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Long covid and medical gaslighting: Dismissal, delayed diagnosis, and deferred treatment

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ABSTRACT

While we know a lot more about Long Covid today, patients who were infected with Covid-19 early on in the pandemic and developed Long Covid had to contend with medical professionals who lacked awareness of the potential for extended complications from Covid-19. Long Covid patients have responded by labeling their contentious interactions with medical professionals, organizations, and the broader medical system as "gaslighting." We argue that the charge of medical gaslighting can be understood as a form of ontological politics. Not only do patients demand that their version of reality be recognized, but they also blame the experts who hold gatekeeping power over their medical care for producing a distorted version of said reality. By analyzing results from an online survey of Long Covid patients active on social media in the United States (n = 334), we find that experiences of contention and their reframing as "gaslighting" were common amongst our respondents. In short answer responses about their experience obtaining medical care for Long Covid, our respondents described encountering medical professionals who dismissed their experience, leading to lengthy diagnostic odysseys and lack of treatment options for Long Covid. Even though we are limited by characteristics of our sample, there is good reason to believe that these experiences and their contentious reframing as medical gaslighting are exacerbated by gender, class, and racial inequalities.

1. Introduction

In the United States, where our study is based, a June 2022 nationally representative survey conducted by the Centers for Disease Control, estimates that 19% of adults who have had Covid-19 are experiencing Long Covid, thus about 7.5% of U.S. adults suffer from Long Covid (CDC, 2022). Long Covid comprises a wide range of ailments ranging from brain fog, fatigue, and prolonged weakness to severe and debilitating conditions causing memory loss, impairment in concentration, and degraded mobility (Lopez-Leon et al., 2021). In a quest to understand better their illness, educate other long-haulers, and gain public recognition for their symptoms, Long Covid patients have turned to each other online to share information and collectively define the condition (Callard & Perego, 2021; Miyake & Martin, 2021; Rushforth et al., 2021). Even when post-Covid care centers were established to provide integrative care for Long Covid patients, patients continued to play an active role in referring each other to such centers, working with physicians there, and participating in patient-led research to better characterize the condition

(e.g., Davis et al., 2021). In effect, Long Covid has galvanized a new movement of long-haulers that seeks treatment, remedy, and recognition of their ailments. Like patients of other forms of contested illnesses, Long Covid patients have criticized medical professionals for "not taking their complaints seriously due to physicians' lack of knowledge about the condition, or the general inability of medicine to provide effective treatments" (Sebring, 2021). In this study, we document accusations of medical gaslighting by Long Covid patients, and analyze these claims as a form of ontological politics (Mol, 1999, 2003), where patients demand that their reality be recognized and also point an accusatory finger at the distorting effect of experts' gatekeeping power, which they frame as a form of "abuse".

We report findings from an online survey conducted from October to December 2021 of Long Covid-19 patients in the U.S., who use social media platforms to search for information about their condition and exchange reports about their experiences with other affected individuals. In this article, we ask: *What is the experience of Long Covid patients in obtaining medical care in the U.S.?* This paper uses individual accounts

from Long Covid patients to explore the challenges of living with these prolonged health conditions that are still not fully understood. In particular, these personal testimonials open a window into the way long-haulers view their interactions with medical science, hospitals, doctors, policymakers, and the public. Their accounts of patient-doctor interactions demonstrate that an emerging chronic disease as Long Covid gives birth to a plethora of practices of self-evaluation and self-treatment in response to what long-haulers often bemoan as medical misdiagnosing, lack of expertise, failure of care, and outright abandonment. Specifically, through an analysis of short answer responses, we found that patients frequently framed their accounts of interactions with medical professionals through the language of "gaslighting."

We begin by providing background to Long Covid in the United States and the lessons learned from other chronic and contested illnesses. We then elaborate on our theoretical framework that understands the talk of medical gaslighting as a form of ontological politics (Mol, 1999, 2003). We then detail our findings by noting that patients applied the critique of medical gaslighting to three aspects of their experience: dismissal by medical professionals of patients' reports of symptoms, the diagnostic odyssey of Long Covid, and deferred treatment due to the lack of treatment options. We end by discussing how these experiences and their reframing as medical gaslighting are very likely accentuated by processes of marginalization, along gender, class, and racial identities, and identify areas of future sociological research.

2. Contested illnesses and long covid in the United States

Studies of patients suffering from chronic, contested, and orphan illnesses have shed light on the fraught relations between medical professionals and those seeking treatment (Dumit, 2006). In many of cases, "patients experience these encounters as a system in which they must 'prove' their illness and their suffering through mobilizing facts" (Dumit, 2006, p. 577). Patients have a "'legitimacy deficit'—a phrase that highlights the complex, contingent, and contested character of legitimating disease" (Kempner, 2014, p. 10). Patients suffering from chronic fatigue syndrome (Dumit, 2006), migraines (Kempner, 2014), fibromyalgia (Barker, 2005), and Lyme disease (Dumes, 2020) have all had to contend with the inability of medicine to treat their unexplained illness, as well as with tremendous difficulties in getting medical professionals to believe their health-related complaints. As these studies note, there is a significant gendered component to these diseases: Often, medical complaints voiced by female patients are dismissed by male medical professionals, and are treated as unreliable reporters of their own symptoms (Barker, 2005; Kempner, 2014). The attribution of reliability or unreliability is a social, interactional process that can be shaped by gender and/or racial-ethnic differences between patient and physician (de Vaan & Stuart, 2022; Green et al., 2018). The typical consequence of such attribution, familiar from the history of "female" illnesses, is that patients' symptoms are not accorded the status of being the signs of "real," physical disease, but are treated as evidence of a "mental" problem, perhaps the product of "anxiety," or cryptically dismissed as "psychosomatic" (Barker, 2005; Kempner, 2014). Patients often work with one another in constructing a shared illness identity, and contending with the "similar-but-different" quality of their individual illness experience (Barker, 2005). Such legitimacy work in sorting through patient experiences, however, is not something that is always legible to evidence-based medicine and mainstream medicine (Dumes, 2020).

Patients have also often had to accumulate various forms of lay expertise to cope with their conditions and lobby biomedical researchers to further investigate their complaints (Epstein, 1995; Kerr et al., 1998; Prior, 2003). The experiences of chronically ill patients are also comparable to those of individuals with a disability, as patients regularly find themselves navigating medical systems and social structures that are not designed with their best interests in mind (Mauldin & Brown, 2021). In the context of the pandemic, online patient communities have similarly allowed individuals with Long Covid to share their illness experiences,

obtain advice on how to interact with medical professionals, and engage in forms of mutual commiseration (e.g. Au & Eyal, 2022; Barker, 2008; Eysenbach et al., 2004; Maslen & Lupton, 2019; Petersen et al., 2020). What is different with Long Covid, however, is the scale of the problem. Unlike rare diseases, Long Covid has affected large swaths of the population, thereby enabling individuals to find each other and organize much more quickly than in the past. Moreover, Long Covid takes place against the background of several decades of previous struggles over contentious illnesses. Hence, Long Covid patients are able to draw on some of the strategies and repertoires developed by previous waves of patient activism, who have dealt with similar problems.

