

Research Paper

Disbelief, dualism and post-viral alliances in pandemic times

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This manuscript explores the ways in which the future of long COVID was both always circumscribed and expertly managed. When long COVID emerged, it was immediately recognized as a contested condition, and as such, was destined to carry the baggage of many complex forms of suffering that came before it. However, those suffering from long COVID managed to harness the energy of the pandemic crisis to produce new opportunities and new possible futures, not only for themselves, but for others with contested conditions. These dimensions are examined through a close look at an interesting alliance that formed between those suffering from long COVID and those diagnosed with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), most prominently in the United States and United Kingdom; how this alliance has been both fruitful and challenging; and the roots of dualism that underlie widespread ontological and moral assumptions within medicine.

Long COVID and Legitimacy

All in Your Head

The coronavirus pandemic arrived quickly and dramatically in early 2020. In February, the World Health Organization (WHO) noted that approximately 20% of COVID-19 cases present as severe or critical, and that the recovery period can range from two weeks in mild cases to up to six weeks in more severe cases (World Health Organization 2020). By May, patients were alerting health care professionals and the public that the recovery period may be much longer than initially thought. They began to collect data related to the prevalence of such ‘long haulers’ and soon such cases were being widely discussed in political, medical, and popular settings (Callard & Perego 2021). Very quickly, these discussions of chronic infection or ‘long COVID’, as it would soon be named, became polarized.

Skepticism and doubt about the origins and legitimacy of the condition appeared. Michael Sharpe from the University of Oxford suggested that long COVID may be *socially spread* by media coverage and advocacy groups (Monbiot 2021, Sharpe 2021). Jeremy Devine argued that by ‘drawing attention to and legitimizing the ever-present threat of long COVID, medical authorities will lead a large group of impressionable patients to believe that their COVID-19 symptoms have not resolved and that they are helpless victims of an unrelenting sickness’, noting that ‘a fixed belief that one is ill and unlikely to recover’ is a central feature of many

psychosomatic conditions (Devine 2021). Reinforcing these suggestions, a professor diagnosed with long COVID described his journey to recovery from long COVID as one of using his mind to retrain his body. He speaks of finding relief by refraining from ‘constant monitoring of symptoms’ and ‘reading stories about illness and discussing symptoms, research or treatments’, and instead ‘seeking joy, happiness, humour, laughter’ (Garner 2021).

These contributions introduce and/or strengthen various interconnected ideas about long COVID. Some of these ideas are causal, having to do with psychological or social influences on long COVID, and how those influences might also offer relief. Other closely related ideas that arise in these statements are moral. Between the lines, it is suggested that the responsibility for one’s suffering and healing, and therefore blame, lies in oneself.

‘Please Hear Our SOS’

Soon, patients began to react to these suggestions that long COVID is merely the result of social influence or a weak mind. Countless descriptions of patients feeling unheard and disbelieved began to circulate (Cheston et al. 2025). A narrative analysis of long COVID patient experiences notes that challenges related to seeking support were ‘compounded by the frustration of trying to convince family, friends, and health care practitioners of the legitimacy of their illness’ (Kaufmann et al. 2023, p. 1). As one patient put it, a ‘medical student asked me if I was faking my symptoms to get attention from my husband. I was like, are you fucking kidding?’ (Lu 2022). Another patient describes their efforts to be taken seriously in the context of health care:

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, quoted by Au et al. 2022, p. 6).

This patient worked hard, and spent a lot of money, to provide evidence of her suffering that would be taken as real. Many others suffering from long COVID ‘used various tactics to claim epistemic authority’, but doubts related to their suffering lingered (Callard & Perego 2021, p. 3). In the early days, desperate to be believed and understood, a collective of patients launched a campaign called ‘Long COVID SOS’, sharing a video in many languages, pleading ‘we need to be believed... please hear our SOS’ (Long COVID SOS 2020).

Situating this Tension

I aim to explore these tensions related to the origin and legitimacy of long COVID, and in doing so, reveal the way in which the future of long COVID was always circumscribed. When long COVID emerged, it was immediately recognized as a contested condition, and as such, has always carried the baggage of many complex forms of suffering that came before it. This inherited history has limited the possible futures for long COVID patients. However, those suffering from long COVID managed to harness the energy of the pandemic crisis in order to produce new opportunities and new possible futures, not only for themselves, but for others with contested conditions.

