. Researchers tended to believe that once a specific biomarker could be found, interest in the field would increase. But to find that one biomarker, they needed funding for their research.

Bartering in Biomarkers

Biomarkers matter not just for the consistency of a diagnostic entity in the abstract, but also for patients themselves, as they attempt to carve out livable lives with a condition shrouded in doubt. While it may seem esoteric, the word biomarker was familiar to nearly all of the patient activists I encountered, the fodder of everyday conversation: waiting on line for the bathroom at a conference, making small talk before the video meeting began, during intermission at a film screening—all became venues for a discussion of the term. For activists in ME Progress, the hunt for a single biomarker was a well worthwhile one that they believed could bestow legitimacy. Moreover, biological data yielded from tests became, for some of my interlocutors, a currency that could unlock material supports and interpersonal belief, sharpening the reality of ME/CFS via distinctiveness.

When I asked an interlocutor who had both fibromyalgia and ME/CFS if she saw the conditions as related, she was emphatic that she could tell which symptoms were from fibromyalgia and which were from ME/CFS: "It's two distinct issues that I can feel the difference of." When she lacked other ways of proving which symptoms were caused by which conditions, felt-sense took the place of biological data. Similarly, at a seminar in Mountain View, California, with Dr. Martinez, one of the top ME/CFS doctors in the nation, a patient brought up Lyme disease. Was it an overlapping trigger, or were the two being confused? It was quickly batted down. Sitting in a reclining chair to manage his symptoms, another patient said we should not "go there," as Lyme was a "real can of worms." An awkward pause ensued as Dr. Martinez attempted both to validate experience and explain why he saw them as separate diseases. There was no evidence that tick-borne infection is being

reactivated in the bodies of ME/CFS patients, he said, unlike other viruses like Epstein-Barr or herpesviruses. Dr. Martinez observed that many patients, "especially East Coast patients," believed in a possible link between Lyme and ME/CFS, but that this could be attributed to the much higher overall prevalence of tick-borne illness on the other coast. He repeated this emphasis on coastal differences multiple times, evoking a literal, geographic border between Lyme and ME/CFS. In both cases, I was struck by the immediacy with which comorbidities were dismissed. It was as if they feared one diagnosis threatened to destroy the existence of the other. Even when they existed in the same body, ME/CFS and its comorbidities needed to be made separate in order to avoid "clashes and confrontations" (Mol 2003: 6) between them. The hope of a biomarker was the hope that ME/CFS could become a disease-in-itself: a single, unique biomarker would prove that someone really has ME/CFS.

But there was a risk to this proposition. One of my Bay Area interlocutors, Amy, told me that she would be overjoyed if they discovered a biomarker, but she worried that some patients could be left behind. "For the people that don't really have it and think they do, that's going to be devastating," she said. Overshadowing this proposition was the potential that, in her words, such a patient without biomarkers "probably looks like a little malingerer," even if they really do have ME/CFS. Just days before my conversation with Amy, I had talked to Dr. Sanyal, an ME/CFS researcher who was working on an inexpensive, but specific diagnosis test that measured the deformability of red blood cells. While he acknowledged similar concerns and likewise stressed the importance of a biomarker, he predicted that such tests would include more people than they would exclude, solving the problem of underdiagnosis.

By contrast, a handful of patient activists I encountered believed a biomarker could prove ME/CFS to be overdiagnosed. Joel exemplified this position. I met Joel for the first time at a fundraising event in Manhattan that took place in a hospital seminar room in 2017. In the relative privacy of the hallway, Joel stopped me to voice his criticisms of the event, speaking in hushed tones and looking over his shoulder. He was one of the few people who consistently spoke candidly—albeit only privately—about rifts in the ME/CFS community. His main concern was that co-morbidities were overshadowing the real issue at hand: specificity. He opined on the perils of overly broad diagnostic criteria: "The issue is if you say, 'Hey, do you have post-exertional malaise? Are you fatigued?'" Imitating an eager patient, Joel raised the pitched of his voice, nodding animatedly, "'Yeah! Yeah, I do! I have that!' And so, of course they'll find psychiatric comorbidities." He also criticized a prominent female member of the community—whom all other patient activists I encountered described as "like a superhero for us"—for tweeting too much about her comorbid conditions. I found Joel's discussion to be gendered, not only in its directness, but also in its willingness to venture into a territory that might cast people with ME/CFS as hysterics, a feminized condition. People with too many complaints or primary depression might not "really" have ME/CFS. Joel expressed his ambivalence: "Half of me says, 'Well how the hell do you do that if you have this illness?' The other half of me says, 'Well, obviously, it's just not quite as severe as is mine.'" A biomarker and uniform case definition, Joel hoped, might sort these border wars out.