Existing studies on Long Covid patients have shed light on the importance of online spaces that help patient communities come together around their shared illness. Social media groups, in particular, help facilitate the exchange of knowledge and experience between patients, and raise awareness of their plight (Callard & Perego, 2021; Miyake & Martin, 2021; Rushforth et al., 2021). Existing research has also contrasted the difference between dominant narratives of Covid-19, which focus on the acute phase of infection rather than the prolonged struggle that Long Covid patients face, which leads to the invisibility of Long Covid patient narratives in the public sphere. Social media groups, in particular, have enabled individuals suffering from Long Covid patients to counter this marginalization by banding together and organizing patient-led research initiatives. Such emergent online communities have been at the forefront of developing "best practices" to help those suffering from Long Covid better manage their chronic and often debilitating symptoms. Long Covid communities have also drawn on patient-led research that has played a crucial role in translating illness experience into rigorous studies and influencing medical practice. This dynamic has enabled Long Covid patients to further identify sub-types and sub-groups within the community of long-haulers (while others have argued for the necessity of a unifying term, see Munblit et al., 2022). Specifically, what has emerged is the distinction between a sub-type that is symptomatically similar to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and a different sub-type characterized by a central symptom similar to Postural Orthostatic Tachycardia Syndrome (POTS). ME/CFS is characterized by extreme fatigue and sleep abnormalities, while POTS is a blood circulation disorder marked by extremely elevated heart rate following even very minimal effort. The causes of ME/CFS and POTS are not known.

Before we discuss how gaslighting relates to the concept of ontological politics, a few clarifying words also need to be said about Long Covid in the U.S. context. Two specific factors shape the experience of our respondents: First, as noted above, American Long Covid patients are able to draw on the strategies and repertoires developed by earlier waves of patient activism, in a political and medical system that is attuned to claims of individual rights, especially by middle-class activists. This is by no means true across the globe, where repertoires of patient activism and the social meaning of disease differ. A similar language of ontological politics is likely to be found in contexts with a similar history of patient activism (UK, France, Germany, etc.) but not necessarily elsewhere. Second, the fragmented and privatized nature of the U.S. healthcare system makes it fairly unique among industrialized nations. Our respondents' experiences, and perhaps their reaction to these experiences, are shaped by the prohibitive costs of testing, diagnosis, and treatment often born by patients, by the difficulty of maintaining continuity of care in a fragmented healthcare context, and by the consequent demand that patients take responsibility for their own health (Reich, 2014, p. 38), and act as "managers" of their own healthcare team in the context of the "great risk shift" (Hacker, 2019, p. 137).

Absent authoritative guidelines and protocols on diagnosing and treating Long Covid, much of the costs of obtaining medical care are born by American patients. Utilizing the repertoires of patient activists that came before, long-haulers have organized to research their own conditions and lobby for recognition. Post-Covid care centers, such as those at Mount Sinai's Center for Post-COVID Care and Montefiore-Einstein's

COVID-19 Recovery Clinic primarily located near urban centers such as New York City, were set up to provide integrative care and coordinate between various medical specialists (Walter, 2021). The U.S. government has also pledged over $1.15 billion USD to Long Covid research by December 2020, while the National Institutes of Health has begun to recruit a cohort of 40,000 Long Covid patients through the *Researching COVID to Enhance Recovery* (RECOVER) initiative (Kaiser, 2021). While patient groups have criticized RECOVER for its slow start, there is some hope that the focus and attention on Long Covid will translate to clinical solutions for patients. Our study, however, speaks primarily to the experiences of those who caught Covid-19 and developed Long Covid in the U.S. early on during the pandemic.

3. "Gaslighting" as a rhetoric of ontological politics

Gaslighting is an "increasingly ubiquitous term used to describe the mind-manipulating strategies of abusive people, in both politics and interpersonal relationships" (Sweet, 2019, p. 851). Our data does not include the perspective of medical professionals, and we must therefore remain agnostic about their reasoning and motivations. There is a difficulty here, because the language of "gaslighting" is calculated to compel the listener to take sides. From this point of view, our agnosticism is not neutral, and the label of "gaslighting" could be hurled at it as well. What our data shows is that Long Covid patients mobilize the language of gaslighting to understand their own experience and to frame their interactions with medical professionals. This invocation of gaslighting precedes Long Covid, as past patients have used the language of medical gaslighting to make sense of their experiences with medical professionals, when they have felt that their concerns about their own health and wellbeing have been dismissed (Sebring, 2021). The language of gaslighting calls attention to the "privileging of biomedical expertise over lived experience" (Sebring 1952, 2021), where the doctor "as a spokesperson for the institution of medicine, has the power to pronounce what is real and what is not" (Sebring 1956, 2021). In doing so, the medical professional acts as a gatekeeper. Individual patients present the medical professional with subjective claims, "symptoms," in medical parlance, and the medical professional can bestow upon them the status of objective "signs" that are legitimate and deserving of recognition by the medical system. Possessing appropriate cultural health capital—knowing how to report one's symptoms—thus becomes an important condition for being able to access adequate care (Collyer et al., 2017; Shim, 2010).

The lack of such capital, or any other difficulty in translating symptoms into signs, can result in lengthy diagnostic odysseys, during which patients undergo successive tests, are sent to consult multiple specialists, are given provisional diagnoses that are then "ruled out," and must endure uncertainty about their condition (Jutel, 2009; Timmermans & Buchbinder, 2010). Most importantly from our perspective, as these diagnostic odysseys lengthen, patients find that their status as reliable reporters of their symptoms is questioned. Writing from the perspective of applied philosophy and ethics and drawing on the experience of the chronically ill, this consequent downgrading of one's moral status has been described by various researchers (see Blease et al., 2017; Buchman et al., 2017; Fricker, 2017; Kidd & Carel, 2017) in terms of epistemic injustice. These authors advocate for various forms of epistemic humility from medical professionals, who are urged to listen to the lived experiences of their patients and acknowledge the limits of their expertise. In our study, we find that this representation of medicine as unresponsive to the claims of Long Covid patients to be pervasive, with the rhetoric of gaslighting being tightly connected to the experience of medical odysseys.

How to understand this talk about medical gaslighting from our Long Covid respondents? The first point is that the term "gaslighting" is culturally available. Sebring (2021) and Sweet (2019) have noted its recent popularization. We have found numerous mentions of "gaslighting" in essays and news coverage about Long Covid (e.g. Camero, 2022; Cooney, 2021; Goldberg, 2020; Mariani, 2022), in widely watched

Youtube videos (e.g. Newshub, 2021), and in patient "survival guides" (e.g. Lowenstein, 2022) that have circulated online. For instance, a "best practices guide" from the patient group Survivor Corps urges post-COVID care centers to ensure that all health care providers be "versed in the vast array of post COVID symptoms being reported to decrease the possibility of gaslighting or patient dismissal" (Survivor Corps, 2021). The abundance of talk about medical gaslighting in popular media thus provides a frame for patients to organize and understand their individual experiences with the medical system.

