

THE UNIVERSITY OF CHICAGO

**It's not 'anxiety':
gendered bodies and contested illness
among COVID-19 'Long-haulers'**

By

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August 2022

A paper submitted in partial fulfillment of the requirements for the Master of Arts
degree in the Master of Arts Program in the Social Sciences

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Abstract

Researchers estimate that ten percent of people who have had COVID-19 experience prolonged symptoms. Often referred to as *Long COVID*, these symptoms, which can include fatigue, shortness of breath, brain fog, sleep disorders, fevers, gastrointestinal symptoms, anxiety, and depression, can persist for months and can range from mild to incapacitating. In some cases, new symptoms arise sometime after initial infection or evolve over time. While still being defined, these effects are now collectively referred to as Post-Acute Sequelae of SARS-CoV-2 infection (PASC) in the United States, also known as mild-covid or Long COVID. These patients call themselves “long-haulers” and they are facing doubts from medical providers about their symptoms when seeking services and treatment. Although research studies have indicated women are more likely to be long-haulers, it is, in fact, women who have reported experiencing difficulties negotiating a diagnosis by the medical community, repeatedly being told "it's just anxiety." How does disbelief and delegitimation affect the illness experiences of women with contested illnesses? This article seeks to examine the search for illness legitimacy and its effects among women in the United States with Long COVID.

Keywords

Coronavirus, COVID-19, Long Covid, Illness Narratives, Symptoms, PASC, Epistemic Injustice, Contested Illness, Medical gaslighting, Illness Legitimacy, Access/demand/utilization of services, Gender/sex differences in health and health care, Sexual and gender minorities, Social determinants of health, Experiences with illness

1. Introduction

The primary care physician that I'm with now, the person who responds to our MyChart messages is very rude. I've had even some BIPOC fellow long hauler sisters look at it. They're speechless. So, it's very dismissive. To the point where I've had to say I feel like I'm being dismissed. I'm not sure if it's because of my race. I'm not sure if it's because of my gender. But I need you to listen to me and see what I'm saying. ... There's no sense of urgency of trying to get me fit in. I don't believe that doctors need to stop what they're doing. I understand they have patients, and they're busy. I get it. But there's no sense of even trying to get me an appointment in. No virtual option. Nothing. ... I don't think they realize the magnitude, the urgency that's needed for long haulers. So, the type of messages are just, again, go to the ER, just go to Urgent Care. There's nothing that we can do. My last doctor's visit I had maybe earlier this year, he looked at me in [the] face and basically said there's nothing else I can do for you.

In early 2020, an outbreak of disease named Coronavirus (COVID-19), caused by SARS-CoV-2, originated in Wuhan, China and struck the world. The virus caused a pandemic of unprecedented proportions, collapsed the globe, and prompted the World Health Organization

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(WHO) to declare COVID-19 a global pandemic in March 2020 (Cucinotta, Vanelli 2020). Two years later, as of June 2022, there have been more than 500 million confirmed cases of COVID-19 globally, and *more than six million deaths* (WHO 2022). In the United States (U.S.), the nation surpassed the one million mark for official, confirmed deaths from COVID-19 on May 12, 2022. It is estimated, however, the real number of deaths is much higher than reported (Johns Hopkins Coronavirus Resource Center 2022). In fact, COVID-19 was the third leading cause of deaths in the U.S. in 2020, behind heart disease and cancer (Shiels et al. 2022).

Given the wide-ranging implications of the COVID-19 virus, there is no doubt the pandemic has had devastating effects on multiple aspects of quality-of-life for individuals in the U.S. Certainly the virus outbreak is not only a disruptive moment in the nation’s history, but also yet another inflection point in the experiences of vulnerable groups in America. One of these major groups, commonly known as ‘long-haulers,’ are those individuals suffering from COVID-19 related disease that persists longer than the more common, two-week infection period. While still being defined and debated, the major health governmental bodies, clinicians, and the media are now collectively referring to this disease as *Long COVID*. In the past two years since the pandemic began, much research has focused on the effects of acute COVID-19 cases, including hospitalized patients. As such, it remains unclear why disbelief abounds (Yong 2020; Verduzco-Gutierrez 2021) when it comes to people suffering with Long COVID symptoms, especially women. As a long-hauler myself, I argue that by feminizing Long COVID, the biomedical industry not only perpetuates notions of women as ‘hysterical’ and fails to fully address chronic illnesses mainly affecting women, but causes further injury to women – especially those at the intersection of already marginalized and disproportionately impacted populations – by delegitimizing their illness and obfuscating the real impacts of Long COVID, which include

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racial disparities in healthcare access, and effects on motherhood, labor/employment and mental health.

In the U.S., the Government and Accountability Office estimates up to 23 million people have been affected by Long COVID (U.S. GAO 2022), and the U.S. National Institutes of Health have given the disease a name – Post-Acute Sequelae of SARS-CoV-2 infection (PASC) or ‘Post-Covid syndrome’ (Collins 2021) – although it was initially named by patients as ‘Long COVID,’ to describe the persistent nature of the illness. The U.S. Centers for Disease Control (CDC) have identified the collection of Long COVID symptoms to include “fatigue, shortness of breath, brain fog, sleep disorders, fevers, gastrointestinal symptoms, anxiety, and depression, and they can persist for months and range from mild to incapacitating,” (CDC 2022) although patients report more symptoms beyond these (Crook, et al. 2021). In some cases, new symptoms arise sometime after initial infection or evolve over time.

These COVID-19 long-haulers, in particular, have reported facing contestation from medical providers about the legitimacy of their symptoms when seeking diagnoses, services and treatment (Roth, Gadebusch-Bondio 2022). The quote at the beginning of this introduction is just one example of this contestation from the viewpoint of a long-hauler who chose to participate in this study. Researchers estimate that *ten percent* of people who have had COVID-19 will experience prolonged symptoms, and research studies have indicated women are more likely to be long-haulers (Bai, et al. 2022; Salmon-Ceron et al. 2020; Tran et al. 2020). In fact, women with Long COVID symptoms have reported experiencing difficulties negotiating diagnoses and treatments by the medical community, repeatedly being told ‘it’s just anxiety’ in the various stages of their illness journey (Rubin 2020). The purpose of this study was to examine how disbelief and delegitimation affect the illness experiences of women with contested illnesses.

