SICK WORK

Exhaustion, Labor, and Invisible Illness

Emily Lim Rogers

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EMILY LIM ROGERS

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Prologue

The Ill Observer

This book examines what it means to be ill through an ethnographic study of myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), a debilitating disease defined by post-exertional malaise. It focuses on its patient activist movement, the relationships people have with medical institutions, and their imbrications with capital, the family, and the state. This prologue is personal, political, and methodological at once, taking Ruth Behar's *The Vulnerable Observer: Anthropology That Breaks Your Heart* as a starting point. In that canonical text of feminist anthropology, Behar breaks through the myths of the ethnographer as a distant, objective observer and instead encourages us to use the personal as part of our method. In general, I do not do that in this book. But it's worth pointing out that Behar's very first example of "the vulnerable observer" is a disabled one. Citing psychologist and writer Kay Redfield Jamison's *An Unquiet Mind*, a memoir about mood disorders and madness, Behar spends a considerable amount of time discussing how (mind)embodiment, too, contributes to the observer's vulnerability.[1] One of the quintessential vulnerable observers, then, is the ill observer.

Yet doing vulnerability "wrong," Behar writes, is not only embarrassing but also humiliating. I write about my own chronic illness here with trepidation: I share the fear that it will flop. But I decided part of being vulnerable was to accept this risk. I follow Behar's command that any discussion of vulnerability be "essential to the *argument*" of the ethnography.[2] My aim is to accomplish two things: first, to discuss how embodiment enhanced rather than hindered ethnographic method in this book, as has been discussed in the turn toward "disability as method."[3] Second, I want to highlight the gap between my body and my interlocutors' and address directly, in the second person, the people with ME/CFS who might be reading this. Not to mention the fact that, as Michele Friedner,

Devva Kasnitz, and Zoë Wool observe, people who write about disability are often assumed to have that same disability themselves, and I want to be clear I do not have ME/CFS.[4] The more substantive goal is to explain some of the things you are about to read, and how I got here.

All fieldwork takes place in a body, and this took place in mine. As Gloria Anzaldúa put it, "The body is the ground of thought."[5] Embodiment informed my work from the very beginning of my academic career. Just a few months before my first semester in college, I developed symptoms that doctors could not explain. I experienced (and still sometimes experience) episodes of horrific whole-body itching without any rashes to investigate, easily lending itself to psychologized interpretations. The invisibility yet the intensity of the symptoms was maddening, and it led me on a search for diagnoses. I would stay up late at night, unable to sleep, Googling in bed from the then-new technology of the smartphone, hoping for answers. Night after night, my efforts were futile. Probably as a coping mechanism, I intellectualized my condition in college, and trying to separate my mind from my body, I studied medical sociology, history, and anthropology. With all our critique of medicalization, I pretty much gave up on a diagnosis—until I heard about a new diagnosis called "mast cell activation disorder" encountered through my fieldwork six years later. I looked it up and bookmarked it—was this the revelation I had hoped for? I put myself on a waitlist for the premier mast cell doctor in the country, located just north of New York City, where I lived at the time. She was mostly out of network but happened to accept my insurance. I waited over a year. My insurance changed over the course of that year, and by the time I got to see her, I was no longer in network; she would be cash-only. So cash—or rather a credit card—it was. I went in and immediately got the diagnosis. If Behar subtitles her book "anthropology that breaks your heart," what I have here is "fieldwork that makes you sick": It gave a name and diagnostic framework (mast cell activation) in which to understand my body.

I tried the treatments the doctor prescribed, but they made little difference. What did this diagnosis do, or not do, except send me into debt? Over the span of my fieldwork, I collected several new diagnoses along the way (fibromyalgia, orthostatic intolerance, gut dysbiosis, Ehlers-Danlos syndrome—all of which are often comorbid with ME/CFS). Some of them allowed me access to field sites I would not have otherwise gotten into, such as a support group for people with ME/CFS and fibromyalgia. ("You're one of us now," my friend Noor told me as she gave me permission to come into the group.) While I felt touched to be welcomed into the community, I felt no sense of relief when I got a diagnosis. I was never very attached to any of these labels, and some of them I do not even identify with.[6] I am very lucky that my symptoms are mild enough that I manage

them on my own through changing my diet, avoiding chemical triggers, and lying down during the day. Other days are really hard. Because I have a connective tissue disorder (one that is also often comorbid with mast cell and indeed ME/CFS), my joints are loose and I never have a single day without pain. Right after my fieldwork concluded, in my walk-up apartment, I fell down a set of stairs (narrow, railingless, and not to building code) and permanently tore a tendon in my ankle. I began using a cane, becoming "visibly" disabled. Four years later, at a pro-Palestine encampment, I was brutalized by the police, who, out of nowhere, grabbed me by my cane and threw me to the ground, causing an also-permanent tear in my shoulder. As someone who already has a joint disorder, I do not have much hope in (re)habilitation.[7] Maybe internalizing the "discourse of butch stoicism" Alyson Patsavas describes, sometimes I just suck it up and hyperextend my body, even though I know it may make things worse.[8] I remain resigned to the fact that medicine might not do that much to help me.

Although I was allied with people with ME/CFS due to my proximate diagnoses, I also have other forms of (dis)identification I care about, beyond being chronically ill or disabled, that most of my interlocutors did not share. (I do not mean to further erase people of color, working-class people, and queer people in the ME/CFS movement, but we have to acknowledge they are profoundly underrepresented.) Given my personal experience with disability, I can't help but think it is not just medicine, but quite frankly abolishing the police, private property, inaccessible buildings, and American militarism that would "solve" disability. I felt ambivalent about diagnosis-based activism, which too often makes disease into a literal "single-issue cause"—when we do not, as Audre Lorde says, live single-issue lives.[9] It risks siloing chronically ill people from one another and from other identities. There is a history of intersectional activism, demonstrated by the Black Panther–disability solidarity, that Sami Schalk points out, despite the whiteness of contemporary disabled and chronically ill communities.[10] My position as queer, Asian American, and masculine-presenting also impacted the research itself and my experience in the field. I was young (in my mid-twenties) when I conducted it. During my fieldwork, it was often assumed that I was *not* a patient myself—some people assumed perhaps my mother or an aunt had ME/CFS, or even that I was someone's research assistant. These racialized and gendered assumptions extended to the academic reception of my work. When I walked into an anthropology conference, someone told me she "assumed I would be a white middle-class femme woman" based on the topic. (Privilege check: We bougie butches do exist.)

From my vantage point, to make sense of my own embodied experience and what I saw in others' lives, I needed a more capacious analysis of contested chronic illnesses that extended beyond medicine alone. This is why the book, as you will see, is not strictly "about" ME/CFS, despite the fact that this is the first academic monograph to center it. The book is informed by feminist and queer critique as well as a commitment to historical materialism, and at times it will move swiftly across disciplines.[11] I believe all these fields are necessary to develop a precise picture of what medicine does for us, and what it does not do, aspects of which resonate with critiques of the family and the exaltation of the romantic couple form. I feel similarly to Sally Munt, who wrote about ME/CFS in the context of queer attachments: As I grew more disabled over the course of writing this book, it was difficult to not have a spouse or partner to care for me, as is often a presumption, "in sickness and in health."[12] I am not close with my biological family. You might notice that I thank a robust network of queers in the acknowledgments. But, ultimately, I am severed from my chosen queer family because of the nature of academic dislocation, where you follow the job and not your heart. This critique of the family and of the nature of academic life is quintessentially feminist, and it is no coincidence that Behar is my starting point.[13]

If we were to heed these critiques, material support for chronic illnesses—that are public rather than private—would be necessary to end some of the violences the nuclear household enacts. Queer theory also provides us with a way of rethinking the bed/room, as queer theory has contended with the sexualized bedroom as political.[14] Meanwhile, disability studies and disabled activists contend with the bedroom in a different sense: The *bed* can be a site of politics when people live in debility that relegates them to it.[15] Both are ways of getting at the question of the domestic sphere and the ways ME/CFS is caught up in both its trappings and potential.

I say all this to acknowledge that, because I come to this book in a different body, this might not be the book my interlocutors wanted me to write. The book might seem to not be "about" ME/CFS at all, but rather about all the things that precede and structure it. So now let me address my interlocutors, and people with ME/CFS more generally, head-on.

I acknowledge the stakes are high when so many people have gotten so much wrong about your experience. I also acknowledge that any form of exertion crashes you. Even by reading this book, which (I hope) better equips you to fight for change, you might actually feel worse and less equipped to do so, at least for today. I was often told that reading articles, sending emails to representatives, or attending meetings crashed you. I do not take the effort that you made in helping me construct this book for granted. I do not think the kind of fatigue you

experience is the same as those of non–chronically ill readers. Given how generous many of you were with your time, and how optimistic you were that I would help your cause, I feel a pressure to do right by this aspiration, even though I know I will not and cannot get everything right about your experience. There may also be scientific disagreements, but this book is not so much about getting the facts down right as it is about understanding why others do not. I hope, nevertheless, that this book can be of some use to you and me. As I got sicker with an illness frequently comorbid with—although not the same as—ME/CFS during the course of my fieldwork, I relate to you, despite the proximity-yet-distance between your chronic illness and mine. I hope this book will do some justice to your stories, in whatever small way, and I hope that all readers with ME/CFS may recognize some small part of themselves in it.

Writing an academic book is not a political project in and of itself, but all books have a politics. As I type this, I'm not sure what it means to write a book in the first place, when our colleagues and comrades are getting captured, brutalized, and disappeared. In the medical context, there is no starker example of this than the "Big Beautiful Bill" of 2025, a bald-faced move to transfer money to the rich by taking away care from the poor. I am not sure what it means to center a book on a difficult-to-get diagnosis when all healthcare is getting gutted. I don't know what it means to write about ME/CFS when Donald Trump threatens to disband the National Institutes of Health entirely. Yet, at a time of the dismantling of both the social safety net and research funding, let it be noted that ME/CFS has always faced these challenges. It is my conviction that ME/CFS is a lens through which we might reveal certain things at the core of our fucked-up world. I hope that what I provide here may give us one hint at a more capacious politics of illness, one that is ultimately a critique of the state, capital, the family, and racial formations. This book does not "imagine otherwise." It looks at why we are stuck. It does not present alternatives, but it is not Thatcherite either (with her famous line to justify neoliberal order, "There is no alternative"). Rather, in laying out the underlying systemic causes that perpetuate the oppression of disabled and chronically ill people, I hope it shows things don't have to be this way. We need more than ever to remember that right now, as we live in a time of mask-off authoritarianism, ongoing genocide, rampant transphobia, and neo-eugenics. My approach in this book is to grasp ME/CFS at its root. To invoke Angela Davis in her paraphrasing of Karl Marx, this means, after all, that I hope to gesture at least to the *need* for something more radical.[16] May such a project liberate us all. There is so much work to do. We have no choice but to keep doing it. We need every single one of us, and we cannot leave people with ME/CFS behind.