The second point is that "gaslighting" is political language. Claims of medical gaslighting are a tactic in the broader struggle for recognition that Long Covid patients have faced. We make a small contribution to the study of contested illnesses by noting how the language of "gaslighting" gives this struggle the character of what Mol (1999) calls "ontological politics," namely a politics where what is at stake is how the value of being "real" gets distributed between symptoms, signs, subjective reports and objective tests. As Mol writes, "a shared, coherent ontology is not required for treatment and prevention practices. Incompatibilities between objects enacted are no obstacle to medicine's capabilities to intervene—as long as the incompatible variants of an object are separated out" (115). This is particularly relevant for Long Covid due to the diversity of attributed symptoms, ranging from neurological impairment to cardiovascular damage (Lopez-Leon et al., 2021). Similarly, much of the doubt cast by skeptics also point to the "underlying conditions" that complicate the attribution of symptoms to Covid-19 infection. This ontological multiplicity stands in contrast to the "closure rhetoric of research publications: these are written as if there were a single reality all should be able to agree on, in the end" (89). Mol (2003) contrasts this "closure rhetoric" with the reality of hospital treatment, where multiple enactments of disease are separated out and co-exist without ever needing to be reconciled. She notes, however, that some enactments—e.g. the pathology report—because they come at the end, can be presented as the "final word" that undermines the veracity of other enactments.

Something similar happens during the diagnostic odysseys of Long Covid patients, during which the objectivity attributed to medical tests, which come after the interview and are given the status of potential endpoints of the process, can result in denying patients—especially women, minorities and those with disabilities—the status of reliable reporters of their symptoms. By drawing on the language of gaslighting, Long Covid patients seek to turn the tables on medical professionals. Gaslighting is an agonistic language of ontological politics, which challenges the doctor's closure rhetoric. Not only do patients demand that their reality be taken seriously by experts who wield the power and resources to dispense potentially life-saving medical care, but they also level the accusation of "abuse" at them. By framing the clinical encounter as gaslighting, Long Covid patients contest the objectivity accorded to judgments and tests that come at the end, presenting them as just one version of reality, or worse, as a willful distortion of reality.

A third point is that the rhetoric of gaslighting, inclusive of this article as it is written, partakes of what Giddens (1990) calls the "double hermeneutic". Any attempt in this article to maintain a scholastic distinction between "emic" and "etic" points of view is doomed to fail. Like other patients of contested illnesses, Long Covid patients have become lay experts of medical science. The language of "gaslighting," however, testifies to their reflexive incorporation of social and feminist studies of science and medicine into the repertoire of medical self-advocacy. Long Covid patients are thus also lay experts of social science. Long-haulers have taken "gaslighting" from feminist analyses and attached it to their own lay analysis of medical discourse. This paper adds another layer to "gaslighting" by bringing it into conversation with the concept of ontological politics. No doubt this is not the final word. As noted earlier, calling something "gaslighting" aims to compel the listener to take sides. Our own rephrasing as ontological politics is more equidistant.

Finally, similar to previous chronic illnesses, there is also a significant gendered component to Long Covid. Because ontological politics involves

power, processes of marginalization are particularly salient in shaping the recognition of claims as "real" or "imagined". Previous studies of chronic and contested illnesses have identified a gender component to the patient-physician relationship: where physicians who are often male dismiss the knowledge and experiences of their female patients (Barker, 2005; Dumes, 2020; Dumit, 2006; Kempner, 2014). Many leading advocates and community organizers in the Long Covid space are women who learn from previous patient movements (Löwy, 2021). This is reflected in the gender identification of our survey respondents, as well as in some reports about encountering gendered stereotypes when seeking care. We make no claim that our sample is representative of the overall population of Long Covid patients, but the fact that the rhetoric of gaslighting is voiced mostly by the women in our sample lends plausibility to our interpretation.

4. Data and methods

In the following, we analyze a collection of short answer responses of 334 U.S.-based survey respondents suffering from Long Covid who use various forms of social media to access information about their condition. In this section, we detail how we distributed the survey, characteristics of our sample, and the procedures we took to analyze our data.

4.1. Distribution of survey

This study was reviewed by Columbia University's Institutional Review Board and the online survey was hosted on Qualtrics, an online survey platform. Survey participation was anonymous, and respondents were also offered the opportunity to participate in follow up interviews at the end of the survey. The survey takes roughly 8–10 min to complete and included 22 questions, which contained multiple-choice questions and short answer responses. Only respondents above the age of 18 were allowed to complete the survey, and the survey was administered in English. The survey's completion rate—or those who started the survey and completed it—was over 70%. In our qualitative analysis, we included 26 incomplete responses, where the Long Covid respondents only omitted the last page of the survey containing demographic information, but completed the remainder of the questionnaire that included the short answer response that we focus on here. We also collected over 91 follow-up interviews, but have not yet completed coding and analyzing them, and they are largely omitted from this analysis. We only reference these interviews in our discussion about positive interactions with medical professionals, specifically around the concept of epistemic humility.

Respondents for the online survey were recruited through periodic posts on Long Covid and Covid-19 patient Groups and SubReddits on Facebook and Reddit. This also included posts on Instagram and Twitter using relevant hashtags such as #LongCovid between October and December 2021. While we were interested primarily in the experience of Long Covid patients and those who identify suffering from the condition, the survey was also open to recovering and recovered Covid-19 patients and those "unsure" about their health status—as Long Covid can often develop with considerable delays. We were careful to only post in groups that were open to the public (Eysenbach & Till, 2001), and did not contain rules that prohibit researcher access. In many cases, we messaged the group administrators for permission to post a link to our survey. As with all online surveys, we caution readers from generalizing and over-interpreting our findings. Scholars have noted elsewhere that several common problems can occur in online surveys, including nonresponse bias, noncoverage errors, and sampling errors (Sills & Song, 2002). However, as Eysenbach (2004) argues, "it is sometimes just a question of defining for which subset of a population the conclusions drawn are assumed to be valid" (1). Our online survey sample was voluntary and consisted of regular social media users with Long Covid symptoms.

4.2. Characteristics of sample

More on the demographic characteristics of this subsample of 334 Long Covid patients can be found in Table 1. The mean age of our Long Covid respondents was 42 (min = 19, max = 73, median = 42, std dev = 13). Overall, the Long Covid patients who took part in our survey were predominantly female, white, and well educated. Our respondents were also mostly employed, lived in suburban areas, earned above the average household income, and identified as liberal/Democrat. These characteristics introduce a bias in our findings towards the well-educated and well-resourced, as well as towards those with access to the Internet and information about patient forums and social media groups. These demographic features make it difficult to say with certainty how the available sample of respondents skews our findings, for instance, by privileging the negative experience of long-haulers with doctors over other possible experiences. On the one hand, patients who are relatively well-off and well-educated should be less likely to be dismissed by doctors for their symptoms due to their command of medical information and their access to higher quality care. On the other hand, long-haulers in this demographic group are also likely to be more versed, as noted earlier, in feminist analyses of medical gaslighting, as well as forms of self-advocacy and online organizing. We cannot distinguish between these two factors and presume that some interaction between them is responsible for the relatively high proportion of reports of negative experiences in our sample. Finally, our sample clearly underrepresents individuals who identify as conservative and Republican. The likely reason for this self-selected omission is that in a period of heightened political polarization, social science research, especially about Covid-19 and issues of trust in medical experts (prominently mentioned in the survey description sent to potential respondents), is generally coded as liberal-leaning in conservative social milieus, especially when it is conducted under the auspices of an Ivy League University. Our advertisement thus was likely met with skepticism and rejection among this group.