2. Literature Review

The first research about the disease now known as Long COVID emerged from a self-organized, patient-led group of patients named the *Patient-led Research Collaborative* in the United Kingdom, in the spring of 2020. The team of researchers in neuroscience, public policy, health activism, participatory design, and data collection and analysis produced the report “What does COVID-19 Recovery Actually Look Like?” (Patient-Led Research Collaborative 2020) on May 11, 2020. Their report was the first to contest the narrative that COVID patients typically recover after two weeks, providing evidence that COVID-19 symptoms were being underreported in research and were not limited to fever, shortness of breath, and cough, but spanned other systems in the body including cardiovascular, neurological and gastrointestinal. The research survey indicated early on that subsets of COVID-19 patients were being excluded from testing, since testing was only available to those experiencing the standard symptoms of fever, shortness of breath, and cough (Patient-Led Research Collaborative 2020).

Three days before the *Patient-led Research Collaborative* published its report, geographer and historian Felicity Callard was the first scholar to emphasize the disease severity of the illness we now know as Long COVID, publishing an essay in *Somatosphere*, contesting the classification system of COVID-19 (borrowed from Wuhan, China) and criticizing the United Kingdom (UK) government’s characterization of a significant portion of Covid cases, including her own, as ‘mild.’ Callard argued characterizing such cases as ‘mild’ obfuscates the illness experiences of many who assert that their symptoms are anything but ‘mild’ or ‘moderate,’ and rather meets the objectives of hospitals interested in effective health service delivery, alleviates panic in the general public, and gives the impression that people do not need to properly shield themselves from the virus (Callard 2020a). While not directly referring to this

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phenomenon as ‘epistemic injustice’ at the time, Callard did underscore the importance of listening to the patient and their experiences as the illness is being shaped, warning of the “effects of the slippage between its [use of the term ‘mild’] application to both symptoms and illness” (Callard 2020a).

However, Elisa Perego, an archaeologist from Lombardy, Italy was the first to actually coin the term *#LongCovid* on via Twitter on May 20, 2020, to describe her own experience with COVID-19 as “cyclical, progressive, and multi-phasic.” (Callard and Perego 2021). The term resonated with other patients on Twitter and other fora and filled the gap in public health discourses where Long COVID patient experiences did not match what was being reported about COVID-19 (Perego et al. 2020). In September 2020, Perego and Callard collaborated, along with an interdisciplinary group of scientific, female scholars and other long-haulers, including Laurie Stras, Barbara Melville-Johannesson, Rachel Pope, and Nisreen Alwan to make a case for an epidemiological definition of ‘Long COVID’ and to advocate it be used as the official name for the illness (Perego et al. 2020). By the close of 2020, Callard published a historical account of her illness experience, observing not only how Long COVID patients helped shape the thinking about the COVID-19 epidemic, collectively, by sharing their symptoms and experiences via social media as they were debilitated by their symptoms, but arguing this type of thinking has the power to change how we chronicle epidemics, by shifting the temporal and spatial forms in which they occur (Callard 2020b).

In January 2021, Callard and Perego argued that Long COVID is the first patient-made illness and advocated for patient experiences to be taken into account as illnesses are being defined because legitimizing the patient’s experience has proven to be a critical factor in understanding the symptoms of disease (Callard and Perego 2021). At this point, Callard and

Perego highlighted the struggles of Long COVID patients who were seeking illness legitimacy using Miranda Fricker’s concept of ‘epistemic injustice’ (Fricker 2007).

In September 2021, Ilana Löwy, science historian working at the intersection of gender studies and biomedicine, was the first scholar to describe how Long COVID is being treated as a psychosomatic condition, comparing it to the patient experiences of those with other feminized invisible illnesses such as myalgic encephalomyelitis, also called chronic fatigue syndrome or chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), and common in women (Löwy 2021).

German scholars Phillip H. Roth and Mariacarla Gadebusch-Bondio, in January 2022, shed light on how subjective evidence of Long COVID patient experiences were shared on social media and other venues, and how that evidence was politically employed in public health discourses (Roth, Gadebusch-Bondio 2022). This has been a very different experience than the visibility CFS/ME patients, for example, have been able to achieve. Roth and Gadebusch-Bondio suggested Long COVID patients were successful in gaining exposure for their suffering, in part, because of the role that healthcare professionals played as patients in this context, because their reported experiences added credibility to the Long COVID narrative (Roth, Gadebusch-Bondio 2022).

3. Background

3.1 U.S. healthcare system and gender inequalities

In the U.S., the healthcare system is complex, and consists of several independent organizations including physician practices, specialized facilities, hospitals, nursing homes, research centers and more. Some of the main features of the healthcare system include the fact that there is no centralization; there is no single governing agency, which results in minimal

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integration and coordination among agencies or facilities. Inequities in access and healthcare outcomes abound in this highly expensive, decentralized system.

Additionally, Western biomedicine – the model employed in the U.S. – is characterized by its reductionistic approach to illness; it “reinforces the idea that diseases are isolable entities, found everywhere, and without moral or social significance” (Lock 2002). The fact that the patient’s experience is treated as separate from the context (e.g., geography, culture, events) in which their illness occurs seems to be a crucial gap in the understanding and healing of diseases that occur within a society. This separation of the individual from nature is a contributing factor in the disparate health outcomes of U.S. patients.

In the context of the COVID-19 pandemic, gender inequality in the global healthcare system has contributed to the ability, or inability, of women to access medical care, services and treatment (Su 2022; Heise, et al. 2019). For the purpose of this study, I will refer to the term ‘gender’ to be defined as “the different roles, responsibilities, and activities of women and men, which are socially constructed and result in different social expectations, opportunities, and experiences” (Nowatzki 2011). Therefore, I will examine the topic of disbelief and the search for illness legitimacy through the viewpoints of interlocutors who identify as *women* with Long COVID. It also should be noted that any discussion about gender in the U.S. cannot be held without examining the effects on women through the lens of class and race. Scholar Kimberlé Crenshaw refers to this concept as “intersectionality” to describe how people who belong to multiple identity categories (i.e., race, gender, class) have experiences that are shaped by these multiple, overlapping systems (Crenshaw 1991). I will employ the concept of intersectionality in the case of the long-haulers who I spoke with as part of my research project.