Introduction

Promising an update on a mysterious "fatigue epidemic" plaguing women in the United States, a 1989 issue of *Ladies Home Journal* asked its readers to consider the following question: "Am I sick, or am I tired?" "Considering that most women now have jobs outside the home—and put in over twenty hours per week on housework," the article continues, "it's hardly surprising" that American women have trouble distinguishing everyday fatigue from a newly emergent illness sweeping the nation.[1] Despite the "unsurprising" nature of its symptoms, the syndrome in question was one that got its name from a Centers for Disease Control (CDC) investigation just one year prior. It was widely covered in the news at the time but frequently derided as "Yuppie flu." And nearly four decades later, doctors and researchers still don't fully understand or adequately treat it. The syndrome in question—the one so difficult to parse from everyday conditions of labor—was termed *chronic fatigue syndrome*, or CFS.

Today, CFS (also known as *myalgic encephalomyelitis*, or ME/CFS) is considered a serious, debilitating condition of uncertain cause that affects more than three million Americans, more than HIV/AIDS and multiple sclerosis combined.[2] The first federally investigated outbreak of ME/CFS in the United States occurred in the Lake Tahoe region in 1984, when ninety patients (mostly white, mostly female) presented to doctors Paul Cheney and Daniel Peterson with swollen lymph nodes, general malaise, and unshakeable fatigue.[3] At the time, many, both in the media and in the medical profession, believed ME/CFS was triggered initially by a virus but sustained by the stress of middle-class life, found almost exclusively among white "highly educated" females.[4] The entity remains a medical puzzle, patients are disbelieved, researchers enter a field mired in controversy, and physicians must parse out illness from health. No biomarkers

or definitive diagnostic tests exist for ME/CFS. Research is notoriously underfunded: In fact, it receives the lowest funding per disease burden of any US entity.[5] Insurance coverage for the condition is spotty. Disability insurance is especially hard to come by, as the condition faces a crisis of belief and of biomedical verification. Yet most people with ME/CFS are unemployed, nearly half have determinable impairment, and around one-quarter are bed- or housebound.[6] The symptoms they experience vary wildly in their form and predictability. In addition to the cardinal symptom of disproportionate exhaustion after any form of exertion (physical, cognitive, emotional), people with ME/CFS may experience flu-like symptoms, get "brain fog" (cognitive lapses), or find themselves with unexplained sensory sensitivities to light and noise. Another day they might be fine and try to push themselves by going for a walk or to work, for instance, but the next day, they are bedridden. ME/CFS, in other words, is typified by the atypicality of its symptoms.

Confining them to their homes, ME/CFS severs many people from social life completely. But sometimes people living with it are able to band together, forming a vibrant community of patient activists that has experienced renewed success over the past decade, with the National Institutes of Health (NIH) providing its biggest research grant yet to CFS research centers in the fall of 2017, and an activist-produced documentary about ME/CFS, *Unrest* (2017), made its nationwide debut on PBS in January 2018.[7] More recently, the context of the COVID-19 pandemic has brought ME/CFS into the spotlight in ways not seen since at least 1990. A significant subset of people experiencing the chronic sequelae of acute SARS-CoV-2 infections—known as Long COVID—have received diagnoses of "post-viral fatigue" and are increasingly being incorporated into the paradigm of ME/CFS.[8]

Sick Work takes up ME/CFS as its protagonist, but it is not a biography of it. Rather, this book argues that formations of labor, the family, and the state shape not only the experience of illness but who can be ill in the first place. ME/CFS has often been described as an "invisible illness," but following my interlocutors in the ME/CFS activist community, I maintain it can more aptly be described as an *invisibilized* one.[9] When I entered homes, I *saw* the illness: People lived life in bed, struggled to get to the bathroom, could not cook a meal, and donned earplugs for sensory overload. Yet they are isolated and ignored. Because, in the United States, healthcare is tied to having a paid job, ME/CFS presents a particularly apt example of the relationship between the (non)emergence of an illness and changing forms of labor. Following the anthropologist George Marcus, *Sick Work* "follows the object" of ME/CFS across sites and scales to probe these troubled relationships between biomedical knowledge and social structures, and

what people are forced to do when these structures fail.[10] There are two aspects to this argument. First, living in an ill body takes *work*: Any form of exertion creates symptoms for people with ME/CFS, and yet they must advocate for themselves at the doctor's office so that they can get a diagnosis, gain the belief of the disability claims office so they can get approved for vital material supports, and appeal to their for-profit insurance companies so that they can receive healthcare. Second, shifting arrangements of labor create the necessary historical context by which a disease can come into being, draw public health urgency, and be valued as a research priority—or, by contrast, get stuck in biomedical limbo. As the *Ladies Home Journal* article illustrates, work shapes this landscape, such that some symptoms are reincorporated into capitalist everyday life for some subjects, and others raise alarm.

A gendered and racialized disease, ME/CFS unsettles US anxieties about who deserves to be sick. ME/CFS affects people of all races and genders, although it is systemically underrecognized in working-class people of color.[11] It is diagnosed disproportionately in white, bourgeois, cisgender, and heterosexual women, a fact that I witnessed in my fieldwork. ME/CFS is not a new disease. Outbreaks of what would now likely be called ME/CFS have occurred throughout history: Los Angeles, California, in 1934; Akureyri, Iceland, in 1946; London, England, in 1955. But in the United States, it was first systematically investigated and acknowledged by the federal government in the mid-1980s. It was first called "chronic Epstein-Barr virus," then, by the late 1980s and early 1990s, "chronic fatigue immune dysfunction syndrome" (CFIDS). In 1988, the CDC officially named it "chronic fatigue syndrome," a term that many activists today think is belittling but that nonetheless is still used in the second half of the most widely used contemporary parlance, myalgic encephalomyelitis, or ME/CFS. When ME/CFS first emerged in its current iteration in the 1980s, media representations focused on the figure of the white bourgeois female. Today, the "Yuppie" image has shifted. But for now, let me say that I bring up the figure of the white bourgeois female with chronic fatigue not to promote this patient profile, but because the stereotyping of ME/CFS impacts everyone, and Black and brown poor people of color the most, in addition to gender-nonconforming and queer people.[12]

ME/CFS causes what the community and ME/CFS experts refer to as "crashes." Crashes refer to disproportionate—and sometimes unpredictable in timeline—waves of fatigue and other forms of malaise that occur after exertion, whether physical or cognitive. Crashes negate the mechanical, input-output idea of energy and normative temporality: One could crash directly following exertion, the day after exertion, or even several days after exertion. A crash could last a day,

or it could last a lifetime. ME/CFS is hard to describe to those who do not have it. My interlocutors often describe ME/CFS as feeling like a permanent flu—or, as one said, "the worst hangover of your life." While it is defined by fatigue, as a saying in the patient activist movement goes, "It is way more than being tired." When *any* form of exertion pushes people with ME/CFS into debilitation, daily life tasks—brushing one's hair, showering, cooking a meal, caring for children, working a job—become only intermittently possible. Treatment options are limited at best, and there are no consistently successful treatments for ME/CFS; in fact, zero treatments or therapies have been approved by the US Food and Drug Administration (FDA). For most, the only consistent thing that alleviates their symptoms is lying down in bed. The bed thus occupies a significant place in ME/CFS social worlds. Many of my interlocutors called into our interviews from bed, and very few were able to meet up in person. The bed frequently confines people with ME/CFS into private space. It can make socializing and working impossible. Most consequentially, ME/CFS activists try to make their invisible illness visible, but traditional visions of activism, as "bodies in the streets," are untenable.[13] This debility loops back on itself: The invisibilization of activism means the illness remains *politically* invisibilized and medically dismissed. As we will see, this bind is especially knotty in the American context, where work and care are bound together.

Energetic Economies

Healthcare in the United States requires standardized diagnostic codes before treatment and reimbursement, and these codes may vary dramatically by insurer within a mostly privatized insurance system.[14] For the duration of ME/CFS's history in the United States, this system of care has coexisted with a neoliberal socioeconomic context in which subjects are increasingly compelled to "take charge of their own health."[15] Diagnoses are socially and politically charged points of contestation between patients and experts, wherein certain disease categories become "illnesses you have to fight to get."[16] ME/CFS emerged at a pivotal moment in the politics of health and healthcare in the United States; over four decades, it has proven itself to be stubbornly resistant to singular explanations—biomedical, cultural, or otherwise. Despite its considerable disease burden, and despite decades of patient activism, ME/CFS remains a highly ambivalent entity in clinical practice and the cultural imagination.[17]

I maintain we must look both inside and outside the clinic—and, specifically, to changing material conditions of work and shifting arrangements of capitalism—to understand the shaping of ME/CFS and its dismissal. The economies surrounding the emergence of ME/CFS are energetic both culturally and

materially.[18] After all, ME/CFS rose to prominence in the high-key 1980s, with all its technological advancement and aerobics and stimulant drugs and synth pop—and the accelerated pace of work and affective orientations toward it.[19] Indeed, as anthropologist Norma Ware observes in her interviews of people with ME/CFS conducted in the late 1980s and early '90s, people with the disease "are slowing down as the world around them speeds up."[20] Bodies and economies exist in perpetual relation: As historian and anthropologist Julie Livingston puts it in the context of medical examinations in the mines of Botswana, "Local meanings of able-bodiedness [are] shaped by external standards, both industrial and medical," and the "disparate yet overlapping concerns of industry, mission, and government melded into a singular experience" that defined what counted as disability.[21] Changing arrangements of work themselves enable certain bodies and disable others, taking away a requisite for livelihood in a capitalist society.