4.3. Analysis of data

The short answer question we qualitatively analyzed was: "How would you describe the experience of obtaining medical treatment and support for these long-term symptoms of Covid-19?" We inductively and

Table 1
Characteristics of Long Covid Subsample (n = 334, with 26 missing complete demographic information).

Characteristic		Number of Respondents (% in parentheses)
Age (Mean = 42)		
Gender	*Female*	230 (75%)
	Male	69 (22%)
	Other	9 (3%)
Race	*White*	234 (76%)
	Black	12 (4%)
	Other	62 (20%)
Education	*Graduate degree*	94 (31%)
	Completed College	118 (38%)
	Some College or Below	96 (31%)
Employment	*Full/Part Time*	166 (54%)
	Unemployed	17 (6%)
	Other	125 (40%)
Residence	*Urban*	103 (33%)
	Suburban	154 (50%)
	Rural	51 (17%)
Household Income	*$100,001 or over*	116 (38%)
	$60,001-$100,000	79 (26%)
	Below $60,000	103 (34%)
Political Identification	*Liberal/Democrat*	153 (50%)
	Conservative/ Republican	37 (12%)
	Independent/Other	117 (38%)

systematically coded all responses from U.S. Long Covid patients (n = 334) on a qualitative analysis software Atlas.ti, where we read through each response in the survey and then grouped each response with emergent themes that were discussed between the different authors. This procedure follows the spirit of abductive analysis, where contesting interpretations were "fitted" onto the data in order to best capture the experiences described by respondents (Tavory & Timmermans, 2014). The abductive approach best suited this project due to the various bodies of literature that we draw from in the social studies of health and medicine. The themes identified and the proportion of respondents reporting these experiences are detailed, along with exemplary quotes that reflect these themes.

We also conducted a quick robustness check to see how potential demographic characteristics such as gender may impact these short answer responses. Caution should be taken when interpreting computational text analysis as it is ill-equipped to tease out nuances of meaning, and we urge readers not to draw conclusions from this robustness check. In our survey, respondents were asked what their gender identity was: man, woman, non-binary or third gender, an option where they could self-identify, and a "prefer not to disclose" answer (for a discussion of the use of sex and gender in health research, see Greaves & Ritz, 2022). A limitation of this sample is the lack of inclusion of individuals who identify as having a non-binary gender, with only 6 individuals identifying as non-binary or third gender. Due to this limited sample, we exclude these 6 responses from the following sentiment analysis, but include these responses in our findings. 1 additional respondent chose to self-identify and 2 chose not to disclose. In our analysis of male-female respondents, we first looked at the gender breakdown in the length of responses for men and women. We found that women tended to write more in response to the question, averaging 281 characters, while men tended to write shorter answers, averaging 193 characters. Second, employing a commonly used sentiment analysis package in R, *syuzhet*, that draws on a dictionary to decide whether a word reflects positive or negative sentiment, we scored each post to see if the responses by men or women differed in valence. On average, we found that responses about medical interactions from women tended to include words with more negative sentiments (a mean score of −0.24, indicating an overall negative valence using the syuzhet algorithm), compared to men (0.04, indicating an overall positive valence). Both of these indicators suggests that the women taking our survey were more explicit and detailed in recounting their experiences, and were more likely to use negative terms to describe their interactions with medical professionals. These gender differences may be related in the Tolstoian sense that there is typically more to say about negative experiences than positive ones.

Finally, the timing of *when* respondents began suffering from Long Covid shaped how they described their illness experience: those who started experiencing Long Covid early on would likely have had a much more difficulty of getting medical professionals to trust their accounts. Those who began to suffer from Long Covid more recently, will likely have encountered a greater number of medical professionals aware of Long Covid. In our survey, 65% of our respondents reported that their acute Covid-19 began in 2020 (with 37% reporting that they were infected during the first six months of 2020), and so our findings also reflect Long Covid experiences during this earlier phase. Through the simple sentiment analysis algorithm in R, we also found that the short answers of Long Covid patients who were initially infected in 2020 on average scored more negatively, −0.20, compared to those who were infected in 2021, -0.09.

Before discussing our findings next, we should also note a few caveats about the term "patients". There are many different types of illness experiences with Long Covid. For instance, when asked to report their symptoms and experience with Long Covid, one respondent noted that their "sense of taste [is] altered for certain foods" (Respondent #166), while another wrote about "chronic fatigue, dizziness, post exertion fatigue, loss of taste and smells, body tremors, dysregulation of temperature, cardiac arrythmia, dramatic tooth decay, sharp pains in mouth,

head, left arm" (Respondent #222). Those experiencing relatively non-disruptive symptoms may not identify as Long Covid "patients". It is likely that many of the conditions described above are further intensified by the multiple challenges more affected patients face.

5. Findings

The themes discussed below are not mutually exclusive, and responses typically contained several themes. We found through our qualitative coding that an overwhelming majority of short answers reported negative interactions with medical professionals, described in 265 (79%) of responses, as compared to 69 (21%) that mostly described positive interactions. 20 (6%) posts were coded with both positive and negative experiences. There were also 14 (4%) of posts that were ambiguous in their positive and negative valence. We also identified three major themes in these reports of negative experiences with medical professionals: dismissal of Long Covid illness reports (n = 114, 34%), prolonged diagnostic journeys (n = 130, 39%), and lack of treatment options for Long Covid (n = 137, 41%). As we discuss later, while the term gaslighting was largely associated with the first theme, we interpret its use to apply also to the two other themes. Gaslighting seems to serve as a totalizing term characterizing the overall impact of interacting not only with a specific medical professional but also with the medical system as a whole. Gaslighting thus blends individual clinical encounters with organizational issues and more systemic concerns. Additional minor themes are discussed in the context of the three main themes identified.

A note of clarification is needed here about how we operationalize the registers of the individual, organizational, and systemic: By individual clinical encounters, we refer to the interactions that patients have with medical professionals, typically in clinical and other medical settings. Individual-level factors shaping patient experiences can stem from issues of power differentials between patients and physicians but also interpersonal dynamics such as directness, impatience, or rudeness of medical professionals towards patients. Meanwhile, organizational-level issues refer to how medical care is organized in the U.S. through a system of unintegrated care that is split up into specialties across various medical professionals. The patient experience of navigating these organizational hurdles produces a considerable degree of frustration and an abundance of negative encounters between patients and the medical system. In addition to complaints centering on these individual and organizational level factors, we found that our respondents also articulated complaints couched at a higher, systemic level, having to do with principles of medical training, diagnosis, and expertise in mainstream biomedicine, to which they often referred as "Western" or "school medicine". When we say, therefore, that the critique of "gaslighting" also operates at the systemic level, we refer to instances when patients were characterizing not their individual encounters with doctors or the challenges of navigating the organizational landscape of the U.S. healthcare sector, but what they perceived as the inherent limitations of "Western medicine" in providing holistic treatment for Long Covid sufferers. In the ontological politics of Long Covid, accusations of medical gaslighting produce a spillover effect between these different levels.