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In biomedicine, there is a long history of sexism, beginning with differentiating views on female biology and gender classification. According to his research, American historian Thomas Lacquer’s *one-sex-model* and *two sex-model* theory states women were originally viewed as “imperfect men” in the former and “beings determined by their sex and sexuality” in the latter, at the end of the eighteenth century (Bueter 2017). Additionally, women’s health has remained severely understudied for decades. In fact, clinical research has primarily been androcentric, with women largely being excluded from clinical drug trials (Rosser 1994) despite the fact that, “in developed nations, women outlive men by an average of 7 years” (Regan 2013). The result is an approach to medicine that is largely designed by men, for men. Even as medical professionals, men outnumber women, by nearly two to one (AAMC 2020).

The inequalities in gender in the U.S. expand to healthcare treatment as well. An alarming example is the differences in treatment and care of cardiovascular disease – the leading cause of deaths of both women and men in the U.S. (Shiels et al. 2022). In a 2020 Harvard health study of more than two million patients, researchers concluded that women were not prescribed aspirin, statins, and blood pressure medications as often as men (Zhao et al. 2020).

3.2 Women’s bodies and medical contestation

That women historically have been viewed as merely reproductive creatures has proven detrimental to women’s health outcomes. Nowhere can this be seen more than in the history of medicine treating women’s health issues as nothing more than ‘hysteria,’ although the definition of the condition has evolved from its symptoms being attributed to “a dislocated, wandering uterus” which, thereby, could only be applied to women (Bueter 2017). While this concept of women’s health issues did not endure through the ages, it laid the foundation for a biomedical

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profession that continues to dismiss a patient's subjective experience based on gender, referring to "patients' complaints as hypochondriacal, or simply as fantasy" (Lock 2002).

The problem with the biomedical profession categorizing women's illness as 'hysteria' is that it delegitimizes the women's experiences in the patient setting and makes it more difficult for them to achieve diagnosis and treatment. This problem can be viewed as *contested illness*, which can be understood as "illness that is dismissed as illegitimate – framed as 'difficult,' psychosomatic, or even non-existent" (Moss, Teghtsoonian 2008). Medical anthropologist Norma Ware's concept of contested illness states there are two forms of disbelief: trivialization, where the patient's symptoms are rejected; and delegitimation, where illness is dismissed as psychological (Ware 1992). The problem of disbelief and delegitimation also has been labeled as *medical 'gaslighting'* in academic and public health discourses, media and popular culture. Kate Abramson, who specializes in philosophical feminism, conceives of gaslighting as a form of manipulation in which one person tries to gain control over another by undermining not only the other's reality and perceptions (Abramson 2014), but "the other's conception of herself as an independent locus of judgment and deliberation" (Spear 2019). A more recent approach to analyze disbelief and delegitimation is through a medical ethics perspective and Miranda Fricker's concept of epistemic injustice, where "someone is given less credence than they deserve" (Andow 2010).

Dismissing the female patient's subjective experience often obfuscates the social, cultural, economic and political context in which the illness occurs. Margaret Lock, medical anthropologist, describes this phenomenon in her book, *Exotic No More: Anthropology on the Front Lines* in a case study of Greek immigrant women in Montreal in the 1980s. The female garment industry workers' symptoms came to be classified as a psychosomatic condition called

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‘nevra,’ or nerves, that was often medicalized with antidepressants rather than addressed within “the larger cultural and political realities of the lives of sufferers” (Lock 2002).

The tendency for biomedicine to contest certain ‘invisible’ illnesses, has occurred with some such as fibromyalgia, CFS/ME¹, and burnout, where patients experience symptoms that cannot be confirmed with current diagnostic testing or visibly seen (Moss and Teghtsoonian 2008). Persons suffering with CFS/ME, for example, have criticized the biomedicine industry for pathologizing the illness and for the current diagnostic label of ‘chronic fatigue’ not adequately capturing the severity of the disease (Open Medicine Foundation Canada 2022). In fact, researchers acknowledge that CFS/ME falls at the bottom of the hierarchy list of diseases that are important, or favored, by physicians, (Blease, Geraghty 2016) even though the illness affects more than 2.5 million Americans (Blease, Carel, Geraghty 2017). What is especially unique for the millions of individuals suffering from the disease is that a diagnosis can take years because no one has yet to develop a proper diagnostic tool to confirm, so “it remains a diagnosis of exclusion” (Harvey, Wessely 2009) where clinicians have to remain dedicated to searching for the cause.

The case with CFS/ME also underscores the importance of the patient’s narrative as they navigate the biomedical system to seek care for their illness symptoms. The search for an explanation and diagnosis is one of the key parts of the CFS/ME patient’s narrative that Pia Bülow describes as ‘the pilgrimage’ (Bülow 2008), which is important to a patient’s illness journey because it legitimizes their experience. By not legitimizing the patient’s illness experience, the biomedical community is, in part, erasing the patient’s experience and rendering their distress as invisible, to hide their suffering. American medical anthropologist Arthur

¹ The term of the CFS/ME illness is controversial and disputed by patients and clinicians alike, as it often viewed as not an adequate label to describe the severity of the disorder (Blease, Carel, Geraghty 2017)

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Kleinman wrote at length in the twentieth century about the illness experience, describing how “[s]tudies have repeatedly documented that pain patients feel biomedical practitioners routinely delegitimize the experience of their illness, pressing them to believe that it is not real or, at least, not as serious as they fear it to be” (Kleinman 1995; Hilbert 1984). For this research study, Kleinman’s works prompted for me the question, how does illness delegitimacy, or being made to feel disbelieved or invisible, affect the experiences of women with chronic illnesses?