This does not mean that ME/CFS (or any other form of debility) is "not real" because it is "socially constructed" and culturally mediated. It does not mean fatigue from work is equivalent or even comparable to the post-exertional malaise of people with ME/CFS. To invoke science and technology studies (STS) scholar M. Murphy in their work on sick building syndrome and anthropologist Mara Buchbinder in her work on chronic pain, "Is it real or not?" is not the right question for our purposes.[22] But let me be absolutely clear—especially for readers in the ME/CFS community on one hand or skeptical onlookers on another—that my answer is that I unwaveringly believe ME/CFS is a serious, organic disease.[23] The question I ask is why others do not.

In this book, to explain this puzzle, I present a new contextualization of ME/CFS. ME/CFS's story as a diagnostic entity in the United States began in 1984, the year of the Lake Tahoe outbreak. That was the same year that Robert Gallo prominently deemed HIV to be the cause of AIDS. AIDS activism reached new levels of militancy, and popular awareness of the reality of viruses was particularly acute.[24] But, contrary to the patient profile of AIDS patients as existingly stigmatized groups (as gay, sex workers, Haitians, or IV drug users, for example), the media covered ME/CFS patients who were disproportionately white bourgeois women. Beginning in the 1970s, young women were entering the professional classes at new levels. Thus, the Yuppies, a nickname for "young urban professionals," emerged in the national imagination: They were ambitious go-getters characterized by their youthful activity, conspicuous consumption, affluence, and preppy style. It was precisely 1984, the same year in which the Lake Tahoe outbreak occurred, that *Newsweek* deemed "The Year of the Yuppie."

Throughout the 1980s and early 1990s, the media referred to ME/CFS as "Yuppie flu," an affliction linked to the pressure to succeed and to the stress

of upwardly mobile home and work life, with disproportionate impacts for women, given the gender division of reproductive labor. While it belies the severity of influenza, the way *Yuppie* modified *flu* served to emphasize its mundanity: Everyone gets the flu every once in a while, and most make full recoveries and only the "weak" and elderly die. Remember also that COVID minimizers refer to COVID as "just a flu" or even a cold, as if everyone is supposed to get over it and "return to normal," which always means a return to work and the everyday energetic machinery of capitalism. In the 1980s and early 1990s when the moniker loomed large, Yuppie flu marked ME/CFS as a problem of work rather than sexual deviance, another contrast from HIV/AIDS. Cultural anxieties surrounding women as a professional class, I contend in this book, produced a key context in which ME/CFS emerged.[25] The national media's focus on white bourgeois women naturalized them as the sufferers of ME/CFS while simultaneously perpetuating stereotypes that dismissed them. A psychiatric model of ME/CFS emerged, wherein ME/CFS symptoms may indeed be triggered by a virus but become chronic due to the patient's "false illness beliefs," as stress from middle-class life was transformed into "disease." A legacy of long-standing connotations of hysteria, this psychiatric paradigm remained a dominant one throughout the 1990s and continued into the twenty-first century, especially in the United Kingdom.[26] Over the past decade, though, this has begun to change. It is increasingly rare to see the "Yuppie flu" label in US news media.[27] Studies proclaiming the virtues of psychological treatment have been criticized, and researchers investigating organic, rather than psychological, causes for ME/CFS have been granted funding by the NIH.[28]

Despite recent gains, my interlocutors consistently complained that they still experienced the echoes of the Yuppie flu stereotype, and often felt that "chronic fatigue syndrome" minimized their condition. When asked for their theories behind why ME/CFS was so stigmatized, several said things like my interlocutor Amy: "It's something about the name. I think it's the word 'fatigue.'" Something about it felt like an inadequate description. After a long day at work, their friends and family would often reply that they, too, were tired. In reality, they hardly experienced the array and severity of symptoms that people with ME/CFS experience. But to understand the dismissal of ME/CFS, we need to admit that fatigue of a *general*, non-ME/CFS sort is a widespread problem in the United States. Injecting labor into the history of science, medical anthropology, and critical disability studies, this book situates ME/CFS in embodied political economy.[29] The very origin of the fatigue concept coincides with the birth of industrialization in the nineteenth century. In fact, the term *fatigue* did not enter English-language medical journals until the very final decade of that century but became a major

problem as managers sought to maximize the productive capacities of laborers—to, as Karl Marx said, reduce to a minimum the natural limits of the body.[30] In the neoliberal context when scientists began to attribute "stress" to poor coping skills (connected to current regimes of "self-care"), exhaustion became subsumed into a side effect of capitalism to be solved by individual choices rather than by medicine or management. In a very literal sense, stress and exhaustion constituted the outside of what counted as impairment in American capitalism. Though this is not the case in all countries, in the United States, stress was and continues to be systematically excluded from workers' compensation claims.[31]

The state plays an important role in maintaining this minimization. The United States has historically repressed populations, particularly racialized ones, through the stigma that comes from medical labeling: for example, terming Down syndrome "Mongoloid idiocy" to oppress Chinese people, or blaming Black victims of police shootings for their own murders, retroactively diagnosing them with "excited delirium" and deeming it the cause of death.[32] But state power can also function through a *denial* that a medical problem even exists. The slashing of the American welfare state in the 1980s was justified by well-entrenched cultural ideas of the deserving and undeserving poor, but this time with two key antagonists that animated Ronald Reagan's agenda: the welfare queen and the disability fraud.[33] Both are defined by draining state resources due to their purported disrespect for two key institutions, notably the main avenues from which Americans receive health insurance: work and the family.[34] As Reagan proclaimed in a prominent 1986 speech bemoaning a putatively bloated welfare system, "It's a family crisis," interlinking fiscal responsibility with conservative family values.[35] The figure of the welfare queen—based on a real woman named Linda Taylor—cannot stay with one husband, has child after child out of wedlock, and drains systems of state support. She is disreputable for her sexuality and refusal of the heteronormative family. She is also a racialized trope. The real-life Linda Taylor's own racial classification is slippery: She was likely mixed race and had personally identified as having Native and Mexican heritage, though documents sometimes list her as white and she sometimes passed as such. In one retrospective portrayal, her racial ambiguity is folded into her suspicious nature, pointing to the ways state systems rely on static biological categorizations.[36] But in the popular imagination, the epitome of the welfare queen was an inner-city Black woman who could not keep a husband to support her and did not want to work a job but nonetheless drove around in luxurious Cadillacs.

This book insists on the fact that while the welfare queen was in many ways a foil to the Yuppie stereotype, people with ME/CFS—a diagnosis in doubt—nonetheless live in her shadow. I follow the framework of disability studies

scholar Jina Kim, who aims to "crip the welfare queen" by pointing to the common structures shaping the struggles of both disabled people and poor Black women.[37] As historians of disability have pointed out, Reagan's claims of rampant disability fraud are connected to long-standing fears of "disability fakery" that assume "real" disability is static, stable, and visible.[38] Impairments that cannot be easily measured were met with suspicion in the 1980s context of welfare rollbacks, as historian Keith Wailoo emphasizes in the case of chronic pain.[39] Moreover, as Sunaura Taylor points out in "The Right Not to Work," disabled people touch a particularly American nerve when human beings are valued only for their productive capacities.[40] Who can receive care is conditional on a moral citizen-subject whose impairments are transparent and blameless.[41]

Medicalization as Debility/Capacity

As a study of how a diagnosis comes into being and the ways people advocate for the reality of disease, this book revisits the thorny question of *medicalization*, a concept that has straddled the medical humanities and disability studies and justice movements. Critiques of medicalization emerged in the political context of deinstitutionalization in the 1970s. The term *medicalization* has a long history and particular, often negative, connotations. Classically, scholars like Peter Conrad and Irving Zola have described medicalization as a process of social control.[42] Ivan Illich even dubs it "medical imperialism."[43] Of note, scholarship on medicalization has disproportionately focused on the politics of what have been called "contested" or "emerging" illnesses, new diagnostic categories that face incomplete acceptance, scientific uncertainty, and social doubt. Prominent case examples include fibromyalgia, chemical sensitivities, environmental illness, posttreatment Lyme, Long COVID, and indeed ME/CFS—understandably so, because they all present a real-time glimpse into the medicalization process.[44] Scholars acknowledge that the politics of medicalization are fraught: On one hand, people want recognition for disease, and on another, they may present instances of medical social control. Contested illnesses are also disproportionately feminized, leading to a skeptical scholarly eye on medicalization. Canonical feminist scholarship has explored longer histories of the "sexual politics of sickness," viewing medicalization as a patriarchal imposition that pathologizes women, turning normal bodily phenomena into problems to be solved.[45]

But in the case of ME/CFS and other underrecognized but debilitating conditions, certain subjects *want* to be recognized as ill. The term *medicalization* deserves some unpacking. Note that it contains a dual meaning: Medicalization is the process by which something becomes understood as medical in nature, but

it also connotes a normative territorial shift, with medicine "taking over" more and more aspects of life.[46] These are two different things. This book insists we have to step back and consider whether and how incorporation into medical paradigms bestows an objectifying, controlling gaze, and whether medicine is even its square one, given patients themselves sometimes lead the way (a prime example is Long COVID, a term that originated from patients up rather than clinicians down).[47]

Here, I seek to go beyond the repressive hypothesis that assumes the creation of a medical problem leads inevitably to clinical authority and institutional control. Medicalization is not a singular process or all-or-nothing proposition, and it can be socially and politically mixed in causes and effects.[48] Disabled writer and activist Eli Clare notes his own fraught experience with the politics of diagnosis as a trans person in need of care. For all his critique of medicalization and cure, gender identity disorder was a diagnosis he "actively sought out."[49] In another example of medicalization's ambivalences, anthropologist Didier Fassin uses the example of drug users to show that medicalization can actually lead, counterintuitively, to *de*pathologization by replacing the moral deviant with the blameless patient.[50] But for which subjects can this be true? In the American cultural context, I maintain, both the drivers and ramifications of medicalization have everything to do with longer histories of sorting out deserving and undeserving subjects along racial, gender, and class lines. Whose disability makes them blameless, and whose disability makes them a fraud? This book drills down into the material forces behind these determinations, which are medical and social at once.