5.1. Dismissal of illness experiences

At the level of the individual clinical encounter, respondents reported being treated as unreliable reporters of their symptoms, an experience that many of them characterized as the *dismissal of their illness experiences* (n = 114, 34%). It was in these passages that our respondents most commonly invoked the term "gaslighting" as a rhetorical weapon in a struggle of ontological politics, a struggle over what counts as "real" versus "imagined". Some 91 (27%) of our respondents invoked additional terms that we view as directly related to gaslighting (e.g., gaslit, dismiss, ignore, serious, in my head, anxiety, believe, disbelieve, prove), but others also spoke to this experience of dismissal more generally and with other terms. While doctors referred to "objective" tests (metabolic

panels, blood work, etc.) as proof of their version of reality, patients wielded in response the accusation of "gaslighting" to dismiss the meaningfulness of objective measures and adjust reality to their "subjective" symptoms. This was necessary especially because—as we explain in the next section—many of our respondents contracted Covid-19 during the early months of the pandemic when tests were scarce and so lacked "proof" of their status. But in addition to this, patients were frequently told that their symptoms were caused by anxiety or other "mental" conditions. Even if only a few of them were explicitly told this was "all in your head," the discursive function of terms like "anxiety," "mental," "psychosomatic," etc., is to disqualify the patient from being a reliable reporter of their symptoms. While experiencing Long Covid can certainly produce anxiety, and understandably so, anxiety is not the cause of Long Covid symptoms, as the medical professionals encountered by patients frequently suggested. Take for instance the following response:

> "As many standard tests from GP do not detect issues initially, I paid thousands to have imaging and tests done privately. Terrible gaslighting by doctors for the first year of illness. It took over a year to prove my issues were not psychosomatic and since proving that, care has improved. I was treated as an unreliable witness to my own condition" (Respondent #32).

Respondents also pointed to the lack of empathy from medical professionals who were, at times, cruel and dismissive. In these cases, respondents referred to the term of gaslighting to describe their encounters in clinics and hospitals:

> "Gaslighting, gaslighting, and more gaslighting. Literal laughing from the medical providers – from laughing at my low O2 levels when I called into emergency advice line (Apr '20), to laughing at my request for a PCR test when I was reinfected and told to put on clothes for chills (in November 2020)" (Respondent #50).

As noted earlier, these instances of disqualification were often gendered. As one respondent reported: "My condition has been blamed on the following: anxiety & depression, 'women's troubles', and psychosomatic" (Respondent #256). Another noted: "Initially docs suggested everything else (menopause, depression). Blood tests normal or near-normal therefore dismissed. They think nothing found means nothing wrong despite obviously unwell" (Respondent #201). This tendency for gendered dismissal of symptoms no doubt explains why our female respondents tended to report more often negative experiences with medical professionals. However, as we noted previously, we did not ask specifically about respondents' views on how their gender impacted their medical care.

This repeated experience with medical gaslighting caused adverse effects among many Long Covid respondents, not the least of them being the lack of treatment over prolonged periods of time, as a respondent confirmed:

> "In the beginning, it was terrifying. No one believed or understood that covid lasted longer than 2 weeks and it wasn't a life-or-death thing. At the most terrifying point of my life I had to fight not just to live but for people to believe that my illness existed let alone to get help… because 'covid is only respiratory and lasts max 2 weeks'. There are people like me who survived and live (exist because this is not living) in a haze but have never been back to themselves" (Respondent #7).

As the dominant narrative of the disease only emphasized the acute phase of infection, few medical professionals initially considered the possibility of prolonged illness from Covid-19. Long Covid, for our respondents, seemed very much an "illness you have to fight to get" (Dumit, 2006), and additional work was needed to identify physicians that would take their complaints seriously. By using the language of dismissal and gaslighting, Long Covid patients pointed to the ontological politics that unfolded at the individual level in clinical encounters during the early days of the pandemic.

As noted earlier, the dissatisfaction of many long-haulers with the medical care they received also translated into a general critique of "Western" or "school" medicine, seen as unwilling or unable to recognize their symptoms as "real". Some affected long-haulers gave credence to their poor experience with the "Western" medical system through explicit reference to gaslighting. For instance, one respondent wrote: "A nightmare. Gaslighting and denial and doubt. Dismissal. Western medicine has absolutely failed us" (Respondent #80). As a result of their frustration, some patients turned toward *complementary and alternative medicines* (CAM) (n = 26, 8%), a field they perceived to be more willing to acknowledge illness symptoms that were not measurable through standard diagnostic practice. This finding largely accords with previous studies that report patient satisfaction with CAM practitioners, who are able to spend more time attending to the individualized needs of the chronically ill (Broom, 2009; Gale, 2014). These respondents found CAM practitioners to be, in contrast, more attentive to their concerns and more likely to validate their reports. As one respondent recounted: "The only positive response was from a homeopath and I'm currently following his recommendations" (Respondent #100). Another wrote: "My naturopath was the only person that believed me" (Respondent #84).

In the ontological politics of Long Covid, CAM providers often aligned themselves with patients by providing them not simply with treatments, but also with resources with which to shore up the reality status of their reports. We note, however, that at least in some cases the boundary between "Western" medicine and CAM was blurry. At times, medical professionals, partly due to their inability to treat Long Covid, also recommended various CAM therapies for patients: "Involved with long covid clinic but they've done nothing but monitor. However, they have supported my alternative ways of recovering - reiki, lots of supplements, healing meditations, medical massages" (Respondent #42). Another respondent corroborated: "My PCP suggested aroma therapy which I have been doing now for 10 months" (Respondent #18). And another respondent noted: "I spent the whole year looking for answers, switched doctors, tried almost everything doctors recommended from vitamins and supplements to acupuncture and therapy" (Respondent #83). The main distinction in these accounts, we suggest, seems to run not between "Western" and "alternative" medicine, but between what Long Covid patients perceive as the "evidence-based" medical establishment, driven solely by a positivist bias towards "measurable" and "verifiable" symptoms, and the field of "empirical" private physicians inclusive of CAM practitioners, whose business model thrives on winning the trust of their clientele, often by demonstrating their distance from the evidence-based orthodoxy and recognizing self-reported patient experience unequivocally as "real".