4. Methodology

Since many of the long-haulers had already fashioned themselves in online discussion forums and support groups, I was able to find interlocutors through these virtual groups. I was an existing member of the Facebook COVID-19 Long-haulers Discussion Group, and posted an advertisement to the group’s 12,000 members in April 2020. As part of my recruitment plan, I identified two additional groups on Facebook: the COVID-19 Long Haulers Support group with 24,900 members, and a Women’s Covid Long Haulers Support Group with 1,900 members as of April 2020. I found the group creators and moderators to be helpful in directing me to members who might be willing to speak with me, although some members volunteered on their own and contacted me directly. In 2022, I connected with a long-hauler who was a member of a Facebook Black, Indigenous, People of Color, or BIPOC, Long-haulers support group. She assisted with recruiting other BIPOC members to participate by sharing a form for those who were interested to complete.

I conducted interviews in two intervals with 15 women, ages 25 to 49, in the United States, who experienced Long COVID symptoms for six months or longer. The first round of interviews was held in April to June of 2021. The second round was held in April and May of

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2022, due to a pause in research due to my own Long COVID illness. Since the women were located across the U.S. and were still actively experiencing Long COVID symptoms, I conducted interviews alone by Zoom and gave the option to record audio only. Some of the women preferred to conduct the interview by audio and video, so in those instances, I could see the interlocutor. Women chose their interview dates and times, which typically lasted an hour, while some lasted more than one hour. One interview was cut short due to internet issues.

Because they had been managing their symptoms for a lengthy period of time, most of the women were accustomed to talking about their illness and seemed to be comfortable talking to me, perhaps because I am a long-hauler too. Nonetheless, I attempted to mitigate emotional risk by breaking the interview into three parts. First, I asked open-ended questions such as, “Tell me about yourself.” During the second part of the interview, I asked the first half of a pre-arranged set of questions from the McGill Illness Narrative Interview (MINI), an interview protocol for eliciting illness narratives and symptom experience in health research. The last part consisted of a set of questions from the MINI about how the illness experience has affected the interlocutor’s life. After each interview, I wrote a memo to reflect on themes and observations of my conversation with each long-hauler. The interviews were digitally recorded and transcribed verbatim, with names and any identifiable information scrubbed from the transcripts.

Additionally, I sent each participant a follow-up survey in June 2022 to gather demographic and additional information. Although I attempted to gather most of the information during the interview, not all participants answered the questions directly and/or completely. I also found it useful to gather additional data about their citizenship status, family class background, and booster status after the majority of the interviews were held. Although I prompted participants to complete the survey with information at the time of interview, I

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observed some of the participants' answers changed, especially with regard to the participant's age, their children's ages, testing status and whether they had attended a Post COVID Clinic or not. Collecting the participant's testing status at the time their symptoms started was important because, in many cases, Long COVID patients receive a negative test result. It also has been shown that some Post COVID Clinics require a positive test result for admittance (Edwards 2021), and I wanted to know whether this requirement hindered the interlocutor from seeking assistance from a clinic. I speculate the discrepancy in answers about ages could be attributed to brain fog, a common Long COVID symptom, while the answers about testing or Post COVID Clinic could have changed due to the amount of time that passed between the participant's interview and the time of survey. The participants could have contracted COVID-19 again in the interim, or have been accepted to a clinic since the time of interview.

I selected codes and coding techniques as the method to analyze the data, which allowed me to identify concepts and themes to derive meaning from the interlocutors' experiences with Long COVID. First, I used coding methods from *The Coding Manual for Qualitative Researchers*, including Elemental Methods of coding, beginning with Concept Coding, to understand the major social constructs associated with the patient experiences of the interlocutors (Saldana 2015). Through this initial coding cycle, I developed a list of tentative categories and then refined it to a final list of categories, or themes, consisting of the following, in order of most cited to least: symptoms; healthcare providers; relationships; treatment; labor/employment; places; COVID-19 origin stories; tests; diseases/illnesses; vaccine; health insurance; body systems; mental health; government; education; gender; housing; and, insurance. I employed In Vivo Coding during this first cycle to capture verbatim excerpts found in the transcripts to extract from the interlocutor's direct experience. Given the personal nature of illness, I also

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employed a second, Affective Method coding technique, Emotion Coding, to gain an understanding of the range of human emotions that surround the transition to chronic illness and guide the decision-making of the interlocutors as they navigated the healthcare system seeking services and treatment.

5. Analysis

Table 1. Participant Demographics, *N* = 15

| | <i>N</i> | % | | <i>N</i> | % |
|----------------------------------|----------|--------|----------------------------------|----------|--------|
| Age | | | Housing Situation | | |
| 25-34 | 4 | 26.66% | Rental | 6 | 40.00% |
| 35-44 | 6 | 40.00% | Owens home | 8 | 53.33% |
| 45-49 | 5 | 33.33% | With family/friends | 1 | 6.66% |
| Race | | | Employment Status | | |
| White | 7 | 46.66% | Working/Full-time | 4 | 26.66% |
| Black/African American | 3 | 20.00% | Working/Reduced Schedule | 1 | 6.66% |
| Latina | 2 | 13.33% | Working/On Leave | 1 | 6.66% |
| Asian American | 2 | 13.33% | Self-employed | 1 | 6.66% |
| Mixed Heritage | 1 | 6.66% | Unemployed | 6 | 40.00% |
| | | | SSDI | 2 | 13.33% |
| Marital Status | | | Insurance Status | | |
| Single | 7 | 46.66% | Private Insurance | 10 | 66.66% |
| Married | 4 | 26.67% | Public Insurance | 2 | 13.33% |
| Divorced | 4 | 26.67% | Both Public/Private | 1 | 6.66% |
| | | | Uninsured | 2 | 13.33% |
| Child(ren) Status | | | Testing Status | | |
| Has a child(ren) | 10 | 66.66% | Positive COVID-19 Test | 9 | 60.00% |
| Does not have a child(ren) | 5 | 33.33% | Negative COVID-19 Test | 3 | 20.00% |
| | | | Both Positive and Negative | 1 | 6.66% |
| | | | Not tested | 2 | 13.33% |
| Number of Children | | | Post-COVID Clinic Status | | |
| None | 5 | 33.33% | Attending/Has attended a clinic | 7 | 46.66% |
| One | 6 | 40.00% | Has not attended | 8 | 53.33% |
| Two | 3 | 20.00% | | | |
| Three | 1 | 6.66% | | | |
| Family Class Background* | | | Vaccine Status* | | |
| Middle Class | 11 | 73.33% | Pfizer | 6 | 40.00% |
| Poor/Working Class | 3 | 20.00% | Moderna | 4 | 26.67% |
| *One participant did not specify | | | Unvaccinated | 4 | 26.67% |
| | | | *One participant did not specify | | |
| Mean Age of Children | 12 | | | | |

5.1. Contestation and Long Covid: Disbelief and Delegitimation

In my analysis of the participant data, I found that both delegitimation and trivialization of patients' symptoms occurred in their experiences, with delegitimation happening approximately twice as often as trivialization. When prompted whether disbelief occurred more often with male physicians than female, the participants' answers varied. The following quotes are examples which demonstrate how the participants' complaints were delegitimized and dismissed as psychological.