My theory of medicalization is this: Diagnoses emerge or get minimized, become visible or invisible, due to changing formations of capital, arrangements of the family, and infrastructures of the state, in dialectical relation to the ways structural forces debilitate or capacitate bodies through the uneven distribution of resources, care, and violence. In my use of the terms *debilitate* and *capacitate*, I take inspiration from Jasbir Puar and Julie Livingston, who have argued for the term *debility* rather than *disability* to point to the ways geopolitical surroundings and cultural contexts shape how disability emerges as an unevenly distributed and contingent problem.[51] Livingston uses *debility* to yoke the social and bodily aspects of impairment and disability: *Debility* is an umbrella term that refers to what we in the Global North might traditionally understand as *disability*, but also incorporates *disease*, *illness*, and *senescence*—and thus it gets to their common roots and manifestations rather than beginning from a political identity that not all may identify with, or that may not even exist in other cultures.[52] Puar expands on the concept of debility, contrasting debilitation with capacitation,

moving away from a disabled/nondisabled, normative/nonnormative binary. Debilitation is a dynamic biopolitical process whose effects are unevenly distributed along lines of power, where some populations are meant to thrive (capacitated) and others to experience impairment and/or (slow) death (debilitated).[53]

In understanding the kaleidoscopic structural politics of ME/CFS and moving beyond the clinic, this book's analysis of medicalization dispenses with the question of social control and thinner ideas of repressive power. The case of ME/CFS necessitates such a move, as it is a key site of contestation not only within medical knowledge and clinical practice, but in their repercussive entanglement with American institutions. As Sunaura Taylor points out, "the power of doubt and uncertainty" is not just an epistemological concern; it is a political force that can obfuscate structural forces including racism, capitalism, empire, and environmental destruction.[54] As we will see, medicalization can at times enable, or capacitate, bodies by bestowing belief and resources to chronically ill people because of its situatedness in a context where healthcare is tied to work and the family. The denial of a medical problem can, by the other side of the same coin, be debilitating by alienating people from their disability.

An underestimated aspect of medicalization is the nature of the body itself. This book argues that sick work—the embodied work of disease advocacy on personal and political scales—overdetermines what counts as a legitimate disease or disability. Disability studies has laid out two models for understanding disability: the medical model and the social model. The medical model, associated with the medicalization of disabled bodies, is described as the societally hegemonic one, because it focuses on "impairment" (bodily aspects) and aims to "fix" or cure disabled people into "normal" abled subjects. In the late 1980s and early 1990s, disability studies scholars and disabled activists pushed back against this model by presenting an alternative "social model" of disability. The social model emphasizes that it is the environment that surrounds the disabled person—not something "wrong" with the disabled person themselves—that creates limitations. A classic example is a wheelchair user. If not for stairs, a wheelchair user could go about life just as a nondisabled person does.[55] Disability studies and movements have historically shifted the focus away from the body itself and toward the surroundings of the built environment.[56]

But within disability studies, there have been several efforts to push away from the social model and identify analytic and political limits.[57] Most relevantly, what happens to the body, and what happens for those whose bodily impairments lead them to seek medical answers? While these are newly renewed debates in an era of proliferating chronic illness (and the increasing tendency of chronic illness communities to identify as disabled), a brief examination

reveals that these tensions have existed from the very beginnings of the field. In a collection of essays written throughout the 1990s, Simi Linton observed that disability studies has been "reluctant to theorize" impairment, pain, and bodily limitations.[58] Acknowledging these, she writes, could erode some of disability theory's foundational political implications: a focus on impairment that essentializes disability as *bodily* limitation shifts focus away from *social* limitations. Likewise, in an essay published in 1996, disabled activist Liz Crow urges her community to "bring back impairment!" (exclamation point in original), arguing it is "not always irrelevant, neutral, or positive."[59] One of the foundational tenets of disability pride is that there is "nothing wrong" with the disabled person. But for people with ME/CFS, the problem is precisely that they are told nothing is wrong: They are denied their disability. A scholar with ME/CFS herself, Susan Wendell points to the difficulty of reconciling chronic illness and disability—and this question comes down to medicalization: "Some people *are* sick," she writes, and want to be recognized as such.[60]

Moreover, with its emphasis on societal stigma and environmental surroundings, can the social model incorporate bodily phenomena like pain and fatigue that seem so deeply felt—so personal, so unaccommodatable? So unassimilable to disability pride models and instead subject to, as disability studies scholar Anna Mollow points out, "pity"?[61] Margaret Price asks most succinctly, "What shall we do with pain?"[62] And, indeed, what shall we do with fatigue? This is a tricky question for disability studies, especially when this suffering feels unbearable or undesirable—or, as Price says, when we are dealing with a kind of impairment that "impels one to self-injure or to consider or attempt suicide," which, I would add, is a top cause of death for people with ME/CFS.[63] Price observes that pain has been a kind of "limit case" to the field.[64] If Price asks what shall we do with pain, what indeed shall we do with the social model?

It is not coincidental that scholars have referenced pain and fatigue, in particular, as the two party poopers of the social model, raining on its politically promising parade. This is because pain and fatigue are often viewed as intensely private individual experiences rather than political or social ones.[65] As Sunaura Taylor writes, "Impairment has largely been presented as more objective, more biological, and more scientific than disability," rendering it outside the fold of traditional disability studies frameworks.[66] Alison Kafer's point of departure for her "political/relational model" (a "friendly alternative" to the social model) is that chronically ill people have been "among the most critical" of the social model.[67] It's difficult to see the social model at play, she writes, when "social and structural changes will do little to make one's joints stop aching or alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue."[68]

I wish to provide my own friendly counterpoint to this claim. Social structures and societal attitudes *do* disable people with chronic pain and fatigue, because the social world forms the context around which disease can emerge or whether one's disability is denied. Pain and fatigue *appear* to form the "limit" of the social model precisely because the medicalization process here is an embodied, yet highly social, one: It is a form of labor, itself painful and fatiguing, to even get a disease recognized as such in the first place when you are sick and all the structures around you make you sicker. Inserting the laboring body into the equation, this book shows that the social and medical models exist in recursive relation.[69] Like Kafer, I break down the distinction between the social and medical models, but by emphasizing that embodiment and debility are in co-relation with knowledge production in the making of new diseases within the taxonomies of Western biomedicine.[70]

Connecting impairment and knowledge, anthropologist Joseph Dumit has framed contested illnesses like ME/CFS as "illnesses you have to fight to get." He characterizes the medicalization process as one of competing facts and negotiations between experts and patients in the context of a deficit of belief.[71] As he describes it, people "fight to get" an ME/CFS diagnosis by doing their own research, participating in scientific studies, and arming themselves with knowledge in preparation for the doctor. Scholars straddling STS, medical anthropology, and disability studies have shown the intertwining of "lay expertise," activism, and scientific knowledge.[72] But this is not merely an epistemological concern. This book shows that the coming into being of a disease is an ontological and phenomenological concern recursively linked to embodiment.[73] In Lisa Diedrich's discussion of Jen Brea's ME/CFS documentary, *Unrest*, she notes the central role that embodiment plays in conveying the realities of life with ME/CFS in the film. Following her observations, I suggest we further develop a "phenomenological vocabulary" of disease through deeper ethnographic description.[74]

In addition to revisiting disability studies' impairment/disability divide, this book also aims to push back against the medical humanities' divide between "disease" as the thing that doctors treat (and the bona fide entity that biomedical knowledge attempts to explain) and "illness" as the patient's subjective experience of debility.[75] What can even become a disease, in the first place, is contingent on bodies, because it takes a particular type of body to advocate for disease recognition through activism—something definitionally difficult for people with ME/CFS to do. This activism is a form of what I call *sick work*: In this case, it is the embodied labor that it takes to even be recognized as sick in the first place. People with ME/CFS "fight to get" diagnoses in bodies that are exhausted. Research priorities, gender stereotypes, and even the name of the condition itself

have been implicated as potential reasons for the undermedicalization of ME/CFS and of other questioned diagnoses.[76] Syndromes are always already nested in knotty relation to biological, personal, and socioeconomic and cultural domains.[77] I add exhausted embodiments to this nesting. The fatigued body is more than just a "text-like entity," as phenomenological anthropologists would say.[78] It is a living thing whose very liveness scales up to what kind of illness gets counted as a disease in the formation of biomedical knowledge.

Ultimately, and to invoke Marx, disabled people have relationships to medical institutions but never under conditions of their own choosing. Medicalization can either debilitate (pathologize, confine) or capacitate (enable access to resources). People with ME/CFS fight to receive care but only under layered contingencies that are bodily and economic at once. Living with ME/CFS, as one interlocutor put it, "is a full-time job," creating a cascade of effects. In listening to chronically ill people's stories, a new, ambivalent, thorny definition of medicalization surfaces. Marsha, a white woman in her fifties, brings this into relief. She could not work, so she had to achieve a medical diagnosis first and apply for disability insurance second: "I filled out all the forms. It was difficult, but I just . . . I just would *do it*. Pass out on the forms, wake up, do it; pass out on the forms, wake up, do it." This is not a "desire" to be medicalized per se but a will to survival, wherein it is actually the patient that must fight against the tide in the making of a "real" medical object.

Labored Living

Marsha's story is a prime example of sick work. Note that I am using *sick* not to stigmatize people with ME/CFS as diseased castaways, but to use it as other disabled activists and scholars have done: as a way to yoke disability and chronic illness and move away from the narrow connotations of the words *disability* versus *disease*.[79] Throughout this book, we will meet many people engaged in sick work and many ways of doing it. Sick work is the invisible work it takes to live with a chronic illness. Sick work is the work it took for Marsha to stay upright in bed while filling out her forms. Sick work is the work it took for Christine to fly across the country to get an ME/CFS diagnosis. Sick work is the work it took for Noor to drive to the clinic or to wait for the bus when she was too ill to drive. Sick work is the work it took Tina to set up the advocacy call. Sick work is the work it took for Crystal to make it to the protest in Manhattan. Sick work is the work it took Leo to even make it through our interview. Sick work is the body working overtime just to sustain itself. Sick work is the work it takes to be recognized as sick.