To conclude this section, we would like to highlight the experience of a small group of our survey participants (n = 7; 2%), who were medical professionals themselves. Often, this meant that they could access better forms of care. One individual noted: "the fact that I am a physician means that I am able to read about my condition on my own, and my symptoms are not dismissed by my doctors" (Respondent #5). Nonetheless, even they were not immune to being dismissed. Their status as medical professionals did not always guarantee that their complaints were taken seriously. One respondent with medical credentials recounted being dismissed by their own colleagues: "I am a former healthcare professional and I sought treatment at the healthcare system where I worked. I was treated like an anxious child. Nobody listens… Despite concrete evidence that something was wrong with me, such as a heart monitor showing that my heart rate elevated far beyond the normal amount, I was denied basic medication by my local doctors" (Respondent #32). While there are only a few such accounts in our data, they lend additional plausibility to the overall findings. What these varied cases of dismissal demonstrate is that, more often than not, Long Covid patients have had to contend with negative interactions with doctors that fueled mistrust in the medical system. The term gaslighting, while not invoked by all respondents at all

times, became a particularly salient rhetorical tactic for frustrated long-haulers to give credence to their experience of medical dismissal and target medical practitioners trained in "Western" or "school" medicine as culprits for their prolonged suffering.

5.2. Delayed diagnostic odyssey

Second, many respondents resorting to the rhetoric of gaslighting reported *delays in obtaining medical care and prolonged diagnostic journeys* (n = 130, 39%), known in the medical literature as "diagnostic odysseys" (Jutel, 2009; Timmermans & Buchbinder, 2010), which we see as pointing to perceived failures of the organization of medicine. These long-haulers typically commented on long wait times for referrals, their inability to find supportive medical professionals, and their personal worries that delayed treatment might further weaken their health. This was particularly dire during the early months of the pandemic when many respondents reported the difficulty of obtaining official confirmation of their diagnosis because of the lack of tests. The absence of diagnostic results differentiates the early from the later patients and continues to impact early sufferers in multiple ways today:

> "When I was acutely ill, medical professionals were telling me to stay home. I only did urgent care, and doctors assured me that I was dealing with Covid and that I'd get better soon. However, when I didn't get better, and tried to go to specialists for help, I was gaslit because I had a lack of test results confirming the infection. I didn't receive help for many months due to this disregard… the damage (quite literally) has been done" (Respondent #34).

Unable to certify their experiences through a test, these early Long Covid patients were at times viewed by medical professionals as unreliable reporters of their own symptoms:

> "Because I was sick so early, I was unable to obtain positive tests, but all of my acute symptoms were covid-like. Many doctors nevertheless didn't believe I had covid... By the time the antibody tests were available, it was several months after I was sick and that test was also negative, but I also learned these tests aren't infallible. I never had these long-term symptoms before and some doctors framed it as 'you always had this and never realized.' I couldn't go to the Mt Sinai covid clinic because I did not have a positive test" (Respondent #85).

While the majority of our Long Covid survey respondents were able to obtain a test, 86 (26%) of our Long Covid survey respondents were unable to confirm their initial infection. These diagnostic impasses forced individuals with Long Covid to engage in new forms of self-advocacy on social media and offline. A respondent affected by this issue put it: "You don't know frustration until you've had to advocate for your own care against a system that is reticent to adapt while you are debilitated by a novel illness that includes dense brain fog" (Respondent #2). Such prolonged diagnostic journeys prompted many long-haulers to look for the latest studies on Long Covid themselves and engage in a heuristic practice they termed "do your own research". One respondent described these forms of independent research and embodied diagnostic odyssey with the following words:

> "A very long, convoluted journey to a) get a correct diagnosis; b) see many doctors (some horrible gaslighting/some supportive; c) narrow down my medical care team to competent, supportive doctors; d) experiment with various off-label meds to 'cure' this illness: e) take each day at a time as more research continues to emerge; f) literally tracking peer-viewed medical research and primary scientific study about my own illness" (Respondent #161).

As evidenced in this account, the diagnostic journey of Long Covid patients, thus, was replete with frustrating and worrisome delays, false hopes and broken promises, and the ongoing struggle to find medical professionals who would lend a sympathetic ear to their ailments and be

willing to administer different treatment methods. For a long time, these challenges and impediments forced individuals with Long Covid to study the latest biomedical findings on Long Covid and engage in a laborious process of convincing medical professionals of their findings as part of "doing your own research". The experiences of Long Covid patients with their prolonged diagnostic odysseys shows that the ontological politics of Long Covid also play out at the broader organizational level of mainstream healthcare in the U.S., through the many medical specialties long-haulers need to navigate in order to secure a diagnosis.

Diagnostic odysseys, however, ended for many long-haulers not of their own volition but because the *prohibitive costs of medical care in the U.S.* (n = 26, 8%) made it impossible to obtain continued treatment. The abrupt and often involuntary end of treatment prompted affected long-haulers to voice criticism of the fragmented organizational nature of U.S. healthcare but also of the broader economic challenges many of them experienced as they struggled to receive adequate insurance coverage to defray expenses for multiple tests and experimental treatments. Bemoaning the high costs of medical care for their Long Covid symptoms, one individual corroborated: "[I] spent thousands of dollars going from one doc to another. Finally found an infectious disease doc. [But] most docs don't know what the heck long covid is" (Respondent #264). This sentiment was echoed by another frustrated respondent who reported: "I have spent almost $10,000 trying to treat my symptoms, to no avail" (Respondent #109).

Even when doctors who were willing to listen and help were identified, patients and their providers had trouble convincing insurance plans to cover their tests and treatment. Respondents expressed this dilemma: "Best experience with integrative medicine providers. But not or only marginally covered by insurance" (Respondent #186) or "My Dr is great. He had tried different meds in an attempt to combat my fatigue. However, he is limited by what insurance allows" (Respondent #98). By the same token, other individuals with Long Covid also experienced job loss and the financial toll that the lack of insurance inflicted on their livelihoods. As one respondent noted, "For someone who lost their medical insurance when they lost their job, it has been difficult to find proper medical care" (Respondent #71). Long-haulers routinely reported that contracting the coronavirus was not only a life-deranging health event but also an economic tragedy on a personal level from which recovery was exceedingly difficulty. In light of continuous pain and lingering symptoms, resuming work became difficult if not impossible for many long-haulers who reported, as in following case: "I had zero medical insurance for the first year I was sick and I live in the U.S.… My health was so bad, I was pushing my limits working 25–27 h each week. No matter how much I slept, I woke up every day feeling like I got run over by two trucks" (Respondent #151).

The shortcomings of medical coverage in the U.S. medical system thus led to a cascade of negative effects thwarting medical recovery and inflicting job loss and economic pain on many affected individuals. Chief among the challenges faced by Long Covid patients who suffered from severe and debilitating illness preventing them from resuming work was the need to prove their disability: "My disability insurance dropped me due to 'lack of proof and data'" (Respondent #314). This testimony represents a plethora of similar cases pointing to the limits of the U.S. welfare system in supporting Long Covid patients through adequate and continuous health insurance coverage. While many long-haulers used the rhetoric of gaslighting to describe their medical odysseys, being forcibly cut off from treatment due to lack of adequate healthcare also sparked deep frustration with medical providers and despair about personal health outlook. At the organizational level, gaslighting linked these forms of friction between patients and doctors to discontent about the dysfunctional state of healthcare in the U.S. that restricted treatment for Long Covid patients to individuals who were adequately covered by their health insurance to buffer the exorbitant costs of their medical odysseys.