In the next section, I situate the above reactions to long COVID in the history of ‘psychosomatic’ conditions. I then turn towards an interesting alliance that developed in the midst this controversy, and perhaps because of it, between patients with long COVID and patients with myalgic encephalomyelitis or chronic fatigue syndrome. This alliance has been tremendously fruitful in some ways but, in other ways, it remains entrenched in familiar, challenging folds. Following this, I examine the controversies that remain surrounding these conditions and the role that mind-body dualism plays in shaping these. Finally, I end with some musings on the future, especially with regards to where skepticism and medical causation may be headed next.

A quick note on my background and my method: I’m an interdisciplinary scholar, trained primarily in philosophy and interested in ethical and epistemic issues related to the production of knowledge in medicine. With regards to methodology, the data that informs this analysis are various, including newspaper articles, blog posts, empirical and theoretical academic articles, stories in magazines, and social media posts. The materials

are largely drawn from the contexts of the UK and the US, where the controversies I aim to interrogate took on the loudest tones and bled into each other. These settings loom large in the background, giving shape to the contours of the dynamics I outline, and the responses they engender. Prevalence of long COVID looks quite different in different parts of the world, as do patient-led advocacy efforts (Chen et al. 2022). In the UK and US, for example, patient activism took place ‘in a political and medical system that is attuned to claims of individual rights, especially by middle-class activists’ (Au et al. 2022, p. 2).

Contested Conditions: Fuzzy and Fake

This tension between those begging to be taken seriously and those giving reasons why patients shouldn’t be taken seriously reflects a pattern we’ve seen in many instances throughout the history of medicine. This pattern often shows up in conditions in which common symptoms are both psychological and bodily, sometimes known as contested or ‘psychosomatic’ conditions (Dumes 2020). Examples include fibromyalgia, multiple chemical sensitivity, irritable bowel syndrome, chronic pain, Lyme disease and other conditions often characterized as ‘complex chronic conditions’, ‘functional somatic syndromes’ (FSS), or captured by the term ‘medically unexplained symptoms’. Joseph Dumit has described these as ‘illnesses you have to fight to get’, and noted how they are often chronic, contested, legally explosive, fuzzy in their boundaries, and entangled with diverse therapeutic tools (e.g. complementary and alternative medicine) (Dumit 2006).

Responsibility and Deservingness

Monica Greco has argued that such ‘psychosomatic’ conditions are often seen as ‘dispositional’ as opposed to causal or etiological, inviting an understanding of patients that links their illness to a moral failing (Greco 1993). Indeed, narratives of blame and responsibility circulate around these conditions in various ways. Like those with long COVID, patients with such conditions report being disbelieved and doubted frequently, both in clinical and social settings. As Megan Crowley-Matoka writes of chronic pain, patients are frequently challenged with questions of uncertainty, including ‘Is this pain “real”? That is, is it a sign of material, bodily damage? Of psychological distress? Of malingering or even moral turpitude?’ (Crowley-Matoka 2020).

Doubts related to the truth of patient narratives also circulate in the scientific literature. As one chapter describes functional somatic syndromes:

Patients with FSS [functional somatic syndromes] also have a tendency to exaggerate or distort the meaning of symptoms. ... Both chronic pain and CFS [chronic fatigue syndrome] patients demonstrate a greater tendency to overgeneralize or catastrophise the consequences of experiencing somatic symptoms when compared to healthy controls (Moss-Morris & Wrapson 2003, p. 123).

Similarly, research questions often reinforce assumptions that suffering is all in the head and should be resolved there as well. A poster presented at the annual meeting of the American Psychosomatic Society explores whether a stress mindset might be to blame for heart rate variability (Schillings et al. 2022).

All in Her Head

These conditions are seen more frequently in women than men, and patients frequently describe challenges in being believed, taken seriously, or given a diagnosis (Barker 2008, Werner & Malterud 2003). Physical symptoms are often attributed to psychological causes. One patient described being told by a neurologist, “Well, there’s nothing wrong on your X-ray but why don’t you try taking this, because a lot of women”- he used the word “women” – “have a lot of trouble with depression that could cause other symptoms” (Ware 1992, p. 352).