Who was in the group and who was out of the group, therefore, was not only a question for researchers; it was also a question people with ME/CFS negotiated among themselves, even if it was typically taboo to discuss directly. Rarely in my fieldwork did I encounter expressions of disbelief: in support groups and activist meetings, people simply accepted that everyone else had ME/CFS, regardless of who diagnosed them or even if they were formally diagnosed. After all, the very issue these patients wanted to change was the crisis of disbelief ME/CFS faced, and the last thing they needed was another person to question their legitimacy. Privately, however, hierarchies emerged among patients, as they also very much hoped for disease specificity and stratification as roads to legitimacy. They sublimated skepticism of specific individuals with a generalized skepticism over conceptual definition. Colleen, an active patient advocate whom I met at the conference at the NIH, was vocal about her viewpoint during a question-and-answer session following a panel of researchers. She complained that mild patients were being "lumped in" with severe patients, arguing that this mucked up the search for a biomarker. Thus, the effort to single out disease was both perilous and necessary: potentially disruptive to political and social solidarity, but a currency on which legitimation hinged.

Christine bartered in this currency. A former travel nurse in her 50s, Christine was an ME/CFS activist who grew unable to work. For some in the group, the diagnosis of ME/CFS was an epiphanic moment. But for Christine, it sent her on a journey in search of biomarkers. "[My doctor] talked to me and she basically said, 'You have chronic fatigue syndrome.' And I said, 'I don't believe in that'…I didn't believe my diagnosis because I didn't believe in that illness." Christine's initial reluctance to accept her diagnosis was at once about scientific belief and her hesitation to accept her body as disabled. As an upwardly mobile middle-aged white woman, her work as a "Type A" nurse was important to her identity. Indeed, the "biographical disruption" (Bury 1982) caused by chronic illness is mediated by one's existing social position. ME/CFS is a gendered condition haunted by connotations of hysteria, but the disruptions associated with ME/CFS are also about race, class, and sexuality. Unable to work yet facing difficulty getting on disability, Amy similarly mourned the loss of her professional life. A white woman with a doctoral degree, Amy had to quit her career and rely on her husband's insurance policy to receive care. She worried that people viewed her as "a bimbo wife" mooching off her husband, and not the motivated, independent professional woman she had always felt she was meant to be. Christine likewise grew emotional when we talked about the job she had to quit. She was forgetting words due to cognitive decline and facing intractable exhaustion, but she loved her work. When we talked about debility in her day-to-day life, she began to choke up, struggling to speak over held-back tears. But she spoke with confidence and determination when we discussed medical testing, treatments, and her work as a patient activist. In our conversation, accepting her life as a now-disabled person was everywhere punctuated with her concerted search for biomarkers.

Christine's initial reluctance to accept her diagnosis out of a crisis of belief would slowly turn to acceptance, but only after a battery of further tests and doctors' visits conducted around the country—including over $2,500 she paid out of pocket to see one specialist. These visits yielded few definitive answers. Running out of options and unable to work, she chose to take a controversial cardiopulmonary exercise test to develop solid proof to verify her diagnosis. For this, she also traveled out

of state (which presented physical difficulty) and paid out of pocket. The exercise test is designed to aggravate symptoms by having the individual exert themselves to cause demonstrable fatigue. Christine had heard scary stories on Facebook groups, where commentators warned the test further debilitated them, even rendering some bedbound. But she had also heard that her earlier battery of non-standardized tests, in addition to her "subjective" symptoms, would be insufficient to get approved for state and federal disability insurance. This exercise test, she emphasized, was one that "you cannot fake." Patients like Christine must swim upstream against the belief that they are just "burnt out" on both personal and institutional scales. While her symptoms worsened afterwards, she obtained the results she had sought: "For my own knowledge and hopefully to help convince Social Security, do I have this illness? Clearly, I do." Ironically, to obtain disability insurance because she was losing both income and bodily ability, she spent a large sum of money and further debilitated herself. She bet future income against the cost of the test and endured a potentially permanently higher level of debilitation in exchange for proof of debilitation. What Christine described as "a risk [she] took" indeed paid off. But in the absence of a standardized, readily available diagnostic test, Christine was only able to prove debility in ways that sustained debility. She became knotted in a recursive process. The thing on which legitimacy of debility hinged was also the thing that debilitated. The biomarker promised to be a currency, but it came with its own price. It was Christine's trying time with this Faustian bargain that led her to seek out others who shared her experience.