Putting "sick" next to "work" might seem like an oxymoron. It has been pretty much axiomatic that disability and work are two opposing things, even mutually exclusive.[80] Lauren Berlant, drawing on David Harvey, puts it most succinctly: "Under capitalism, sickness is defined as the inability to work."[81] Talcott Parsons declared in 1951 that the "sick role," which must be "socially defined and validated," exempts the citizen-subject from the requirement to work, and "not every case of 'just not feeling like working'" will pass muster.[82] Likewise, in a foundational text for the whole of the medical humanities, Arthur Kleinman's *Illness Narratives* defines work as a realm "free of sickness."[83] I certainly agree that, under capitalism, disability is paid labor's opposite. Materially speaking, of course, the term *disability* began as a noun referring to the payment one received if one could not work.[84] And since the Reagan administration especially, a common American conception, in both the popular imagination and in the legal system, is that "disability means inability to work and that only inability to work proves 'true' disability," as disability studies and legal scholar Karen Tani describes it.[85]

But following critiques of work from feminist, Black, and disabled perspectives, I use sick work to expand the notion of work beyond paid, productive labor and to point to the relationship between invisible labor and invisible illness. As the Marxist feminist Wages for Housework movement, countless feminist anthropologists, and more recently disability activists and scholars like Leah Lakshmi Piepzna-Samarasinha and Akemi Nishida point out, care work, albeit invisibilized, *is* work.[86] While some scholarship has emphasized that, especially among disabled people, care can be radical anticapitalist practice, it is hard to see this at play in ME/CFS worlds when the disease is precisely defined by societal indifference, medical neglect, and involuntary isolation. For instance, Piepzna-Samarasinha points us to the potential of care work in the context of "care webs," wherein disabled people take care of one another rather than relying on formal, (under)paid attendant care from the state, which has historically institutionalized disabled people and kept them in forced dependency. The concept of sick work relates to some of Piepzna-Samarasinha's interventions in *Care Work* and their critique of state-based care, but, notably, people with ME/CFS never had forms of state support in the first place. Unpaid care labor has also been a longstanding theme in feminist anthropology, and, indeed, the anthropology of disability grew out of feminist anthropology.[87] But I wish to point to the labor of simply living in one's own ill body when the state has abandoned you, when familial care is absent, and when isolation is characteristic of the disease.[88] *Sick Work* also takes significant inspiration from disabled artist and writer Johanna Hedva's influential 2016 essay "Sick Woman Theory" (revised in 2022). For the

sick person, "It costs you to do anything: to get out of bed, to cook for yourself, to get dressed, to answer an email. For those without chronic illness, you can spend and spend without consequence."[89] The "limited funds" and "limited supply" that Hedva discusses, however, might be usefully modified by thinking of these energy expenditures not through the consumerist, accumulationist metaphor of saving and spending money, but, rather, describing sick living as a form of labor. If we should recognize and value care work, as the above scholars have done, it is time to recognize and value sick work.

What I call sick work is work, but it is not, however, *productive* labor. Nor is sick work reproductive labor, because sick work is not about rehabilitation into the workforce or the reproduction of labor power: It is treading water in a body that has already been rendered unproductive.[90] Marsha did not wear herself out so that someone could extract profit from her under the traditional labor theory of value. She wore herself out not to reproduce her conditions of living in order to get to work, but because she was simply trying to live. Early Marx distinguished between two forms of labor: "living" and "dead." His musings on human nature and *homo faber* (or "man the maker") contextualize this distinction.[91] Even without capitalism, Marx insists, we would still want to pursue creative capacities that might be described as work yet would not be absorbed into a capitalist system: the classic observation that we would hunt in the morning, philosophize in the evening, without ever having these as occupations. This type of "work" is part of human life. But living labor, a general capacity, gets transformed into "dead labor" in the laboring process in which capital extracts from it surplus value: "Capital is dead labour, that, vampire-like, only lives by sucking living labour, and the more it lives, the more labour it sucks."[92] Living labor precedes exertion's uptake into capital, and it can also be taken back, outside of the productive system: "If the labourer consumes his disposable time for himself, he robs the capitalist."[93]

Taking inspiration from Marx and from Marxian disability scholars, I define sick work as *the labor of living* with chronic illness. Patients with all sorts of chronic illnesses must do a significant amount of labor trying to advocate for themselves, for a doctor to simply believe them, or even just to stay upright.[94] Precisely because of its dismissal and the lack of bioverification that results from it, a disease like ME/CFS requires people to translate impairment into terms understandable by medicine. In this process, as artist and writer Rouzbeh Shadpey puts it, "Illness becomes poetic labor."[95] If people with ME/CFS exert themselves every day just by existing—and if exertion is a fundamental imperative of capital—then why would we not recognize this as a form of work? But instead of recognizing and valuing sick work, sociomedical and state institutions have

deemed people with ME/CFS without economic value *and* undeserving of material support. If anything, exertion instead turns living labor not into dead capital but rather renders subjects into the fold of "the living dead" by isolating them from key aspects of sociality (more on this in chapter 4).

While sickness has been defined as work's opposite, some sick people have to work paid jobs—but, ironically, precisely because they are sick and need health insurance. My conception of sick work draws from Ellen Samuels's notion of "crip time as sick time": "If you work 9 to 5, five days a week, or what is defined as full-time work in the United States, then (if you're lucky) you accumulate a certain number of sick days. There is always a strange arithmetic to this process: maybe for every eight hours you work, you accrue one sick hour."[96] Ware likewise cites time as a reason that people with ME/CFS exist in frictional relationship with the world around them.[97] I connect Ware's astute observation to argue that not only the daily fabric of life with ME/CFS but also the legitimacy of ME/CFS itself rest on capitalism and modes of production.

Sick work, like sick time, is differentially distributed, emplotted in structures of class and racialized, gendered divisions of labor. I want to acknowledge that we could extend insights from sick work to the work it takes to live in other marginalized bodies: Black and brown people facing police brutality, for example, and the recently fast-accelerating hypervisibility of trans people who face transphobic rhetoric and violence. Like Puar, I also think of the example of Palestinians in the West Bank, stopped at checkpoints, where movement takes longer, friction exists at every moment, and thus under disability studies' own definitions we might—though we must do so thoughtfully—term them "disabled."[98] Departing from Hedva's theory, which places all marginalized subjects under the rubric "sick," I am wary of calling the above examples of labored living "sick work"; it risks enacting an imperial version of disability studies in incorporating more and more subjects who do not self-identify as disabled or sick, and we must respect differences even as we create alliance.[99] I choose to focus on the fatigued body here as a means to zero in on exertional economies and energy's crucialness to capital. If some bodies themselves are already "full-time jobs," who's owed overtime?[100]

The powerful relationship between capitalism and debility, thus, operates not only to injure subjects or to deem them worthless due to disability per se. It also operates through determining who is and who is not legitimately ill. I draw from Beatrice Adler-Bolton and Artie Vierkant in *Health Communism*, who write that it is not just that capitalism "constructs" illness—that is, it is not just that capitalism defines bodies in terms of productive value—it is also that capital requires "biocertifications" to declare populations surplus.[101] Similarly,

the late disability activist Marta Russell notes, "If workers were provided with a federal social safety net that adequately protected them through unemployment, sickness, disability, and old age, then business would have less control over the workforce."[102] ME/CFS brings this into special relief because capitalist forces have, from the very inception of capitalism, singled out fatigue as something that must be eliminated by technology or managed by the individual. Capital's fundamental drive is quite literally to turn exertion (living labor) into profit (dead labor). If just "any" kind of fatigue could exempt one from work, then capitalism would short-circuit itself, caught in a contradictory loop.

Here it is not the label of "sickness" but the *absence* of recognition as sick—the inability to qualify for the sick role—that is pathologizing, reconfiguring traditional understandings of medicalization mentioned above. In the 1984 book *The Disabled State* (published smack dab in the middle of the Reagan administration), Deborah Stone puts it succinctly: "Ultimately, the question of which groups of people should be included in a disability benefit program is a political judgment . . . not something dictated by *clinical measures themselves*."[103] The clinic is never just the clinic; it operates in tandem with the state and capital. But turning sick work into successful political movements is an extra difficult task when, as Hedva points out, chronically ill people can perform only invisibilized forms of activism, including from bed. *Act*, after all, is in the word *activism*; movement is required for traditional forms of social movements.

Radial Methodology

You will find this book relatively undisciplined. In order to capture what is essentially a counterhistory (why *isn't* ME/CFS fully accepted?), I had to feel around the edges of the clinic, creating a mosaic of sites and archives. Initially conceived of as ethnographic, the research took on the form of what could be described as a hub-and-spoke model: I radiated outward from my fieldwork with an ME/CFS activist organization, which I call ME Progress (a pseudonym), taking it as my starting point and orienting site. Starting in 2016 and up until early 2020, I observed rallies, scientific conferences, activist meetings, and support groups that I found through the activists, based primarily with ME Progress communities in New York City and the Bay Area, two major geographic areas for ME/CFS activism. I followed ME Progress members as they attended protests, film screenings, talks, scientific conferences, and support groups primarily in their hometowns, and I also connected with them at major conferences across the globe, either virtually or in person. I interviewed fifty of them both remotely and in person, and I conducted formal and informal interviews with about five ME/CFS researchers and

specialists. My focus on patients came with the specific aim of looking from the patients' perspective up rather than producing a clinical ethnography. I sought to understand how illness is enacted both inside and outside the clinic.[104] This approach became not just multisited but also "polymorphous," as Hugh Gusterson puts it in the context of "studying up," and "quantum," to borrow from Abigail Dumes's ethnography of Lyme disease.[105] My fieldwork was two places at once, sometimes literally. Take the Zoom interviews, which took place from both the patient's home (often their couch, recliner, or bed) and my own tiny Brooklyn bedroom. Or even the conferences I went to in person: I sat in overly air-conditioned auditoriums while listening to presentations livestreamed to a much larger global homebound viewership, tuning in from the cruel comfort of their beds.