When I would try to explain myself, he would just cut me off and go, "Nope. That's not what I said. You're explaining. I don't want to hear it. Dah, dah, dah, dah, dah. Yes or no." And when I would try again, he said, "Nope. I'm a doctor. I don't want to hear that. I'll be the one making any conclusions, assumptions, putting the pieces together. I just need a yes or no answer." And so, he was firing so quick that he goes, "Oh, it was a migraine and a panic attack." And I go, "It absolutely wasn't. I've had anxiety attacks before."

And she, frustratingly, said that because there was nothing that they could find as structurally wrong, she thought it was anxiety which was the reason I was breathing incorrectly. So, despite my pushback on that, they really pushed for me to try some anti ... some anxiety meds, which I did for a while but they were ineffective because I knew it was not anxiety. And then after that, she referred me to physical therapy to retrain my brain how to breathe because they decided, "It's not really anxiety."

And she – I had to tell her what to do. Because she was like, "It's just anxiety." I'm like, "No, it's just not anxiety." I could feel it. You know, I need to go to a cardiologist at least to get an echocardiogram, to get a holter monitor, to see what is going on. And she was like, "Okay, well, I can refer you to one." So, she referred me to one because I told her to, and then I went and he basically – that doctor also said, "Oh, it's your anxiety and you're out of shape." And I've heard a lot of people say that their doctors say that.

The one doctor that discharged me – and I wish my son was here – he was trying to tell me that I was making everything up, that I could really breathe, I really wasn't that sick, and I was gonna be okay. There was no reason for me to be in the hospital, and they were discharging me. And I told my son about it when I was getting put in the car, and he literally called and reamed out the hospital administration.

Interviewees also recalled instances where their pain and symptoms were trivialized.

So, one of the doctors at the primary care physician at the time was just disregarding everything that I said. She was like you need to go get tested for Crohn's. So, that's part

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of the reason I got the EGD and colonoscopy done. The GI found no Celiac, no Crohn’s. Nothing. Again, for that too, found inflammation. From my biopsy inflammation.

He told me you don’t have COVID, you have the flu. And I said, “Yeah, I do. I already have a positive test.” And he said, “What day are you on?” And I told him I think – I don’t know; at that point it was, like, nine or eight. I don’t know. He said, “Okay. Days eight through twelve are the hardest. Go home and tough it out and you’ll get better. You’re young.” Everyone told me, “You’re young and healthy. There’s no reason you shouldn’t get better.” And so, I begged for medication. I was, like, I literally can’t even take Gatorade. He’s, like, “Just keep trying to sip Gatorade.”

Rather than experiencing either only delegitimation or trivialization, I found that the participants’ reports extended beyond Ware’s theory of two types of disbelief. Interviewees reported experiencing feminization of their illness, outright ignoring of their complaints, or were made to believe their symptoms signified another illness. They reported physician’s comments related to subjects associated with female embodiment, including those about fatness and motherhood, suggesting that physicians used other means to silence long-haulers.

And they put me in the exam room. My son’s with me. I’ve got my cane. And the doctor comes walking in, gives one look at me, and he decided then and there that the reason why I couldn’t breathe was because I was overweight. I tried to explain to him the depression I felt from being isolated from everybody and the anxiety I felt from being around people ‘cause I just have a feeling if I catch this shit again, it’s gonna kill me. He looked at me, and he said, “You’re fine. You just need to exercise, and you’ll be fine.”

In fact, the provider was another middle-aged woman with children who said, “Enjoy your time off from your kid” because I didn’t seem ill, and I guess I didn’t seem very run down, and so, we had a normal conversation; I must therefore have been – I passed as cognitively functional, and that was it. We just talked about “Get some rest after the trip,” she said, “take an extra day off or something,” but that was it.

Additionally, the doubt and the dismissal did not only come from doctors or the biomedical community, but from spouses, family, friends and colleagues.

You know, like one person, you know he didn’t do residency, but he was like, are you sure it’s not your kids, you know? And I’m like really? You think that after having kids, like 6 years, or it would have been 5 years later, like all of a sudden I’m super fatigued? It’s not the first 2 years? Are you crazy? And uh, another one, that I said I kept saying I was really tired and um you know and then she would be like, me too! That’s just me every day! And I’m like, no. No. You don’t know.

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They never came out and said it, but you can tell. It was responses, like, is it really that serious? It doesn't take all of that. Where you can really tell, okay, they just don't get it. Or you're still in bed? Why are you in bed so early? Things like that. So, it's almost embarrassing. Sometimes when I'm just in bed, I'm embarrassed to be in the bed. I just have to surrender to the fact that I need rest. So, yeah. Phrases like that that tell you indirectly that clearly I don't get it. It's minimized.

The participants described their confidence levels, or lack thereof, in biomedical professionals, government and healthcare institutions and how they strived to make their experiences matters of concern (Latour 2004) for biomedicine and contest what is, or can be, epistemic knowledge. Participants reported emergency room physicians not addressing their concerns, and instead referring them to specialists; whereas, specialists referred patients to hospital emergency rooms. The redirecting of patients suggests it is necessary to examine how the institutional policies developed by hospitals, healthcare providers, and insurance companies (i.e., the U.S. healthcare system) affect the outcomes of Long COVID patients, as this dynamic can be an example of structural violence (Farmer 1996) in action.