United in Impairment

In the absence of biomarkers or discrete diagnostic tests, symptoms quite literally define ME/CFS, and shared experiences of impairment united the ME/CFS communities I studied. While some patients sought answers through testing, not everyone could access it, and those who could did not always receive the same results. Equally significant in everyday interaction in patient groups was what I call "symptom talk." In contrast to Linton's (1998: 529) observation that disabled communities may be reluctant to acknowledge impairment, impairment was central to the social life of ME Progress. The reality of impairment not readily validated by medical authority was what led many to seek out other forms of support, and the commonality of impairments was what bound groupings together. Patients described their experiences with "brain fog" (a type of cognitive dysfunction involving lapses in memories, mental errors, and difficulty with concentration) or "crashes" (post-exertional fatigue), which were not so much specialist lingo as the stuff of everyday conversation, a practical epistemology of illness (Kroll-Smith and Floyd 1997). The heterogeneity of symptoms provided consistent fodder for conversation: Though post-exertional malaise is the cardinal symptom of ME/CFS, chemical sensitivities, allergies, irritable bowels, dizziness, chills, blurred vision, joint pain, and headache often appeared in conversations. Symptom talk is particularly crucial in the context of online, disembodied space. Members of the group, primarily homebound, came together on video chat platforms to meet others with ME/CFS and to discuss some of the most intimate, private aspects of their lives. Members would come and go as their symptoms got more or less debilitating. Camaraderie, community, and solidary were forged

through symptom talk. It established a commonality of experiences, a basis for trust in a group of otherwise strangers who were only tenuously networked.

Symptom talk was ubiquitous on message boards and social media. The symptoms could be endlessly varied, and not always classically related to ME/CFS. For instance, Lucy, using hashtags common among people with ME/CFS and other chronic illnesses, asked the community: "Question for [people with ME/CFS]… On bad days does anyone else get other symptoms with their [post-exertional malaise]? I am sniffing like I have a cold—again (it's regular). …Is that just me?" Interestingly, Lucy's tweet did not ask for medical advice. One reply was a simple, "Nope, not just you. Me too." Another: "I sneeze a lot, it seems to help the tightness in my chest when it's hard to breathe." As these allergy-like symptoms were not necessarily typical of ME/CFS, another reply suggested it might be another (often comorbid and likewise emergent) illness: "I wonder if it could be [mast cell activation disorder]? Which I don't know much about but see mentioned [on Twitter] a lot." In symptom talk, the function symptoms serve is not necessarily to get to the bottom of a medical problem. Symptoms serve as social prostheses (Biehl and Moran-Thomas 2009: 271), articulations that place the symptom talker within the social world of people with ME/CFS.

But symptoms are not just about talk. They constituted a crucial point of trust and commonality, but they also structured worlds in embodied ways. An example from field notes during an ME Progress video call meeting is illuminating:

> Ilana is a black woman in her 30s who is newly involved in planning protests. There are many other folks on today's call, but Tina, the group's de facto leader, is absent—as we speak, she's on an airplane, en route to the all-cash, no-insurance doctor's appointment in the Silicon Valley ("I trust my doctor in New York," she had told me, "but if I can get 4%, even 2% better, it's worth pursuing"). I had offered to take minutes for Tina while she was gone, and as the meeting closes, I offer again to take minutes for the next one. "Thank you," Ilana tells me, "because the brain fog is strong up here." After a conversation about logistics, Ilana closes the meeting: "I know it's 2, and I don't know about you guys, but I'm fading a bit." We discuss when we're meeting next, given it might not be next week. "It's a holiday weekend," I say. Ilana replies, as if making small talk, "Oh yeah? What holiday is it?" "*Every* holiday!" Janet says with a laugh. At this point, Virginia, a middle-aged white woman from Long Island, interjects in a lightly teasing, but mostly empathetic, mode: "Oh, that brain fog!". After a moment's pause, Janet gives the answer away: "Easter *and* Passover!" Ilana does not respond to the brain fog comment, but adds that she is not used to keeping track of holidays due to her schedule as a nurse: "Hospitals never close."