This book also presents a history of ME/CFS, although it's just one way of telling it. The "hub" that was my fieldwork kept leaving me with questions I could not satisfyingly answer until I looked backward in time. For example, my interlocutors raised the question of why the CDC chose *fatigue* in the naming of the diagnosis in the 1980s, when in fact, the disease goes "way beyond fatigue," as one said. I chewed on this question and decided I needed to go back to the origins of fatigue, which lie in industrial management science. What makes fatigue sound benign, and how does it thread through to the dismissal of ME/CFS? I also considered why activist groups contained so many bourgeois white women. In addition to the more obvious reasons (resources, privilege, bias), I went back to consider how fatigue became associated with white women over the course of the twentieth century. This meant I spent time in labor and feminist archives that tracked anxieties over white women in the paid labor force and their "double shift" at home. I was also surprised to see so many comparisons with HIV/AIDS among both the ME/CFS activists themselves and even the framework of ME Progress, which was inspired by AIDS activist groups such as the AIDS Coalition to Unleash Power (ACT UP), primarily active in the late 1980s and early 1990s. Moreover, AIDS and ME/CFS were contemporaneous, and some of the few places one can find anything about ME/CFS in the archives were in fact gay and lesbian archives, for reasons I go into further in the first interlude. Therefore, I looked to these archives to understand the place of viruses and syndromes in the cultural imagination.

I had to dispense with fantasies of spending time in a single site or archive. I would not call the methodology "radical," yet etymologically speaking, to be radical means to grasp the problem at its root, as Angela Davis points to.[106] I try to grasp the nature of ME/CFS at its "rootedness" in historical and cultural context, and the book unsettles traditional ways of doing research. This is a happy

accident in retrospect, but at the time, fieldwork did not feel wholly satisfying. I wished I could do more in-person work, and it was not my aspiration to do the vast majority of the research remotely. But as my mentors always reminded me, sometimes failures are findings. The distinction between being "in" versus "out" of the field broke down when the object under investigation was an unstable target.

There are implications here for all researchers, not just for those studying chronic illness. Unintentionally, because the research was conducted before COVID-19 began, the book provides one road map for doing fieldwork in "patchy" ways in our brave new postpandemic world.[107] Consider that in the coming years down the publication pipeline, we will see many an ethnographer attempt to cohere what was by necessity their ruptured or disrupted fieldwork during COVID-19. We ought to embrace incoherence while not romanticizing or fetishizing remote ethnography.[108] In other words, there was nothing sleek or sexy about why I chose a virtual or hybrid method—it is because people with ME/CFS are debilitated and isolated due to their social, political, and medical dismissal. As a reminder, people with ME/CFS were one of the few groups for whom stay-at-home orders in the early phases of the pandemic changed little about their day-to-day lives.[109] So it is important to stay away from "novelty" and instead recognize the "crip wisdom" that disabled people have long held.[110] Building on Black, decolonial, queer, and feminist critiques of traditional anthropological method, disability anthropology invents methods when the world is not made for disabled people—and this precedes COVID-19.[111] By acknowledging this, the book attempts not only to reveal the implications for method, but also to demonstrate something fundamental about embodiment's frictional interface with the world.

Outline

This book examines sick work across multiple levels, sites, and scales. I start by situating *who is allowed to be ill* in changing formations of labor and show that the line between sickness and work is a shifting one: Work sets the stage for which impairments are normal and which are pathological—and for which situated subjects. Chapter 1, "Side Affects," thus starts us off with a prehistory of ME/CFS, contextualizing the invisibilization of debility in changing formations of work over the course of the twentieth century. I conduct an archaeology of the cultural idea of chronic fatigue by contextualizing it in labor history. Specifically, I launch from the origins of fatigue in late nineteenth-century scientific management and track it through to changing arrangements of gendered and

racialized labor, culminating in the absorption of fatigue into the new paradigm of "stress" in the late 1970s. In this regard, I show both how white women became a cultural and political lightning rod for anxieties over exhaustion and capitalism and also how "chronic fatigue" got subsumed into a normal side effect (or side affect) of capitalism. If capitalism runs on fatigue, I argue, then people with ME/CFS (although experiencing a qualitatively different kind of fatigue) threaten to unravel it by demonstrating the centrality of sick work to our iatrogenic system of labor and healthcare.

In chapter 2, "Proximate Causes," I take us to the mid-1980s through early 1990s to explore the birth of the modern ME/CFS patient activist movement. ME/CFS first emerged as a formal diagnostic entity when it was investigated by the CDC in 1984, the year that Robert Gallo announced his finding that HIV caused AIDS. In both cases, activists had to perform the labor of transforming a neglected and misunderstood disease into a visible and well-funded one. I argue that HIV/AIDS and ME/CFS were substantively intertwined, in their similar and overlapping activist movements and in the scientific paradigms used to investigate them (in particular, the virus-to-syndrome model). But they also faced divergent patient profiles from the beginning: People with AIDS were stigmatized because they belonged to "morally deviant" groups, whereas people with ME/CFS were stigmatized and dismissed precisely because they were held to be privileged Yuppies. AIDS found a virus to match the syndrome, whereas ME/CFS continues to be questioned. Invisibilization functions through both the gravitas of identified scientific causes and the ways differently positioned bodies impact what kinds of activist causes can unfold. In examining patient activism as sick work, this chapter shows the recursive links between medicine and politics.

Chapter 3, "Energy Deficits," continues this examination of medicine and politics by looking at ME/CFS's lack of biomarkers (objective, discrete biological indicators of disease) and the sick work that people have to do in their absence. This includes both self-advocacy and political advocacy. I argue that biomarkers serve as forms of symbolic and material currency: They capacitate people with ME/CFS by unlocking resources from state and private insurance systems, and they are also intersubjective currency, allowing people with ME/CFS to find interpersonal validation and belief. Sometimes, biomarkers even validate the reality of disease to the person who has ME/CFS, confirming that it's not "all in their head" despite medical dismissal and social doubt. But it takes *work* to be ill: People with ME/CFS must go to expensive doctors, travel to specialists, and participate in arduous tests, all because they cannot work jobs, creating perpetual energy deficits. They also have to spend money to go to these doctors, even though they cannot make money working a job.

Chapter 4, "The Living Dead," turns to ways people with ME/CFS live through the invisibilization caused by scientific uncertainty and perpetual debility. It revisits the fraught question of the politics of medicalization, which I argue is not about false consciousness but about forming activist worlds under the crushing weight of denial. This chapter looks at how people with ME/CFS relate to medical research to cultivate hope on both individual and collective scales. It contextualizes this work in what has been described as "a living death": a life in isolation without prospects for getting better. Mourning their past lives, people with ME/CFS attach to the futurity of science to live on in the protracted debility of the present. This protracted debility, though, is not caused by medical ignorance alone. It is thoroughly structured by the fact that narrow forms of biocertification determine what kinds of lives disabled people can live under a system of care contingent on paid labor, the family, or meager avenues of state support.

There are three interludes, or "rests," between the chapters. They are pauses in the book, invitations for readers to literally rest. By design, they are brisk. They are metanarratives that typically zoom out to a larger stake or political implication of the project. Finally, the book ends with an "*un*rest," a nonconclusion that contains reflections on what comes "after" the chronic.

Redefining medicalization as a function of labor, *Sick Work* shows how medicine mediates our relationships to work, which requires of us labor in return. This book is not a clinical or laboratory ethnography, nor is it even about people's relationships to the doctor's office (I did not accompany people inside). It is also not a triumphant story of how people fight back against medical authority. It instead focuses on those "conditions not of our own choosing": gendered and racialized regimes of labor, the cultural salience of science, and the relationship between the state and the family. It grapples with the apparent paradox of why people both push back against medicine and desire its approval.[112] To invoke Berlant, I am interested in the ways that people attach to biomedicine despite this rejection, caught up in its apparatuses, in ways that create stuckness and inertia, leaving ME/CFS in a state of forestalled legitimation and the people living with it trapped in that lacuna.[113] I skirt around the borders of biomedicine to understand what it incorporates and denies, why and how it does so, for whom, and when.[114]

Notes

PROLOGUE: THE ILL OBSERVER

1. Behar, *The Vulnerable Observer*, 9.

2. Behar, *The Vulnerable Observer*, 14.

3. Durban, "Anthropology and Ableism"; E. Rogers, "Virtual Ethnography."

4. Michele Friedner, Devva Kasnitz, and Zoë Wool, "What I Wish I Knew About Anthropology and Disability: Notes Toward a More Enabling Anthropology," *Anthrodendum* (blog), January 10, 2018, https://anthrodendum.org/2018/01/10/what-i-wish-i-knew-about-anthropology-and-disability-notes-toward-a-more-enabling-anthropology/.

5. Anzaldúa, *Light in the Dark*, 5.

6. Or maybe I disidentify with them, neither sanguine about their political potential nor able to handle what would happen in their absence: Muñoz, *Disidentifications*.

7. More recently, in July of 2025 and in the middle of final revisions on this book, I fell down another set of stairs and sprained my "good" ankle. I later completed physical therapy with flying colors. That ankle is mostly "normal" but will never quite feel the same. For people with connective tissue disorders, relationships to medicine and medicalization are especially fraught. We people with Ehlers-Danlos syndrome (EDS) and connective tissue disorders must manage a double bind. On one hand, physical therapy is necessary to help us navigate everyday life. On another, we will never be fully "cured." Assistive devices are highly controversial. Sometimes, they worsen the injuries that come with EDS and make us *less* likely to access public space. Other times, they make us more likely to access public space by helping us avoid further injury, go up stairs, carry an object. Many, like myself, vacillate between these poles, which are political and personal at once. Can't we have pride in our canes, our rollators, our ankle braces? But these very devices that allow access can often take it away—and in reality, no one really thinks physical therapy is about "curing" EDS or internalizing the medical gaze. There is much more to say, and I hope someone writes about this. For now, as this book will show, I will say this: Disabled people have relationships to medical institutions but never under conditions of their own choosing.

8. Patsavas, "Recovering a Cripistemology of Pain," 211.

9. Lorde, *Sister Outsider*, 138.

10. Schalk, *Black Disability Politics*.

11. Elsewhere I'll call this methodology "radial," but moving among different sites, scales, and theoretical orientations could be deemed, as Muñoz does, queer, and a form of "cruising" between topics: see Muñoz, *Cruising Utopia*.

12. Munt, "Unhealthy Attachments." On "the couple form," see Brilmyer et al., "The Ontology of the Couple."

13. Weeks, "Abolition of the Family"; S. Lewis, *Abolish the Family*; D. Davis, *Battered Black Women and Welfare Reform*.