5.3. Deferred treatment

Finally, examples of gaslighting in the accounts of respondents we surveyed included instances in which medical professionals were *unable to treat* (n = 137, 41%) their Long Covid conditions, pointing to a perceived systemic failure of medicine and gap in scientific knowledge. In such cases, respondents reported that they were "told that it will just take time to heal, no treatment available". Such sentiments of medical defeatism often congealed in the notion that medical science had no treatments available to treat the self-reported medical condition: "I just keep getting told 'It's covid. Nothing we can do'" (Respondent #16). In the absence of treatment, respondents recounted that doctors resorted to offering medical ersatz solutions that were assumed to provide general-ized relief: "My doctor said it would just take time. He recommended a daily brisk walk and Pepcid AC for the GERD, but no other treatment. I was able to have a chest X-ray, EKG, and labs done to rule out severe problems, but no treatment was provided for the mild symptoms I had" (Respondent #48).

It is important to emphasize that mistrust of doctors was not simply caused by a lack of available treatments, but because doctors routinely failed, at least from the patient's perspective, to put in the effort and genuine concern to find out about effective remedial procedures. What compounded patients' negative impression of doctors was also their lack of adequate knowledge about the status of emerging research on Long Covid and a sense that they lacked epistemic humility—the will to acknowledge the limits of medical expertise amid deep uncertainty:

> "Every doctor appointment induced a lot of anger about their inability to process emerging studies which I (even though brain fogged) explained to them. They even lacked basic knowledge about human biology, immunology to understand these studies. For that reason, I stopped to go to doctors" (Respondent #58).

This experience of absent epistemic humility was also echoed by a respondent, who highlighted the unwillingness of medical practitioners to come to terms with the limitations of their professional expertise: "I still have doctors that don't know what to do or stall or make excuses. I am trying to get a new neurologist because mine doesn't know how to treat me and refuses to admit that" (Respondent #25). If personal stub-bornness and professional pride clouded doctors' better judgement to explore better treatment solutions or refer patients to more knowledge-able colleagues, other long-haulers experienced the seeming indifference and lack of empathy from medical professionals as another alienating factor. One patient recalled: "I've seen a dozen specialists who shrug their shoulders, are dismissive, and say 'we just don't know'. They aren't interested in working with you to truly get you well. They just give you a pill to manage a symptom and send you on your way" (Respondent #87).

For many patients, these isolated experiences combined into a more general critique of U.S. or even "Western" medicine, and a turn towards alternative medical conceptions of holistic care imagined to be offered by other cultural traditions outside of Western medicine: One long-hauler put this way the perceived inadequacy of Western medicine: "That's not medicine, and that's not treating the body and person as a whole" (*ibid*). Still, others saw doctors' inability to treat their Long Covid symptoms as characteristic of the different silos in which medical spe-cialists in the U.S. receive their training and conduct their professional work as well as evidence that their disease was rooted in systemic and interdependent features that cannot be easily standardized:

> "It's been difficult in that disciplines of medicine are very segregated. This illness affects various major body systems and it can be daunting to see a specialist for each symptom. I've attended a long covid clinic. The treatment team has been great but no real answers of course" (Respondent #123).

Several respondents also reported regional variations in their treat-ments, reflecting the privatized and fragmented nature of healthcare in the US. They noted that they were unable to access adequate care because very few medical professionals in their area were aware of Long Covid. As one respondent wrote: "There are no Long Covid clinics but maybe two in all of Maryland. Not to mention, most doctors in the area have no experience treating patients with Long Covid" (Respondent #4).

Overall, because of the inability of most medical professionals to help and treat their condition, Long Covid patients have had to turn to each other for help, as one respondent attested: "Health professionals are clueless as to help and dismissive in the things they don't understand. I've learned more helpful information from FB support groups than from doctors" (Respondent #27). In short, a range of unfavorable impressions and personal frustrations in encounters with medical professionals, chief among them doctors' continued inability to treat Long Covid and the lack of epistemic humility about the limits of their professional expertise, contributed to undermining the trust of long-haulers in U.S. or Western medicine as a whole. These fissures prompted many Long Covid patients to turn towards patient-led support groups on social media for help and support and develop self-directed evaluative practices of "doing my own research". Thus, the rhetoric of gaslighting, typically applied to indi-vidual clinical encounters or the organizational problems of disjointed specialties, expanded to include the medical system and biomedical knowledge as a whole, and the lack of recognition that these broader structures give to Long Covid.

At the same time, patients who were able to access specialized *post-Covid care centers* (n = 29, 9%), such as at Mount Sinai in New York City, dedicated to diagnosing and treating Long Covid symptoms, reported better experiences and were more hopeful. For some respondents, these post-Covid care centers were able to help them manage their symptoms. Importantly, such dedicated treatment facilities, unlike general medical practitioners, had professionals on staff who were willing to believe "subjective" illness reports in the absence of "objective" diagnostic confirmation – not least because they themselves or their colleagues suffered from Long Covid (see for example this early interview with Mount Sinai physicians, Cooper, 2020). Such facilities were also able to order additional tests seeking to pinpoint the ailments of individuals if initial diagnoses remained inconclusive. One respondent who received treatment in a post-Covid care center reported: "I was able to get ap-pointments at the Covid Treatment Center at Mt Sinai. I must say they were extremely thorough and got me to the right specialists for the right tests to rule out significant damage to the lungs/heart" (Respondent #52).

While the integrative model of these clinics helped bridge the otherwise siloed compartmentalization of medical specialties seen else-where in the U.S., the issue of testing resurfaced in these facilities as well. This was because many post-Covid care centers, at least initially, refused to accept patients who failed to provide a "confirmed" diagnosis of their Covid-19 symptoms. One respondent described this experience as fol-lows: "I'm lucky I live in NYC with great access to care, and was able to obtain treatment at Mt Sinai's post COVID care center. Despite the CDC's guidance that a PASC [Post-Acute Sequelae of SARS CoV-2 infection] diagnosis be given based either on documented COVID or antibodies OR based on clinical interview, many specialty clinics do not accept [pa-tients] without documented testings" (Respondent #44).

Likewise, one of the problems that persisted in these centers was the lack of available treatment options. Even long-haulers who were able to obtain appointments at post-Covid Care centers learned that effective treatments for their conditions remained elusive because most facilities were only equipped to help monitor and manage symptoms but not to heal them. One respondent put these deficiencies with the following words:

> "With the help of colleagues, I was able to get into the Johns Hopkins Post-Acute Covid clinic… They have diagnosed me with post covid POTS and MCAS (Mast Cells Activation Syndrome) but the treatments we are currently using haven't overall drastically improved my cir-cumstances. I know it takes time but I am wishing there were more

trials for experimental treatments like monoclonal antibodies available" (Respondent #8).

What these examples show is that even in specialized facilities where patient complaints were listened to and seen as credible, one of the fundamental challenges of Long Covid—treatment options—did not disappear. Rather, the continuous scarcity of remedies in the first phase of the pandemic revealed that medical science as a whole was experiencing a crisis of viable solutions as it confronted a newly emerging chronic disease that many doctors and scientists struggled to fully understand.