When Virginia interjected, she attempted to extend an embodied relationality into disembodied virtual space. But the ramifications of these symptoms interfaced with social position. What was a clear instance of brain fog to Virginia was for Ilana attributable instead to her working conditions as a nurse. The witnessing and mirroring of phenomenological components of illness helped validate that disease was even there—evoking Biehl and Moran-Thomas's characterization of symp-

toms as protheses for intersubjective recognition (Biehl and Moran-Thomas 2009). Symptoms congeal tenuously into a disease, and they cohere a biosocial world (Rabinow 1996)—but not, in this case, because they were verified molecularly. Symptom talk sustained the reality of disease in the absence of biomarkers (Lian and Nettleton 2015), becoming the everyday substrate for this community of patient activists. Symptoms, and not objective data, became the stuff extracted from one body, transferable to another. They were the thing that could define one person's experience as falling under the same name, "ME/CFS," as another's. Yet the impairment symptoms cause is always lived in socially situated bodies. In the case of ME Progress, the ways that impairment interfaced with social position stymied both self-advocacy (e.g., the energy to get on disability insurance) and activist worlds. This points to the recursive nature of debility and the perpetual co-constitution of illness (subjective experience) and disease (biomedical object)—an imbrication with paradoxical consequences for these patient activists.

"It's Called Activism for a Reason"

While the shared experience of impairment was the tie that bound people together, it also created double-binds for the activists in ME Progress by structuring the forms of political action that were possible. They were embedded in conditions of constraint and contradiction that both allowed for movement and limited its effect (Fortun and Cherkasky 1998). A life of suffering without end was what inspired activism and formed the basis of a politics. Patients were asking for societal legitimation, more research, and better treatments, so that their lives might be made more livable in the future. And yet, absent these things in the present, the activists confronted a challenge in the meantime: If political change involved action, debilitation blocked the types of action that was possible.

Tina, a seasoned AIDS activist, public health professional, and person with ME/CFS, astutely diagnosed this double-bind. After a poster-making session for an upcoming rally at another activist's Harlem brownstone, I gave Tina a quick lift in my car to her apartment on the Upper West Side. This was only the second time we had met up in person, one-on-one, over the duration of my fieldwork. Seeing me as an understanding outsider and in the rare bubble of a private automobile in New York City, she used the opportunity to discuss some harder truths with me. She wished that people with ME/CFS would more willing to take risks, to put themselves out there. Power, she reminded me, yields little without a struggle. Yet she also said that she understood the conundrum the ME/CFS patient activist community found itself in. "It's called *act*ivism for a reason," Tina said, "It kind of requires action, and we can't really do that." While ME Progress took explicit inspiration from the theatrical—and highly successful—tactics of HIV/AIDS activists, my interlocutors also knew they could only aspire to the most taxing forms of politicking.

My entrée into the world of ME Progress occurred during the first of what would become an annual protest. On a hot May afternoon in 2016, I drove down to the Department of Health and Human Services building in Washington, DC. An imposing Brutalist structure with a wide treeless sidewalk before it, the building offered little protection from the scorching sun, and protesters occasionally stepped out to lie down under sunshields brought from home. Knowing ME Progress was

the one of the most active ME/CFS advocacy groups, and seeing the protest widely advertised on social media, I had hoped for a large crowd and an opportunity to blend in during my first foray into the field. But the group was relatively modest—around 40 people, and I was the only one without a red t-shirt. What filled the expansive concrete complex was not a mass of bodies. Instead, empty shoes filled the space. They were all worn, and each had a message. "Missing playing drums in his rock band," read a tag attached to a pair of red plaid Converse shoes. High heels: "Missing salsa dancing." Boots: "Missing hiking." Expanding on this theme of making absence present, activists carried signs that mimicked missing persons posters, complete with a name and picture: "Missing for five years," a poster with a smiling white middle-aged woman read. Some opted to use "before" pictures, representing how active the person was before getting sick. Pictures of rock-climbing men and marathon-running women were among the array of posters. Others opted for pictures of their bedbound relatives: "My dad has been missing for eight years," read a poster, carried by a child, with a picture of a bearded white man, with glazed over eyes, lying on a couch with a neck pillow.

My interlocutors told me they strived to represent those who were unable to show up, to fight for their illness, in ways that were legible as political action. They were faced with the task of continually reformulating what counted as politicking. They got the most participation when the advocacy work involved things that could be done from bed: sending letters to Congressmen, to local public health officials, and to doctors, all of whom they are trying to convince of the reality of their disease. Such actions may seem inconsequential, but they would crash patients for weeks on end. A homebound life in exhaustion, where sociality exists primarily in disembodied virtual space, contrasts with the vision of protest as "bodies in the streets." Without physical presence in civic society, people with ME/CFS experienced debilitation recursively. No bodies in the streets, no recognition, no research funding. No research funding, no treatments, no bodies in the streets.