In other cases, patients are explicitly told that their pain or suffering is not real, but is simply imaginary, as in the experience of this patient with a diagnosis of fibromyalgia, who described an encounter with a doctor to an online support group:

...She went on to tell me the fresh out of med school approach to fibro is exercise [sic], diet. I said what about the pain. She preceeded [sic] to tell me the pain was “ALL IN MY HEAD, THERE IS NO PAIN, YOU JUST IMAGINE THERE IS” (Patient, quoted in Barker 2008, p.27; emphasis in original).

In the past, hysteria covered a similar territory (Showalter 1985), a term that often referred to a complicated array of possible symptoms, as well as a particular personality, one that is ‘manipulative, egocentric, and/or histrionic’ (Jo Hsu 2024, p.205).

A New Addition to the Family

Long COVID fits the bill. It is more common in women than men (Tsampasian et al. 2023), a correlation that skeptics frequently point to. As one patient put it, ‘My condition has been blamed on the following: anxiety & depression, “women’s troubles”, and psychosomatic’ (reported in Au et al. 2022, p. 6). Those with long COVID report widespread experiences of being dismissed as anxious and gaslit, and many seek out treatment through complementary and alternative medicine as a result (Lokugamage et al. 2020). A news article entitled ‘Is long COVID all in the mind?’ describes a typical long COVID sufferer as a ‘well-educated, obese white woman with a history of poor mental health’, bringing to mind the archetype of the ‘psychosomatic patient’ (Simmons 2022).¹ Given how deeply engrained patterns of thinking about contested conditions are, and how quickly doubts related to reality and deservingness arise in response to complicated chronic suffering, it is unsurprising that skeptical responses to long COVID arose so quickly. Indeed, many foresaw this future early on; in 2021, Phillips and Williams wrote of long COVID patients, ‘if the past is any guide, they will be disbelieved, marginalized, and shunned by many members of the medical community’ (Phillips & Williams 2021, p.578).

Given these background conditions, the potential futures available to those with long COVID were limited from the start. In being quickly recognized as a new contested condition, long COVID was always prescribed to take on the battles for recognition that had long been occurring in this corner of medicine. As Barbara Prainsack has noted, ‘The absence of visions about what an alternative, better, future should look like creates facts on the ground’ (Prainsack 2022, p. 24).

‘You’re Tired? We’re All Tired!’

One of the most paradigmatic examples of a contested condition is myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS) (and nicknamed the ‘yuppie flu’ in the past) (Siegel et al. 2018). This condition is characterized by post-exertional malaise (symptoms become worse after effort), and often also involves pain, cognitive issues, difficulties sleeping, and dizziness (Centers for Disease Control and Prevention 2024). The condition affects between 836,000 and 2.5 million Americans, and yet it is estimated that up to 91% of people with ME/CFS have not been diagnosed (Institute of Medicine 2015). It is diagnosed more often in women, and in White people, although BIPOC populations may be especially underdiagnosed (Bhui et al. 2011). While these data sound real enough, the condition is highly contested. A description of the experience of those with ME/CFS from Ware in 1992 rings surprisingly true today: ‘their illness is not “real” at all but rather a fabrication based either on the needless exaggeration of everyday complaints (in which case they are malingerers) or on the perception of imaginary symptoms (in which case they are “crazy”)’ (Ware 1992, p. 355).

Diagnoses of ME/CFS are hard to come by, with many patients visiting countless doctors and attempting to teach them about the symptoms associated with ME/CFS. Patients speak of ‘people constantly

¹ This quotation invites race and fatness into the equation as well. The notion of weight brings forth additional layers of moralizing and stigmatizing related to responsibility for one’s own ill health. As Pausé et al. (2021) note, ‘pandemic responses are pushing renewed energy into the moral panic around fatness, reinforcing the problematisation of fat people as subjects of blame for poor self-management and as burdens on healthcare resources and community wellbeing’. With regards to race, White patients have often been at the forefront of advocacy efforts, but patient populations are diverse (Meriquez Vázquez 2023).