And I have to say I think I was really sick enough I really should have gotten the plasma. My best friend works in an ICU in Chicago and she was like, “Everybody gets the plasma ... everybody.” She couldn't believe that I was not given more treatment. They never had me lay prone, they never ... but again, I was among some of their first COVID patients. Most of them went to a larger hospital here, but they were full when I had to go in.

So, I feel like I probably would ... I definitely know I would have gotten better care at another hospital. I have a friend that went through almost exactly how I was, came home on oxygen, but she had home health coming to her house twice a week. She had a system where it took her blood pressure/pulse, pulse ox, all that and sent it to the nurse every day. I didn't have any of that. So, I just did it on my own.

5.2. Care or contestation? Racial injustice and health care access in America

In her book, *Uncertain Suffering*, anthropologist Carolyn Moxley Rouse explored, through the lens of sickle cell disease, whether health disparities are linked to health care. She argued that the very uncertainties that are responsible for health inequities serve as the

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mechanisms in which doctors can act as advocates for patients through the care they provide via institutional protocols (Rouse 2009). One of these uncertainties is the “uncertain discrimination in terms of the role racism plays in daily clinical interactions” (Rouse 2009).

Racism in the clinical interactions of the study participants of color was observed in this study, and was experienced either overtly or subtly, in some cases. Participants complained of disbelief and of being ignored, dismissed, receiving unequal treatment, getting escorted out of healthcare facilities, or having their symptoms rejected, trivialized or diagnosed as another illness. One long-hauler described the pilgrimage to receive care and a diagnosis as the ‘specialty shuffle.’ The following examples demonstrate racism in clinical interactions.

The ENT doctor that I went to maybe back in 2018 that did my tonsillectomy moved out of where I was going. So, I had to go to a new ENT who was extremely rude. I’m an African American woman. If we put medical gaslighting in the mix, if we put sexism and racism in the mix, we have trauma on top of trauma on top of trauma; and you’re already going through trauma. So, I remember this doctor laughing and giggling with the patient next door but when he got to me – completely different. He probably was with me for five minutes tops. Just no help. So, I remember bawling my eyes out. So, long story short, I’m finally with the ENT that I – I found him finally my ENT from a few years ago. But I had to go through a couple first.

I went to a couple other urgent cares. Again, wasn’t let in. We went back to the ER that I originally got diagnosed at. I couldn’t get through the front door. They said, “We can’t take you.” A security guard followed my friend and I out into the parking lot to even say, “I don’t know what you brought her here.” “You need to find someplace that can – you need to find a COVID unit. We can’t handle you. You shouldn’t have brought her here.”

Either I didn’t register to the doctors as sufficiently in need of something, or I just literally clinically did not quite fit the boxes that they were looking at, and I don’t know which it is, and I kind of – at this point – don’t care, but the Zoom calls did have video on, and so, there was that thing of when I walk into a room, since I was little, sometimes people just seem a little anti-me for no reason that I can really understand, and there was a little bit of that for Zoom, too, I think, for what it’s worth. The mixed heritage thing is a little bit visible on my face.

...the next time I went in for my infusion, it wasn’t until after I was already getting that I realized that I was getting a different type. I was getting the one that’s in two sessions and not weekly. And I had a reaction. And the nurses didn’t really do anything... I actually was vomiting in my mask during the infusion process. And another patient gave me tissues so that I could spit up into that. And I was the only person in the cancer center

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throwing up in their mask. It was a little ridiculous. I started feeling cold and shivering again. I was kind of having flashbacks of the hospital the first time. ... And the nurses were just questioning me. They were, like, “Well, do you have medication? Do you take it on time?” And I noticed that everyone around me was getting a warm blanket and I didn’t get offered a warm blanket.

Racism could be seen consistently in the testimonials of the Black, Asian American, Latina and mixed race long-haulers who experienced contestation in consultations with healthcare providers, or worse yet, didn’t even attempt to seek medical care or treatment.

No because I figured there's nothing they can do. Why keep running to the doctor wasting money and it's nothing nobody could do for you or tell you? Even people in the group, some people are having worse problems than I have, but different situations, it's still like they're saying the same things. It's nothing nobody can do for them.

The unique experiences of the women of color led many to seek out other long-haulers who could identify with the unequal treatment they received. Many shared the problem they faced of not seeing others “who looked like me” in the numerous Long COVID online support groups and, therefore, not joining the groups because they felt like they would not be understood. Their experiences reflect the key Critical Race Theory concept of intersectionality, where they experienced mistreatment based on a combination of their race, gender and disability (Crenshaw 1991).

5.3. Invisible Illness, Visible Problems: Long COVID and motherhood, work and self-identity

When asked about impact of their illness experiences to their lives, I observed three themes in the participants’ responses. First, given that two-thirds of participants were mothers, they described the negative effects on their ability to parent effectively while sick. The women also talked about their roles in their marriages and whether they found their partners to be supportive or not while they coped with illness. In some cases, mothers also were grappling with

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Long COVID in their children and were saddled with how to handle their own fatigue and other symptoms, along with their child's illness.

It's changed a lot. I am scared to work out ever since it fired on. So, I won't do any cardio at all. I am exhausted all the time, so it's really hard for me to do the normal stuff like cook and clean. And that brings on that mom guilt, because I just feel like I'm just wiped out all the time. I don't go as many places because I am scared.

Like I went for a walk with my kids and after that they wanted to go to the playground and I just like couldn't so I just sat in the car while they played. I was, like, so tired that I could barely hold up my phone. It was, just like, oh, so I just couldn't not do anything and had to close my eyes and had to take a nap. I've never been a nap person. I've always been on-the-go and I could never fall asleep in the daytime just because my mind is always going, but like there's been times that I've had to take naps, you know, it's very unusual.

It was like, "I didn't used to be like this. I used to always wanna take the kids outside and things like that." My niece, one of my daughter's best friends, I keep her in the summertime. And of course, 2020, we couldn't do nothing at all. And last year, I didn't wanna do anything with them. So, I was like, "Oh, this year they're going to camp" because I can't sit at home with them all day. Because I know I don't wanna do anything with them.