14. Vider, *The Queerness of Home*.

15. Kim, "The (Crip) Revolution Begins at Home."

16. A. Davis, *Women, Culture and Politics*, 14.

INTRODUCTION

1. Paula Dranov, "Am I Sick or Am I Tired?," *Ladies Home Journal*, September 1989, Box 43, Folder F, Countway Library of Medicine, Boston, MA.

2. CDC National Center for Health Statistics, "Myalgic Encephalomyelitis / Chronic Fatigue Syndrome in Adults: United States, 2021–2022," December 14, 2023, https://doi.org/10.15620/cdc:134504.

3. At this time, the cases were understood to be chronic Epstein-Barr virus. Out of the ninety cases, fifteen were solicited for further investigation because of the severity of their symptoms; all fifteen were white and thirteen were female. CDC, "Chronic Fatigue Possibly Related to Epstein-Barr Virus." An extensive discussion of the many viral culprits for ME/CFS—and the failure of any singular cause to pan out—is in chapter 2.

4. Straus et al., "Allergy and the Chronic Fatigue Syndrome." It is intriguing that this racialization of ME/CFS mirrors early ideas about polio that were also later revised. See N. Rogers, "Race and the Politics of Polio." Many ME/CFS activists point to outbreaks of fatigue in the 1950s as being organically linked to contemporary manifestations of ME/CFS. These outbreaks were, at the time, understood as episodes of "benign polio."

5. The amount of spending on ME/CFS has been among the lowest of any disease category that the NIH has funded for the past several fiscal years, hovering around US$5 million to US$8 million per year, on par with hay fever and similar to amounts for rare diseases. Funding for ME/CFS is quite low in proportion to its estimated prevalence, which is similar to HIV/AIDS or multiple sclerosis: For comparison, HIV/AIDS received US$3 *billion* per year over the same period, and multiple sclerosis received around US$100 million. This means that for every person with ME/CFS, there is around *two to five dollars* in research spending. See NIH RePORT, "Funding for Various Research, Condition, and Disease Categories (RCDC)," accessed December 16, 2025, https://report.nih.gov/funding/categorical-spending#/.

6. Ross et al., "Systematic Review of the Current Literature."

7. National Institutes of Health, "NIH Announces Centers for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Research," September 27, 2017, https://www.nih.gov/news-events/news-releases/nih-announces-centers-myalgic-encephalomyelitis-chronic-fatigue-syndrome-research.

8. Ed Yong, "Long-Haulers Are Redefining COVID-19," *Atlantic*, August 19, 2020, https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/.

9. Mendenhall, *Invisible Illness*.

10. Marcus, "Ethnography in/of the World System."

11. Jason et al., "A Community-Based Study of Chronic Fatigue Syndrome." Without biomarkers for ME/CFS, studies on prevalence have been conducted using phone screenings and questionnaires. These studies have found that working-class women of color are in fact the most likely to experience symptoms of chronic fatigue. But the vast majority of these women have no diagnosis. Early case studies (e.g., by Stephen Straus) raised the idea that the disproportionate number of white, highly educated women presenting with chronic fatigue symptoms could be due to demographic bias in who has the time, money, and cultural resources to locate, go to, and pay for a specialty doctor—only to dismiss it. As Straus writes, "[The demography of this syndrome] may reflect either a bias toward the cohort of sufferers who can best afford a sophisticated medical evaluation or some unique constitutional frailty of such individuals. . . . A less casual appraisal, however, often uncovers histories of unachievable ambition, poor coping skills, and somatic complaints" (Straus et al., "Allergy and the Chronic Fatigue Syndrome," 791).

12. Hsu et al., "Patients as Knowledge Partners."

13. Diedrich, *Illness Politics and Hashtag Activism*, 101.

14. Kaufman, *Ordinary Medicine*. I also thank an anonymous reader for the suggestion of the title of this subsection.

15. Lupton, "Health Promotion in the Digital Era."

16. Dumit, "Illnesses You Have to Fight to Get."

17. It is difficult to pin down the exact disease burden of ME/CFS because, as mentioned, so little research funding is available. For instance, in its analysis of disease burden versus annual research funding, the NIH excluded ME/CFS because no one has calculated the disability adjusted life years (DALY), the way that the World Health Organization measures disease burden, for ME/CFS. A small study has tried to provide an initial estimate, which shows that DALY for ME/CFS is around that of multiple sclerosis, HIV/AIDS, and autism. Dimmock et al., "Estimating the Disease Burden of ME/CFS in the United States."

18. I credit Rouzbeh Shadpey for this terminology. See Rouzbeh Shadpey, "At the Mercy of Limitless Loss," *Weird Economies*, January 15, 2024, https://weirdeconomies.com/contributions/at-the-mercy-of-limitless-loss.

19. E. Martin, *Bipolar Expeditions*.

20. Ware, "Toward a Model of Social Course in Chronic Illness," 305.

21. Livingston, *Debility and the Moral Imagination in Botswana*, 140, 134.

22. Murphy, *Sick Building Syndrome*; Buchbinder, *All in Your Head*.

23. Even the US Centers for Disease Control views ME/CFS as "biological" and "debilitating" and also acknowledges that symptoms may be "severe." I will not belabor this point; whether it is real is not only a boring question for an anthropologist, but it is simply not up for debate. Patient activist organizations have done so much work in attempting to spread awareness, and their articulations are much better than what I can do

here. In addition to listening to the views of my interlocutors and their stories, I would suggest that those wishing to educate themselves explore MEPedia, an online, Wiki-style encyclopedia. US Centers for Disease Control, "Myalgic Encephalomyelitis / Chronic Fatigue Syndrome," May 10, 2024, https://www.cdc.gov/me-cfs/about/index.html.

24. Epstein, *Impure Science*; E. Martin, *Flexible Bodies*.

25. Watkins, "Stress and the American Vernacular."

26. H. Johnson, *Osler's Web*; Spandler and Allen, "Contesting the Psychiatric Framing of ME/CFS."

27. David Tuller, "Chronic Fatigue Syndrome—Health News," *New York Times*, July 17, 2007, sec. Science, https://www.nytimes.com/2007/07/17/science/17fatigue.html.

28. Wilshire et al., "Rethinking the Treatment of Chronic Fatigue Syndrome"; National Institutes of Health, "NIH Announces Centers for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Research."

29. Rabinbach, *The Human Motor*; Lowe, *The Body in Late-Capitalist USA*; Harvey, *Spaces of Hope*; Jain, *Injury*; E. Martin, *Flexible Bodies*; Jackson, *The Age of Stress*.

30. Marx, *Capital*, 526.

31. Cook, "Workers' Compensation and Stress Claims."

32. Metzl, *The Protest Psychosis*; Goffman, *Asylums*; Shah, *Contagious Divides*; Chen, *Intoxicated*; Beliso-De Jesús, *Excited Delirium*.

33. "Deserving and undeserving poor" is from Schweik, *The Ugly Laws*.

34. For the classic exploration of the deviant sexual politics of the welfare queen, see Cohen, "Punks, Bulldaggers, and Welfare Queens."

35. Cooper, *Family Values*.

36. Josh Levin, "The Real Story of Linda Taylor, America's Original Welfare Queen," *Slate*, December 19, 2013, http://www.slate.com/articles/news_and_politics/history/2013/12/linda_taylor_welfare_queen_ronald_reagan_made_her_a_notorious_american_villain.html.

37. Kim, "Cripping the Welfare Queen." See also Kim, *Care at the End of the World.*

38. Samuels, *Fantasies of Identification*; Schweik, *The Ugly Laws*; Siebers, "Disability as Masquerade." See also Megh Marathe's article "Differential Pace: Technology and Inequality in the Making of Episodic Disability," on intermittent disability, which presents a theory of "differential pace."

39. Wailoo, *Pain*.

40. Sunaura Taylor, "The Right Not to Work: Power and Disability," *Monthly Review* (blog), March 1, 2004, https://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/.

41. Carrillo, *When Care Is Conditional*.

42. Conrad, "Medicalization and Social Control"; Zola, "Medicine as an Institution of Social Control."

43. Illich, *Limits to Medicine*.

44. Conrad and Stults, "Contestation and Medicalization"; Barker, "Electronic Support Groups, Patient-Consumers, and Medicalization"; Fair, "Morgellons"; Moretti and Barker, "Suffering Without Remedy"; Ballard, "The Medicalization of Human Condition and Contested Illness."

45. Ehrenreich and English, *Complaints and Disorders*.

46. Conrad, *The Medicalization of Society*.

47. Callard and Perego, "How and Why Patients Made Long COVID"; Mendenhall, "Long COVID Politics and Activism."

48. Ginsburg and Rapp, "The Politics of Reproduction"; Fassin, "This Is Not Medicalization"; Crowley-Matoka and True, "No One Wants to Be the Candy Man."

49. Clare, *Brilliant Imperfection*, 139.

50. Fassin, "This Is Not Medicalization."

51. Livingston, "Insights from an African History of Disability"; Puar, *The Right to Maim*.

52. Livingston, "Insights from an African History of Disability."

53. Puar, *The Right to Maim*, 4.

54. Taylor, *Disabled Ecologies*, 192.

55. Guffey, *Designing Disability*.

56. Hamraie, *Building Access*.

57. Adler-Bolton and Vierkant, *Health Communism*; Shew, "Ableism, Technoableism, and Future AI"; Mollow, "Criphystemologies."

58. Linton, *Claiming Disability*, 138.

59. Crow, "Including All of Our Lives," 209.

60. Wendell, "Unhealthy Disabled," 18.

61. Mollow, "The Disability Drive."

62. Price, "The Bodymind Problem," 274.

63. Price, "The Bodymind Problem," 275.

64. Price, "The Bodymind Problem," 277.

65. Scarry, *The Body in Pain*.

66. Taylor, *Disabled Ecologies*, 96.

67. Kafer, *Feminist, Queer, Crip*, 138.

68. Kafer, *Feminist, Queer, Crip*, 138.

69. E. Rogers, "Recursive Debility."

70. Existing studies of contested illnesses, including ME/CFS, tend to focus on the gap between experience and empiricism—a divide that tracks with the "illness/disease" binary distinguishing between subjective symptoms and biomedical object. Anthropologists such as Joseph Dumit and Abigail Dumes expand understandings of contested illness and the medicalization process beyond overly pat models of medical social control. Dumit describes contested illnesses as "illnesses you have to fight to get" and describes the wielding of facts as forces. Dumes examines chronic Lyme patients and their negotiations with evidence-based medicine. Resisting talking about either "illness" or "disease," she maintains that bodies are "divided" into two.