questioning whether I was sick’ and being called a malingerer (Clarke & James 2003). A familiar response to the term ‘chronic fatigue syndrome’ is ‘You’re tired? We’re all tired! So what!’ (Ware 1992, p. 350). As such, the sick role is frequently unavailable to these patients (Clarke & James 2003). And even when it is, discourses of self-management in care can reinforce doubts related to legitimacy and blame (Risør & Lillevoll 2021). Some authors have characterized the experiences of patients with ME/CFS as one imbued with epistemic injustice, which involves the devaluation of someone’s credibility as a result of prejudice associated with the group they belong to (Spandler & Allen 2018). Blease and colleagues suggest that the uncertainty surrounding the cause and diagnosis of ME/CFS likely impacts how health care professionals take up the testimonies of patients, which then ‘translates into uncertainty about its sufferers’ (Blease et al. 2017, p. 550). Spandler and Allan add that this injustice is further exacerbated by framing of ME/CFS as a psychiatric problem (Spandler & Allen 2018, p. 132). As such, ME/CFS often serves as the poster child for stigmatized, gendered, contested conditions.

A Natural Alliance

Given this, it is perhaps unsurprising that those suffering from long COVID and ME/CFS quickly decided to band together after long COVID arrived on the scene. The overlap between symptoms is particularly striking, something that patients clued in to right away – both conditions are characterized by brain fog, fatigue, muscle and joint pain, sleep disturbance, and neurological impairments (Cheston et al. 2025, Owens 2022). What’s more, despite its contested etiology, many with ME/CFS report that their symptoms were brought on initially by a viral infection. The similar social responses to the conditions were not lost on patients either. Ed Yong writes, ‘As energy-depleting illnesses that disproportionately affect women, long COVID and M.E./C.F.S. are easily belittled by a sexist society that trivializes women’s pain, and a capitalist one that values people according to their productivity’ (Yong 2023).

As early as March 2020, patients diagnosed with ME/CFS spoke out against approaches like herd immunity, warning that ‘Viruses can have catastrophic ongoing effects on a person’s health, long after they have technically ‘recovered’ from them’ (Fiona 2020). As patients with COVID increasingly reported an inability to recover functions after weeks and months had passed, those with ME/CFS reached out. Soon after, advocacy organizations for each condition began working together, aiming to share what has been learned about ME/CFS with those suffering from long COVID, as well as to help those with ME/CFS to benefit from attention and concern related to long COVID (Solve M.E. n.d.).

The Fruits of Alignment

These shared efforts changed things for those with ME/CFS considerably. Most dramatically, the funding opportunities offered to support long COVID research² outshaded anything ever devoted to ME/CFS research, which receives less than any other condition in the National Institutes of Health (NIH) portfolio relative to disease burden (Mirin et al. 2020, Yong 2022). In 2020, the National Institute for Health and Care Research (NIHR) in the UK set aside £18.5 million for research on long COVID, while in 2021, the NIH in the US allocated \$1.15 billion for the same cause (Subbaraman 2021). Such numbers were a sign of significant promise for many ME/CFS stakeholders. Patients expressed hope that they might gain from novel research examining how encounters with a virus can turn into chronic debilitating conditions (Callard 2020, Yong 2022). Some reports even suggest that patients may be receiving better treatment since the pandemic; as the mother of one patient with ME/CFS put it, 1/10 doctors might have taken him seriously before the pandemic, but now only 1/10 ‘will be a real jerk’ (Yong 2022). Physicians who have been learning how to best support ME patients for decades are hoping to share their expertise, and researchers who have been struggling to fund research on ME/CFS are finally finding support (Yong 2022).

² At time of writing, much of this funding has been cut by the Trump administration (Ledford & Kozlov 2025).

The past is also being reimagined through advocacy efforts, making space for new futures to be imagined as a result. The Patient-Led Research Collaborative, consisting of long COVID patients and those with associated illnesses, was born out of the Body Politic, a (now sunset) online support group for long COVID patients, and has published on a variety of research topics related to long COVID and related conditions (Patient-Led Research Collaborative, n.d.). They are also playing a role in rewriting historical narratives surrounding ME/CFS within the scientific literature, performing the past in a new way in order to reshape the future (Oomen et al. 2022). A recent review of long COVID in *Nature Microbiology* led by this group reports that, before COVID-19 ‘multiple viral and bacterial infections were known to cause postinfectious illnesses such as ME/CFS’ (Davis et al. 2023, p. 134). However, things were not so clear-cut before; a summary of a scientific conference on ME/CFS in 2019 outlined ‘several plausible models’ and triggers for the condition, including ‘brain infection (such as by chronic herpesvirus infection), autoantibodies, neurotoxins, or chronic stress’, and gut inflammation (Komaroff 2019, pp. 499-500). This suggests that viral infections may not have been widely accepted as the cause of ME/CFS, but the story may soon be rewritten as if they were.³ As Callard has pointed out, ‘for many with ME, COVID-19 holds the potential to secure ME within epidemic historiography’ (Callard 2020, p. 732).