With regard to work, the employment status of the participants in the study varied, with only one-third of participants still able to work full-time for an employer or themselves. One participant worked at a reduced schedule, and another was on leave from her job, while nearly two-third of participants were unemployed or receiving Social Security Disability Insurance benefits from the federal government. Some participants contracted their illness through work, and others recounted difficulties in negotiating schedules, workloads and accommodations with their employers. They described the emotions that surrounded having to switch to part-time schedules, take leave, apply for unemployment, or how they felt upon learning they were being terminated.

So, it changed my life, definitely, because I didn't go back to my job. I actually had to go on unemployment. So, I didn't have a job. I lost my health insurance once my school health insurance – that ran out at the end of June. So then, that was stressful. I had to collect unemployment for the first time in my life, which I've never done that. That was an

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interesting thing to do. And I got off of that as soon as possible because I just – there's no way I could live on that and pay all my bills and whatever.

That was when I quit my job. That Monday, it just became clear to me that I couldn't continue on in that capacity, that my health was very seriously at risk, and it was scary, because I didn't know how I was going to support my son. So, I just had to step out in faith, and I really prayed about it, and was like, "You know what? I just have to do this. I don't have a choice. If they're not going to accommodate me, I can't work." So, I quit my job that Monday. They did allow me to work part-time from home until they hired a new (professional job position) to take my place.

Well, I kind of accepted it and kind of not accepted it, in part because I didn't even know that I was being terminated. There is another employee who had been out on medical leave for quite some time ... And he Facebook messaged me and said, "Hey, did you get an email?" And I said, "No, I haven't gotten anything." And so, I searched an email that I don't use a couple days later and found out that I had been terminated and didn't know. And I haven't received anything in writing yet. And to me, I think you legally have to send somebody something in writing or have a phone conversation or something. But I hadn't talked to anybody in a while. And the last thing I knew as far as employment was, "Let us know when you get better. We're here for you. We'll support you." And then, I found that out.

I tried applying for jobs – well, I did actually apply for them; I didn't just try – in August and September of 2020 after giving myself a month off to rest because I thought that would be enough – silly me – but that almost killed me twice in September, and after that, I pulled way back and decided to, as I said, settle into trying to rest. And also, I should amend my phrasing slightly, "whether or not I recover," because I don't expect to reach my 2019 baseline or anything like it, but I do think at this point, having improved at least somewhat, I think I should be able to hold some kind of job at this point, but I'm not ready to apply for one yet because I don't want to reset again yet.

The participants also brought up the effects of Long COVID on their mental health, often referring to the 'trauma' of the illness to their physical and mental health.

Yeah. So, the mental, emotional trauma of it all is just as much as the physical piece. My life is different. It's so different. I'm, like I said, slowly but surely I'm getting back out there. I'm doing it at my pace. People have been talking about me. People are, I think, even upset with me because I'm not in the activities I used to be in. I almost felt myself trying to rush back in, but I said, no, I have to heal. I have to deal with this. You all haven't been through this. You may not understand 100%. I can't rush back for you. I wasn't afraid of, okay, I'm gonna die, you know? If I get this virus, I might die. That was not my mentality at all. It was just the way I felt that night, that I was just gonna pass out with my heart rate so fast. That scared me. That really scared me. And so, when I was at the hospital the whole time trembling, that I couldn't control it, I feel like COVID attacked my brain. Like I feel like it legitimate caused some sort of damage that it

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triggered that response. And then when I came back, it was just like the PTSD, what COVID did to my brain, and all that. But yes.

A lot of other people are on disability. I've been one of the ones who has still worked through all of this. There were times I would be in Urgent Care one night and present in front of people the next morning. So, that adds anxiety to the mix, trauma to the mix because I can literally remember so many different Urgent Care visits, and the next morning I'm smiling, facilitating and presenting in front of people and trying to hold it down as much as I can. So, you can throw in anxiety. It makes you anxious. Into the mix, because again, you're fighting for your life, and nobody – nobody can tell you anything.

The top emotions the participants expressed (in order) were fear, frustration, anger, gratitude, and sadness. Kleinman characterizes emotions as the “legitimizing basis that establishes a relationship between a person and a social context” (Kleinman 1995). Therefore, we can derive from the main emotions the participants described, just how they felt about their experiences with Long COVID. It also was clear the illness had affected their self-identity, when asked, “how has Long COVID changed the way you feel or think about yourself,” participants not only described the effects of Long COVID on their self-identity, but also reported the effects of the disbelief they experienced from physicians, spouses, family and friends.

It makes me feel less than. I already feel there was like a stigma with COVID for whatever reason. And as somebody who is generally a type A personality who likes to be in control, who I'm very accomplishment-driven, having something be out of my hands to the extent that it is and not have answers with it has been humbling, but also, it just makes you feel so belittled. Because you do have people that don't believe you or think that there is something that you did. My relatives are all like, "Well, were you drinking a lot or smoking?" I'm like, "No, I don't do any of that stuff. I never did." I don't know what I did to cause this. I didn't do anything. It's lowered my self-esteem quite a bit. I don't like the way I look anymore. I feel like, because I'm so afraid of when it's going to flare up, I just have no desire to really go out in public.

6. Discussion

Since COVID-19 Long-haulers, especially women, have been met with disbelief since the beginning of the pandemic, I sought to examine, through the lens of Long COVID, how

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disbelief and delegitimation affects the illness experiences of women with contested illnesses. In my research, I found there were different concepts that could be used to analyze disbelief and delegitimation in medicine and healthcare. One approach would be to analyze the phenomenon using concepts associated with power and control, such as the psychological concept of gaslighting, in which one agent attempts to manipulate another’s reality (Barton, Whitehead 1969). Another approach would be to use the concept of contested illness as a dimension of power, recognizing illness as being defined by various authorities, structural and institutional mechanisms (Moss, Teghtsoonian 2008). But I found both concepts to be limited in explaining the phenomenon of disbelief and delegitimation of women with Long COVID. When analyzing the study findings, there were examples participants shared that could not be explained within the concept of contested illness because it was limited to the intersection of power and illness, and the phenomenon appeared to encompass dynamics beyond simply authority and superiority in the provider-patient relationship.