Like other patient activists, the people in ME Progress did indeed fight. Mary fought by lying in the shade during the DC protest, fighting her exhaustion from the sun. Joel fought by navigating inaccessible public spaces in his motorized wheelchair, which he had to fight to get covered by insurance so that he could save energy. Tina fought by keeping her day job in public health, which unlocked access to experts and resources yet involved fighting every day keep up with work. Evan fought by going to virtual meetings, which produced post-exertional fatigue he had to fight to get through. These forms of fighting differ greatly from traditional visions of patient movements. The HIV/AIDS activist group ACT-UP, for instance, directly references the fight in one of its signature slogans: "Act up, fight back." This fighting was a confrontational, raucous form of "street theater" with "eye-catching agit-props," created by a large and energized group that produced a vast amount of protest artwork in a very short period of time (Gould 2009, 4). In the 1980s and '90s, members of ACT-UP were "fighting against the clock for their own lives" (Schulman 2021, 57). This temporality is distinct from the protracted suffering of ME/CFS, where patients may be "missing" from public life but do not die the gruesome and spectacular deaths that people with HIV/AIDS did in ACT-UP's heyday. Similarly, it also differs from the "pinkwashing" (Jain 2007) of breast cancer—another gendered disease—wherein the sign of the pink ribbon provides a ubiquitous visual symbol, yet often

serving to obscure the reality of disease in favor of corporate profits. ME/CFS is by contrast a disease of disinterest, without well-known slogans or symbols. The activists in ME Progress faced a double-bind, fighting a taxing battle against both debilitated bodies and normative expectations for activism.

Conclusion

ME/CFS is defined by profound exhaustion and creates significant impairment. Despite this persistent fact, ME/CFS has, over its four decades of existence, struggled to be taken seriously. Decades of dismissiveness have led to several repercussions. No political urgency surrounds ME/CFS, meaning that research is underfunded. This lack of financial support sustains the belief among many experts that the condition is psychogenic, and that biomedical research is unnecessary. This doubt further limits the possibility that a consistent understanding of ME/CFS could be achieved. Underfunding has meant that researchers have struggled to find a clear biomarker—a unique biological indicator of disease—that could be used to definitively diagnose ME/CFS. Without one, people with ME/CFS face immense challenges getting on disability insurance or receiving other material supports, or even receiving interpersonal validation. Without such supports, people with ME/CFS are left to fend for themselves; they create community based on the commonality of their symptoms, which define their disease in the absence of a biomarker. But while these groupings have congealed into a vibrant ME/CFS activist community, symptoms also create impairment; in turn, this limits the forms of activism people with ME/CFS are able to undertake and thus puts a ceiling on the political urgency of the issue. The problem ends up back where it started.

By traversing these realms—from science, to social validation, to impairment, to activism, and back again—this article has argued that these different sites and scales are bound together in a recursive knot that is difficult for people with ME/CFS to untie. The people in ME Progress mobilized politically because they believed in social change: they believed that their experiences of impairment do not have to be this way. But one's mobility impacts one's ability to mobilize, how much action one can perform affects how much activism one can do. This makes it difficult to effect the political changes it might take to achieve successful treatments, a wider availability of knowledgeable doctors, and access to material supports—all of which would tangibly improve the lives of people with ME/CFS and lessen their impairment. The "political" aspects of disability thus exist in recursive relationship to the embodied experience of impairment. What Kafer calls "societal attitudes" (2013: 7) can and do impact the types of resources available to people with ME/CFS. There are real social and structural changes at play. Austerity politics span ME/CFS's existence, with biomedicine the stringent arbiter of who is worthy of care (Wailoo 2015). The bureaucracy that surrounds disability eligibility and American health care is exhausting in and of itself, with more than one interlocutor recounting falling asleep on stacks of paperwork as they fought for financial survival. A cultural suspicion of "disability frauds" is a particularly American societal attitude that compounds the suffering of people with ME/CFS and ripples out to policymaking and continual disinterest (Samuels 2014). These large-scale trends are not unique to ME/CFS, but an important question is why this disease continues to be disproportionately dismissed and

little-understood despite four decades of activism. While taking impairment seriously may risk reinforcing a view of disability as a tragedy, it is also necessary for understanding the binds that people with ME/CFS find themselves in. The example of ME/CFS also illustrates the ways in which impairment is not always an intensely personal (Scarry 1987), depoliticized phenomenon, but can be the very motivation for organizing. Deeper ethnographic description of the knottiness of ME/CFS reveals the multiple valences of fighting for illness, and gestures toward a potentially more capacious view of activism that does not take ability for granted.

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