Crisis as Fuel for the Future

Part of what led to such dedicated funding and attention in response to long COVID was the sense of crisis advocates were able to harness. Arguably, if up to 2.5 million people were already suffering from ME/CFS before the pandemic began, there was already a significant crisis involving post-viral fatigue at play. But despite patient outcry and advocacy, there was little to no recognition of this suffering. Long COVID, however, was tied to a sudden and significant crisis. In 2020, the WHO declared that coronavirus constituted a Public Health Emergency of International Concern, triggering coordinated national and international responses in terms of screening and surveillance. This declaration helped to excel the status of the pandemic to one of a global crisis, in which significant efforts and resources must be expended in response. As Shepler has observed, drawing on the work of Roitman, perpetual crisis does not receive recognition in the way that sudden crisis does (Shepler 2023). The slow suffering of many with ME/CFS is harder to recognize than the novel and urgent suffering of those with long COVID. Once a crisis is recognized as such, new opportunities present themselves; as Roitman writes, ‘accession to crisis engenders certain narrations’ and ‘enables and forecloses various kinds of questions’ (Roitman 2013, p. 10). Long COVID patients were extremely effective at utilizing crisis narratives, ‘mobilizing subjective evidence in online fora’ in order to transform the illness ‘from initially invisible to the public eye into a central feature of the pandemic’ (Roth & Gadebusch-Bondio 2022, p. 7). In doing so, these patients could be described as effectively utilizing ‘crisis futurities’, an orientation towards calamity and dystopia which can ‘drive biopolitical impulses toward protecting life, mitigating human suffering, and experimentality’ (Lorway 2026).

In the case of long COVID, the benefits of this crisis were shared with others. Indeed, a broadening of recognition related to post-viral conditions has been opened up, making space for patient experiences to be seen in a new light, for funding to be distributed at a momentous pace, and for (some) clinicians to recognize suffering where they previously placed suspicion. Headlines read “‘I felt betrayed’: how Covid research could help patients living with chronic fatigue syndrome” (Frangou 2021) and ‘Long COVID Has Forced a Reckoning for One of Medicine’s Most Neglected Diseases’ (Yong 2022). As the director of advocacy for Solve M.E. said of the collaboration with long COVID sufferers, ‘this is an amazing, truly once-in-a-generation research opportunity’ (Frangou 2021). A new affective relationship to the future, one of hope and expectation, was opened up for ME/CFS patients, thanks to the pandemic crisis (Oomen et al. 2022).

As the recognition of the overlap began to grow, many started referring to both ME/CFS and long COVID under one umbrella, as ‘post-viral’ syndromes or conditions, ‘viral onset illnesses’, or ‘post-infectious fatigue syndromes’ (Davis et al. 2023, Frangou 2021). Today, around half of patients who have been diagnosed with long COVID for more than six months meet the criteria for ME/ CFS (Davis et al. 2023, p. 137), and

³ Early research on ME/CFS focused on the Epstein-Barr virus as the possible cause but was abandoned due to replication challenges – see Rogers (2024) and Ware (1992).

efforts are being made to investigate post-exertional malaise in long COVID (Twomey et al. 2022). The distinction between the two conditions is becoming hazy.⁴

Risks of Alignment

Other effects of the alignment between long COVID and ME/CFS may be less positive. In particular, the alliance between all patients experiencing post-viral conditions may mean that issues that have long haunted those suffering from ME/CFS are likely to carry over into the world of long COVID. The battle between those whose see patients' suffering as 'it's all in your head' (IAIYH in internet shorthand) and those who are crying out 'believe me' is deeply entrenched, and has been for a long time, in the world of ME/CFS.