A more recent approach and analytic is to view the problem in healthcare at the intersection of knowledge and illness, through a medical ethics perspective, using Fricker’s concept of epistemic injustice to explain why this phenomenon occurs. Havi Carel and Ian James Kidd have argued this perspective be used to analyze epistemic injustice in medicine and healthcare, as “epistemic problems ... are grounded in contingent features of healthcare systems” (Carel, Kidd 2017). Additional scholars have claimed that belief is more than opinion; it should be considered epistemic. Anthropologist Byron Good argued that ‘illness reality’ extends beyond biomedicine and that it has been the role of the medical anthropologist to study belief and behavior (Good 1994). Gender-based violence researcher Elena Ruíz views this form of

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delegitimation as a form of 'cultural gaslighting,' a concept she developed and which can be defined as "an epistemic expression of structural gaslighting" (Bailey 2020).

The study findings clearly show that by delegitimizing female patient's Long COVID symptoms and experiences, the long-haulers are experiencing a form of epistemic injustice in healthcare where they have been silenced and abandoned with the real consequences of Long COVID, which the biomedical industry and U.S. government are obfuscating. The biomedical industry is not only perpetuating notions of women as 'hysterical,' but it is failing to fully address chronic illnesses mainly affecting women. As a result, women suffering with chronic, or 'invisible' illnesses are experiencing further injury to their identities and realities atop of their suffering with the illness. Those harsh realities include negative effects on their careers, identities and ability to parent effectively. For people from various racial and ethnic backgrounds, this could mean adding further injury to their quality of life already on the margins.

Fricker's original concept of epistemic injustice claims two types of injustice occurs: testimonial injustice, where the knowledge and contributions of certain social identities (e.g., women, sexual minorities, or people with disabilities) are discredited (Fricker 2007); and, hermeneutical injustice, where some social identities "can be structurally prejudiced by unequal relations of power" (Fricker 2006). Epistemic injustice includes a range of practices in communication that lead to discrediting of the 'knower' and can be used to oppress a variety of groups: strategies of exclusion and expression; silencing; distortion; misrepresentation; and, undervaluing one's contributions, to name some of them (Carel, Kidd 2017). Viewing the problem from this perspective reinforces the importance of the patient narrative during the clinical consultation and begs the question: *why* did healthcare systems not take a more

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participatory approach by shifting or pivoting into a 'listening' mode at the onset of the COVID-19 pandemic, focused on gathering information from patients?

In the situation of Long COVID, based on the study findings, it does appear some of the biomedical community's aims are to maintain a sense of superiority and power through knowledge. In this case, the patient cannot and must not know more than the physician; their subjective evidence 'must not' reign over the acquired and professional knowledge of the medical expert. It calls into question what kind of evidence is 'good enough,' 'superior,' and 'accurate.' The other reason this dynamic could take place is because the medical provider knows the limits of his own power. He has limited knowledge and knows the disease is new and so, in the absence of knowledge and treatments, and rather than admit his own limits, he contests the patient's experience. In some cases, physicians did say "I don't know," but those instances may have been sparse.

There are several dangers in the epistemic injustice that women with Long COVID are experiencing. In the absence of validation and legitimacy of their experiences and diagnoses of their symptoms, patients are unable to make sense of their experiences or to create resources that might help them. Also, it imposes on them a lack of epistemic and social agency, on top of their already disabled agency due to illness. There also is a risk to the patients' mental health. By abandoning them and not offering a cure or care, long-haulers are at an increased risk of suicide and developing mental illness such as Post Traumatic Stress Disorder, or Complex Post Traumatic Stress Disorder, in some cases (Sher 2021). Last, if the delegitimation of women with Long COVID is one example of epistemic injustice with a particular group; what does this mean for sexual minorities (e.g., gay, lesbian, bisexual, transexual) and transgender individuals with Long COVID, which are groups who already experience disparities in healthcare (Tabaac 2020)?

7. Conclusion

In this study, I examined, through the lens of Long COVID, how disbelief and delegitimation affects the illness experiences of women with contested illnesses. I found that by delegitimizing female patient’s Long COVID symptoms and experiences, the long-haulers are experiencing a form of epistemic injustice in healthcare where they have been silenced and abandoned with the real consequences of Long COVID, which the biomedical industry and U.S. government are obfuscating. As a result, women suffering with chronic illness are experiencing further injury to their identities, including racial injustice, and negative effects on their careers, mental health and ability to parent effectively.

This study was limited by COVID-19 guidelines, which included guidelines for social distancing and, therefore, all interviews were conducted virtually via Zoom. Other limitations include the minimal representation from Black, Latina and Asian American female long-haulers. Given that the recruitment efforts for the study were limited to online outreach only, it was more difficult to find adequate representation for these groups than others.

Finally, I conclude the study with the following recommendations for physicians, healthcare systems, policymakers, and researchers to address the problem of disbelief and delegitimation of COVID-19 long-haulers:

- Combat the negative stigma of those with Long COVID and other chronic illnesses.
- Develop a shared vocabulary of Long COVID terms and definitions to describe symptoms and severity and aid patients in the articulation of their illness experience.
- Allow Long COVID patients to narrate their experiences using styles that are appropriate to the intensity of their symptoms.
- Evaluate the models of Post COVID Clinics in the U.S. and incorporate a one-stop shop design for clinical consultations to ease the burden of Long COVID patients’ narrating their stories and symptoms in multiple care settings.
- Encourage U.S. healthcare systems to redirect their interests to also focus on learning from the patient about Long COVID symptoms and how to treat the disease.
- As part of the National Institutes of Health’s RECOVER Initiative, research the experiences and effects of delegitimation and Long COVID.

8. Acknowledgments

I would like to thank the community of academic scholars who are working to learn all we can about Long COVID and its effects, including those at the forefront: Felicity Callard, Elisa Perego, Nisreen Alwan, Ilana Löwy, Hannah Davis and others. My gratitude to Eugene Raikhel for his education and guidance regarding this topic. I would also like to thank Julius Jones, Sophie Fajardo, Agnes Malinowska, and Rowan Bayne for their helpful comments on various aspects of this topic and paper. Special thanks to my friends and family who made this all possible, especially Senay Tewolde, Matthew Nesvet and Tomasita Hernandez. This paper is devoted to the millions across the world who are living with Long COVID and its associated conditions.

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