71. Dumit, "Illnesses You Have to Fight to Get."

72. Epstein, *Impure Science*; Hartblay, "Disability Expertise."

73. Adams, *Glyphosate and the Swirl*; Mol, *The Body Multiple*.

74. Diedrich, *Illness Politics and Hashtag Activism*.

75. Kleinman, *The Illness Narratives*. As Stefan Ecks puts it, there is a distinction between "disease to be explained" and "experience to be understood," which "entails

an implausible partition between 'disease' as something to be *explained* by the natural sciences and 'illness' as something to be *understood* by a hermeneutic approach." He periodizes this split as co-emerging with the medical humanities in the late 1970s. Ecks, "Three Propositions," 587. See also Abigail Dumes's *Divided Bodies*, an ethnography that aims to "bridge the often presumed gap between illness *experience* and disease *knowledge* by examining how patients *and* physicians 'do' and 'know' disease" (99).

76. Dumes, "Lyme Disease"; Kempner, *Not Tonight*; Murphy, *Sick Building Syndrome*; Jutel, *Putting a Name to It*.

77. Adams et al., "Chronic Disaster Syndrome," 4.

78. Desjarlais and Throop, "Phenomenological Approaches in Anthropology."

79. Susan Wendell discusses this extensively in a footnote in her article "Unhealthy Disabled." It is worth quoting at length: "In this article, I am using 'sickness' and 'illness' synonymously to mean suffering, limitation, and/or loss of function experienced by a person and attributed by her/him (or others) to a loss of health and not to a physical or mental condition present from birth or acquired by an injury to a specific part of the body. I am using 'disease' to refer to some medically recognized diagnostic categories of physical or mental 'abnormality.' Not all sicknesses and illnesses are diseases recognized by medicine, and not all medically recognized diseases cause a person to feel sick or ill. My definitions are based on ordinary use of the words; unfortunately, ordinary use does not make precise distinctions, so there are afflictions that do not fit the definitions neatly (such as chronic inflammation of an injured limb)" (32).

80. A caveat that this claim is highly situated. For example, Jasbir Puar notes in *The Right to Maim* that Gazans become productive subjects *precisely because* they are disabled. She terms this *inhuman biopolitics*, where maiming is necessary to maintain colonial power yet also to "keep labor alive" and so that Israel may profit from their rehabilitation (146). This is also reminiscent of Sunaura Taylor's argument that disabled people are profitable only as "beds." Nonetheless, I'd make a distinction here between profit made from labor and profit made from consumption (even if that "consumption" is a result of forced dependency on the state or state violence). As we will see throughout this book, in the American context some people have to work because they are sick. Tying healthcare to work extracts profit from sick people who have no choice but to be productive subjects.

81. Berlant, *Cruel Optimism*, 95; Harvey, *Spaces of Hope*.

82. Parsons, "Illness and the Role of the Physician," 456.

83. Kleinman, *The Illness Narratives*, 7.

84. Linker, *War's Waste*.

85. Tani, "Disability Benefits as Poverty Law," 1718.

86. Piepzna-Samarasinha, *Care Work*; Nishida, *Just Care*; Nadasen, *Care*.

87. Ginsburg and Rapp, "Disability Worlds"; Matthew Wolf-Meyer, "Forget Care," *Anthropology News*, January 16, 2025, https://www.anthropology-news.org/articles/forget-care/.

88. Piepzna-Samarasinha also highlights the issue of interdependency. But interdependency gets complicated—as they also note—in situations of pain and fatigue, where some disabled people can do more work than others. *Care Work*, 59; Nishida, *Just Care*.

89. Johanna Hedva, "Sick Woman Theory," *Topical Cream*, 2022, https://topicalcream.org/features/sick-woman-theory/.

90. In *Care*, Premilla Nadasen smartly notes that sometimes what we call "care" has been absorbed into the capitalist economy and is in reality "social reproduction" and generates profits. On the flip side and by contrast, sick work is *not* socially reproductive because of what we will see in chapter 4 is a kind of subsocial existence of bedbound, "nonproductive" subjects.

91. Marx, *Economic and Philosophic Manuscripts of 1844*.

92. Marx, *Capital*, 342.

93. Marx, *Capital*, 342.

94. Hsu et al., "Patients as Knowledge Partners."

95. Rouzbeh Shadpey, "Patient of Lyrics, Writer of Clinics" syllabus, Wendy's Subway workshop, December 14, 2025.

96. Samuels, "Six Ways of Looking at Crip Time."

97. Ware, "Toward a Model of Social Course in Chronic Illness."

98. Puar, *The Right to Maim*.

99. There are various ways of thinking through this problem. Puar discusses the unproblematized incorporation of Palestinians as disabled as an (unintentional) product of Western imperialism, critiquing the "80% of disabled people live in the Global South" framework. By stark contrast, Leah Lakshmi Piepzna-Samarasinha penned a piece called "Palestine Is Disabled" in January 2024. Alice Wong's "Crip Call to Action" exists somewhere between these frameworks (posted in November 2023), connecting disability justice to Palestine. There are calls to disrupt disability studies through a decolonial frame, which sometimes means simply adding voices and topics from the Global South. Puar, "Critical Disability Studies"; Leah Lakshmi Piepzna-Samarasinha, "Palestine Is Disabled," *Disability Visibility Project* (blog), January 26, 2024, https://disabilityvisibilityproject.com/2024/01/26/palestine-is-disabled/; Alice Wong, "Why Palestinian Liberation Is Disability Justice," *Disability Visibility Project* (blog), December 2, 2023, https://disabilityvisibilityproject.com/2023/12/02/why-palestinian-liberation-is-disability-justice/; Meekosha, "Decolonising Disability"; Jaffee, "Disrupting Global Disability Frameworks."

Emma Shaw Crane and I have compiled more resources on the website and syllabus project anthropologyforpalestine.org, which we created in December 2023. Optimistically, it seems quite possible that if we keep thinking about it, disability justice and disability studies can call for the liberation of Palestine without flattening experiences. See "Medical Anthropology for Palestine," https://www.anthropologyforpalestine.org.

100. I say this not to slip into a neoliberal model of checking your privilege and CashApping your marginalized friends, but rather to point out the central contradictions in how we think about work. Think "wages for housework" versus "wages *against* housework": It's not about "valuing" bodies "more," but rather tearing the system of valuation apart—more on this in the third interlude.

101. Adler-Bolton and Vierkant, *Health Communism*, 180.

102. Russell, *Capitalism and Disability*, 19.

103. Stone, *The Disabled State*, 129 (emphasis mine).

104. Brown et al., *Contested Illnesses*; Packard et al., *Emerging Illnesses and Society*.

105. Gusterson, "Studying Up Revisited"; Dumes, *Divided Bodies*.

106. A. Davis, *Women, Culture and Politics*, 14.

107. Gökçe Günel, Saiba Varma, and Chika Watanabe, "A Manifesto for Patchwork Ethnography," Society for Cultural Anthropology, June 9, 2020, https://culanth.org/fieldsights/a-manifesto-for-patchwork-ethnography.

108. E. Rogers, "Virtual Ethnography."

109. Emily Lim Rogers, "Staying (at Home) with Brain Fog: 'Un-Witting' Patient Activism," *Somatosphere*, October 5, 2020, https://somatosphere.com/author/emily-lim-rogers/.

110. Piepzna-Samarasinha, *Care Work*; Nishida, *Just Care*; Nadasen, *Care*; Michele Friedner, Devva Kasnitz, and Zoë Wool, "What I Wish I Knew About Anthropology and Disability: Notes Toward a More Enabling Anthropology," *Anthrodendum*, January 10, 2018, https://anthrodendum.org/2018/01/10/what-i-wish-i-knew-about-anthropology-and-disability-notes-toward-a-more-enabling-anthropology/.

111. D. Lewis, "Anthropology and Colonialism"; Pels, "Classification Revisited"; Bolles, "Telling the Story Straight"; Alonso Bejarano et al., *Decolonizing Ethnography*; Weiss, *Unsettling Queer Anthropology*; Behar, *The Vulnerable Observer*; Durban, "Doing It Together"; Hartblay, "Disability Expertise"; Emily Lim Rogers, "The Lapsed Ethnographer: Toward Foggy Fieldwork," Society for Cultural Anthropology, September 6, 2022, https://culanth.org/fieldsights/the-lapsed-ethnographer-toward-foggy-fieldwork.

112. Aronowitz, "From Myalgic Encephalomyelitis to Yuppie Flu," 171.

113. Berlant, *Cruel Optimism*; Friedner, *Sensory Futures*.

114. I draw this phrasing from Donna Haraway, from a must-watch, high-camp 1987 episode of *Paper Tiger TV*: "Donna Haraway Reads the *National Geographic* on Primates," https://papertiger.org/donna-haraway-reads-the-national-geographic-on-primates/.

CHAPTER 1. SIDE AFFECTS

1. This response is almost identical to the one Ware identifies in her case study of people with ME/CFS in the early 1990s: "So CFS sufferers, in trying to articulate their experience, typically elicit a disconfirming response: 'You're tired? I'm tired too! Half the world's tired. The whole world's tired! Big deal.'" Ware, "Toward a Model of Social Course in Chronic Illness." The consistency of this refrain—despite the decades between these two examples—points to how energy is at the heart of capitalism.

2. On overlapping and compounding experiences of race and debility, see Mullings, "Resistance and Resilience."

3. Earlier uses of *fatigue* most often used it as a verb or adjective (e.g., "a fatiguing journey," "his respiration became fatiguing") and interchangeably with *tiring*. The idea that fatigue could be a chronic state, and an investigable object, would not be incorporated until later. For instance, the phrase *chronic fatigue* first appeared (anywhere in the record) in *The Lancet* in 1873, in the *British Medical Journal* (*BMJ*) in 1874, in *Medico-Chirurgical Transactions* (later *Journal of the Royal Society of Medicine*) in 1887, the *Boston Medical and Surgical Journal* (later *New England Journal of Medicine*) in 1888, and in the *American Journal of Medical Sciences* in 1909. Similarly, the term *fatigue* appeared for the first time