The nature of this battle is perhaps most glaring in relation to the controversial PACE trial (Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation), which tested cognitive behavioral therapy (CBT) and graded exercise therapy (GET) for ME/CFS in the early 2000s. When initially published, the results showed these treatments were effective, but patients questioned this, arguing that, in their experience, exercise made their symptoms much worse. They demanded to see the data, but the authors refused. Finally, after a five-year campaign, a tribunal ordered their release. A reanalysis found that the conclusions were not supported by the data (Monbiot 2021). Now, some guidelines, including NICE (National Institute for Health and Care Excellence) in the UK, advise against exercise therapy to treat ME/CFS (Baker & Shaw 2007). Others have removed recommendations related to exercise (e.g. the Center for Disease Control in the US) (Rehmeyer & Tuller 2017), while some still promote it (e.g. the Royal Australian College of General Practitioners (2024)), leaving the field in conflict.

While a similar dynamic arose quickly on its own in response to long COVID, blurring the lines between long COVID and ME/CFS may only exacerbate it. Indeed, those skeptical of the legitimacy of ME/CFS are raising similar concerns about long COVID. Michael Sharpe, mentioned above as an advocate for the 'social spread' theory of long COVID, was one of the lead researchers behind the PACE trial. Advocates are biting back too; one blogger wrote 'the people who for years have been presenting CBT and GET as ME/CFS treatments are now pitching their wares at the Long COVID community. Already they have been applying the same hysteria-based schtick' (Hughes 2021). A recent statement from the ME Association writes that: 'we have been critical of the way in which many clinicians and researchers have failed to acknowledge the important clinical and causative overlaps between long COVID and ME/CFS' (ME Association 2023). Here, we see the familiar debate regarding the origin and legitimacy of these conditions rearing its head again. Despite new waves of hope, funding, and understanding brought about by the pandemic, 'conversations about long COVID have replayed tired debates about ME' (Jo Hsu 2024, p. 199).

Dualism and its Discontents

Mind Versus Body

The Western belief in dualism, in which the mind and body are seen as distinct systems, has its roots in early modern philosophy, which grappled with understanding and explaining the differences between a thing itself (something objective and material) and the experiences we have of a thing (something subjective and immaterial) (Greco 2019). This split between the mind and body has buried itself deep in many of the ways in which we think and know. Rather than assessing the veracity of dualism, Greco points out that it is also worthwhile examining it as a 'historical actuality' and as a 'metaphor we live by', so that we might consider the ways in which it has shaped, and continues to shape, our world (Greco 2019, p. 108). This bifurcation of the mind and the body influences our experiences of illness and our medical system, diagnoses, and research in a variety of ways.

⁴ I emphasize shared advocacy efforts, but others document boundary work between the two conditions (Roth & Gadebusch-Bondio, 2022).

Dualism shows up frequently in descriptions and discussions of long COVID and ME/CFS. Take these two quotations, for example. As Phillips and Williams characterize it, the polarization surrounding long COVID can be located in beliefs about the origin of the illness:

One camp believes that long COVID is a new *pathophysiological syndrome* that merits its own thorough investigation. The other believes it is likely to have a *nonphysiological origin*... those embracing this psychogenic paradigm are reluctant to endorse a substantial societal focus on research or to follow traditional organ-specific clinical pathways to addressing patients' concerns (Phillips & Williams 2021, pp. 578, my emphasis).

Spandler and Allen describe the battle over our understanding of ME/CFS in similar terms:

On the one hand, ME activists argue that a narrow focus on the psychological elements of the illness has blocked bio-medical research and treatment ... On the other hand, the psychiatric profession has portrayed ME activists as blocking progress by campaigning against *any* psychological or psychiatric research investment and treatments (Spandler & Allen 2018, p. 131).

Both of these quotations highlight one way in which dualism tends to show up in discussions of contested conditions, pitting the physical and the psychological against each other. Most often, advocates insist on an organic cause and highlight physical symptoms. In contrast, skeptics point to vague and fuzzy symptoms which are explained as psychological in nature. These competing ontologies, one physical and one psychological, are often at the heart of debates related to ME/CFS and long COVID. On top of beliefs about etiology and symptoms, another leap is often made regarding appropriate treatment. Those who favour physical descriptions typically suggest that a physical treatment is also required, while those who see a condition as primarily psychological tend to suggest interventions at that level as well.

These dualistic assumptions, in which the mind and body are seen as distinct spheres, does not end at the ontological level. As described above, assumptions related to responsibility and deservingness quickly enter the picture as well. If a person's symptoms are seen as psychologically influenced, doubts related to their veracity, and how much compassion ought to be expended on them, often arise. A picture of suffering that is psychological at bottom opens up space for narratives of 'you're faking it', 'you just need to push through', etc.