This provides a gloss on the 21% (n = 69) of respondents, who reported *positive interactions* with medical professionals. Given the above, it is unlikely that they did so because their providers were able to effectively treat their Long Covid symptoms. It is far more likely that what made these interactions "positive" is that in these cases medical professionals listened to their patients, made an effort to do read up on the latest Long Covid research, and were willing to experiment and try out different treatments. As one respondent wrote of their relatively positive experience: "I am not having a problem getting a doctor to see me and those that have, are very understanding of what I am going through but all of them have said this is trial and error …. basically like throwing darts at it" (Respondent #35). Another respondent stated that they were "lucky to have a PCP that believed me and has tried to help the best she can by giving me referrals to specialist and researching long covid" (Respondent #40). Our short answer responses from the survey only provide some evidence for the importance of epistemic humility—largely because the survey may have served as an opportunity to vent about negative interactions. However, in our follow up interviews, we found that respondents discussed much more in detail about the importance of epistemic humility in shaping their trust of their physicians. Take for example, this respondent's description of their positive experience: "Though they don't necessarily know what the solution is, they are constantly reading things. And even if I come to them with something weird that I saw online they'll consider it and look into it and advise me on whether I should do it or not. So overall now I have a really good experience" (Follow Up Interview #41). Another respondent also emphasizes the importance of epistemic humility:

> "Basically in [my doctor's] words he said: 'look, if you have this long Covid, I'm gonna be honest with you, you're better off going there.' He said: 'you know I can treat you for a few symptoms but I'm not gonna be able to help you with a lot of the things that are with Covid. You need to be in a place that's doing research and it's gonna be seeing more of just Covid people because honestly it's gonna be out of my realm.' I have to give him praise and thanks because he helped get me there and he confirmed the fact that you know yeah I do think you have this as well. I think he did a little bit of research himself, he dug into it, and kinda saw it and he communicates with me every now and then. I still of course see him. But yeah he was a big part in getting me into the long Covid clinic" (Follow Up Interview #51).

Through this show of epistemic humility, doctors did much to win over the trust of their patients, even if they were not able to provide immediate relief. There is a good chance, however, that these displays of epistemic humility were also prompted by the social status of these specific patients. Many who reported positive experiences also added that they themselves had access to resources that others did not.

6. Discussion

In this study, we sought to document the experience of Long Covid patients in their struggle to receive medical care and recognition for their chronic suffering in the U.S. We were struck with how often the terms associated with "gaslighting" were used by patients to frame their experience with the medical system. "Gaslighting", as we argue, is a term suited for ontological politics (Mol, 1999, 2003), a concept that refers to

the struggle over what counts as real, who counts as a reliable reporter, and which reports compose the fabric of reality. As Long Covid patients navigate what many perceive as a maze-like terrain of siloed specialties, shifting expert opinions, and evolving scientific knowledge, the rhetoric of gaslighting serves to contest and negotiate their symptoms and illness experience in a tug of war with the medical profession. A sense-making and identity-forming mechanism for long-haulers, the rhetoric of gaslighting also reveals more broadly how different actors in the Long Covid space grapple with what a "real" illness is, what counts as suffering, and what is worthy of public attention. To be sure, there is a certain kind of irony here in how patients engage with the "objectivity" of mainstream biomedicine: Long Covid patients invoke the language of gaslighting to accuse biomedical experts of using "objectivity" to dismiss their subjective complaints at the same time that they themselves work with sympathetic biomedical experts to make their claims more "objective". This dynamic is part and parcel of the ontological politics of Long Covid and exhibits similarities to the experience of fibromyalgia patients (Barker, 2005), who also invest significant efforts to overcome the "legitimacy deficit" of their suffering (Kempner, 2014). These experiences no doubt extend to other conditions, such as chronic, orphan, and contested illnesses, where uncertainty in scientific and medical knowledge has rendered diagnosis and treatment difficult.

In ending, we should also remind our readers that, as Sweet (2019) notes, gaslighting is not simply a psychological phenomenon but also a sociological one: it is rooted in social inequalities such as race, gender, and class, which reflect unequal power relations between patients and physicians. In many preceding studies of other patient groups, individuals from marginalized social groups tended to experience more barriers in accessing healthcare. We also know from the broader literature on medical sociology and the social determinants of health that these forms of inequality and accompanying identities pattern access to healthcare (Link & Phelan, 1995). This is a limitation of our study, which consists of a sample of online Long Covid patients who are majority White, well educated, high income, liberal-leaning, and suburban. Future research should look specifically at marginalized groups, and the rhetorical strategies that respondents from these groups draw upon to make sense of and contest their care experiences.

The three major themes we found through the qualitative coding of our short answer responses indicate that ontological politics indexed by the rhetoric of gaslighting do not remain confined to the individual encounter between patient and physician but encompass the organizational and systemic levels. At the level of the individual, clinical encounters with medical professionals dismissive of patients' Long Covid experiences prompted many of our respondents to invoke the language of medical gaslighting to describe these experiences. At the level of the organization, Long Covid patients criticize the fragmentation of U.S. mainstream medicine into siloed specialties. Long-haulers also voiced criticism of the undue economic burdens imposed by prolonged medical treatment in absence of adequate healthcare coverage. At the systemic level of the medical system, Long Covid patients respond to the inability of current biomedical knowledge to treat or cure Long Covid by blurring its boundaries with CAM.

As we tried to make clear from the onset, these complaints are not discrete and bounded, but rather intertwined and inseparable. These varied issues speak to how the broader politics of Long Covid bleed into the individual struggles faced by patients. What Long Covid patients experienced and labeled as "medical gaslighting" was partly a product of structural problems with the handling of Long Covid care—such as the lack of treatment options, the early unavailability of covid tests and the over-reliance of doctors on standard panels of tests—as well as more interpersonal problems—such as the lack of clinical empathy that prompted medical professionals to dismiss the experience of their patients (Vinson & Underman, 2020). What is different, perhaps, with Long Covid, is the speed, scale, and sheer number of patients who have come forward, which has shone a light on these experiences in ways unlike previous patient movements. If indeed, such struggles over what is real is

a competition of marshaling "facts", then Long Covid patients have been able to organize themselves for biomedical and epidemiological research to quantify and characterize their experience. These changes in scale of the patient population allows researchers today to more closely examine these dynamics that were previously harder to study. The tradeoff here is the speed at which such processes unfold, making it harder to analyze phenomena that previously would occur over the years, if not decades.

Furthermore, future research should look to the proliferation of medical gaslighting as a discourse that seems to have been increasingly taken up by patient activists, as well as how changes to the work conditions and clinical approach of physicians can alleviate the experience of patients with chronic and contested illnesses of being gaslit. Follow-up studies should investigate whether physicians in later stages of the Covid-19 pandemic began to accept and trust the accounts of Long Covid patients. Researchers should examine whether medical professionals are beginning to display more clinical empathy now, more than two years after the outbreak of Covid-19, and whether this change in attitude has led to more positive interactions and trust between patients and the medical system. Similarly, researchers should look at how different types of Long Covid symptoms affect the clinical experience of patients. While medical gaslighting may be part of the Long Covid experience until now, future Long Covid patients may not have to contend with the same challenges encountered by our respondents if more is done to create more accessible and inclusive forms of medical care.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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