In contrast, if one rejects dualism, it's not clear that a psychological etiology must correspond with a psychological symptom set and require a psychological treatment. An ontological view of the body which allows for causal pathways that cross psychological and somatic lines need not adopt any of these logical jumps, and instead might permit explanations, characterizations, and investigations that cut across these divisions.⁵

Patient Advocacy and Dualism

Patients are well aware of ontological and moral assumptions surrounding the origins of their symptoms. In hopes of counteracting skeptical narratives of their suffering, many also partake in the very same dualism, pushing out of view explanations or interventions that might cut across psychological and somatic lines. In Ware's study of patients with diagnoses of ME/CFS, she found that they contested the psychosomatic characterization of their diagnosis in two ways: by arguing that the illness is primarily physical and by demonstrating that they do not have a psychological impairment (Ware 1992). As one patient put it,

[I knew I was really sick] because I had actual physical symptoms, even though nothing showed up on the tests . . . like sore throat, headache, nausea, temperatures that showed up on a thermometer. One test showed that there was some kind of actual weakness in the muscles. It showed up on this little graph. That was great. (Ware 1992, p. 354).

⁵ This worry is one that is in some ways specific to Western health care contexts, since dualism shows up in different ways in different contexts (Kleinman 1977, Lambek 1998).

This quotation reveals the power of physical demonstrations of suffering, particularly those that can be seen in an ‘objective’ measure like a graph, both in terms of convincing oneself and others. In patients seeking legitimacy, it is strategic to downplay any psychological causes or triggers and to emphasize the physical nature of one’s suffering. This emphasis extends to treatments as well. In response to the PACE trial discussed above, ME/CFS advocates have fought hard to exclude any recommendations related to psychotherapy or ‘pushing through the discomfort’ with exercise from treatment guidelines.

A similar dynamic has played out with long COVID. Many reject wholesale the idea of any treatments that might border on the psychological, holding out instead for a physical explanation and cure, one that will improve quality of life and also underscore the reality of their suffering. This reinforces a dualistic hierarchy in which the physical is real and the psychological is unreal, as well as an ontological picture in which there is no causal avenue between the psychological and the somatic.

The Impossibility of Embracing Dualism

While such dualism may not be ontologically accurate, it’s worth considering what it would cost for patients with ME/CFS and long COVID to speak up against it. Given the context in which contested conditions are received, the costs of highlighting the complexity and interplay between the psychological and somatic domains would be significant. Crucially, inviting such complexity would mean welcoming various moral claims related to responsibility and deservingness into the discussion. As Ware describes it, any links to the level of the psychological come with risks: ‘defining a problem as “mental” or “emotional” means linking it to the values associated with mind in Western metaphysics - hence the notion that psychiatric illness represents a failure of intentionality and volition, a lapse of rational self-control that must ultimately be recognized to be “one’s own fault.”’ (Ware 1992, p. 356).

Spandler and Allen describe patient resistance to psychological explanations of ME/CFS in even stronger terms, indicating that what is being contested is ‘the process of psychiatrisation itself’ which comes with the loss of power, knowledge claims, and rights (Spandler & Allen 2018, p. 129). To group oneself in the company of psychiatrized patients, they argue, is to not only give up on a causal and moral story in which one might be taken more seriously and extended greater compassion, but to fight for a fundamental sense of recognition. A quick glance at the history of mistreatment and abuse in psychiatric contexts, as well as common methods utilized today (restraint, seclusion, involuntary treatment, police brutality) should remind us why anyone may wish to avoid being placed within this category (Friesen 2024). For patients with ME/CFS and long COVID, many of whom already struggle with self-doubt and self-trust, it is entirely logical to resist an explanation that risks confirming these fears and placing them in a category of patients who are even worse off when it comes to being heard and taken seriously. In practice, such resistance serves to reinforce the dualism underlying both sides of the controversy, but is entirely rational.

Facing the Future

Skepticism and Online Contagion

In an editorial written in the *BMJ* in 2002, Keith Petrie and Simon Wessely discuss recent trends related to distrust of experts, healthy lifestyle trends, and fears about unnatural chemicals, predicting that ‘it is only a matter of time before a mass psychogenic illness is identified as being spread electronically’ (Petrie & Wessely 2002). In some ways, the prediction was accurate; as Callard and Perego describe it, long COVID is ‘the first illness to be made through patients finding one another on Twitter and other social media’ (Callard & Perego 2021, p. 2). While they speak of the creation of long COVID online as a success story, in which patient expertise

and advocacy triumph, Petrie and Wessely were concerned that people connecting online can encourage each another to see their suffering as worse than it really is, and in turn, create a novel, anxiety-induced condition.⁶

The prediction of Petrie and Wessely also reflects a growing form of medical skepticism, one in which the idea of online contagion is linked to doubts about the origins and reality of symptoms or conditions. Take the controversial diagnosis of Rapid Onset Gender Dysphoria (ROGD), in which youth are said to suddenly develop gender dysphoria, often after exposure to online communities in which gender transition is seen as socially appropriate (Ashley 2020). In discussions of this (pseudo)diagnosis, the causal story of catching ROGD online is used to raise doubts about its legitimacy; skeptics argue that for these youth, being trans is merely a trend they encountered while surfing the internet, rather than an authentic experience.

Similarly, doubts are increasingly being raised about expressions of mental distress seen on platforms like TikTok. Examining ‘TikTok tics’, Haltigan et al. ask whether symptoms of Tourette’s Syndrome that arise after engagement with TikTok are authentic or instances of ‘psychosomatic social contagion’. The authors note that such tics are more common in females and may serve ‘to seek affirmation and/or draw attention to oneself to acquire social capital in online communities’, while also developing an identity that might mask feelings of depression and anxiety (Haltigan et al. 2023, p. 3). Here, again, doubts are raised for the reader about the reality of such tics, which are set up as either real or performative.

What should we take away from this growing skepticism related to causation and the internet? While we see familiar tropes here, such as an attention-seeking young woman with low self-esteem or the teenager who will go to great lengths to follow trends, there is more introduced in these examples as well. The internet brings forth its own novel associations that offer further fodder for doubts into the legitimacy of suffering, particularly amongst teens (e.g., loneliness, radicalization, misogyny, cyber-bullying, AI companionship), raising novel questions related to responsibility and blame. As such, this new skepticism, and new dualism, in which physical causes are real and online causes are not, heaps even more onto our messy piles of what suffering we are inclined to take seriously and what suffering we tend to dismiss.

Thick Temporality

Moving forward, we must be wary of where and how ontological and moral expressions of dualism show up for us. Our past is awash with assumptions related to gender, suffering, and blame, while our future is filling with novel and yet familiar ideas of whose pain matters. In approaching contested conditions, it is essential that we remember the shortcuts that are deeply engrained in Western ways of thinking and speaking, in which some forms of suffering are deemed legitimate and others are treated with suspicion, and that we are on the alert for new expressions of them.

Remembering the past and anticipating the future can help us to remain aware of these shortcuts. Loewen Walker writes:

The living present is heavy with lineages that mimic, critique and undo our assumed histories, and, rather than wiping away the past or seeking absolution for our actions, we can embrace this thick temporality, recognizing its ability to deepen our accountabilities to those pasts and their possible futures (Loewen Walker 2014, p. 56).

The notion of thick temporality, in which we strive to recognize how the past, present, and future are deeply entangled, is particularly well suited to the controversial territory surrounding long COVID and ME/CFS, given the risks of falling into easy and familiar stereotypes. Callard suggests that long COVID, as a new infectious agent, can help us rethink and reimagine that which is seen as ‘old’ (Callard 2020). This novelty can help us to reenvision something like ME/CFS, which has long lacked visibility, recognition, or support, and is now coming to light within the larger terrain of post-viral conditions, opening up futures of recognition, research, and empathy. But along with these benefits, we must be weary of risks that present to both these, and

⁶ Wessely has also argued the ME/CFS patients can encourage ‘inappropriate illness behaviour’ amongst each other and that ‘attempting to synthesise patient views into the discourse’ is dangerous (Page & Wessely 2003, p. 225, Smith & Wessely 2014, p. 216).

other contested, conditions. We must be vigilant to the ways in which our present is heavy with implicit assumptions related to dualism, both those we have inherited from the past, in which the feminine, the emotional, and the hysterical are deeply entangled, as well as those emerging in our future.

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