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Long COVID, the unending pandemic

Covid longa, a pandemia que não terminou

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Abstract

The article explores the complexity and current uncertainties concerning long COVID, an emerging nosological entity with vague contours and characterised by unpredictable and persistent symptoms and absence of 'objective diagnosis'. Based on accounts of the affected individuals and balancing the review of medical and journalistic literature on the subject, historical approach and ethnography, this work describes and analyses the policies of recognition and care of this condition in a context of epistemic injustice. The article contests the representations of long COVID as a merely transient disorder arguing that, unlike the promises of full recovery, what is taking shape is the emergence of a new individual whose biography is being rewritten by long COVID. For these people, full recognition of long COVID as a distinct pathological entity, coupled with the validation of their experimental knowledge, means more than merely opening concrete possibilities for relief from physical and mental suffering. It also represents justice, repair, and a further step towards the reconstruction of their lives.

Keywords: long COVID; diagnosis; epistemic injustice; recognition and care policies.

Resumo

O artigo explora a complexidade e as incertezas atuais sobre a covid longa, uma entidade nosológica emergente pós-covid-19, com contornos imprecisos e caracterizada por sintomas imprevisíveis e persistentes. Baseado em relatos de pessoas afetadas e equilibrando a revisão da literatura médica e jornalística sobre o tema, a história da ciência e a etnografia em saúde, o trabalho descreve e analisa as políticas de reconhecimento e de cuidado da doença em um contexto de injustiça epistêmica. O artigo contesta as representações da covid longa como uma condição meramente transitória, argumentando que, diferentemente das promessas de plena recuperação, o que tem ganhado forma é emergência de uma nova pessoa cuja biografia passa a ser reescrita com a covid longa. Para essas pessoas, o reconhecimento pleno da covid longa como uma entidade patológica distinta, aliado à validação de seu conhecimento experimental, significa mais do que simplesmente abrir possibilidades concretas para alívio do sofrimento físico e mental. Isso também representa justiça, reparação e um passo adiante na reconstrução de suas vidas.

Palavras-chave: covid longa; diagnóstico; injustiça epistêmica; políticas de reconhecimento e cuidado.

> We're invisible. Invisible. We're still sick and if we don't keep fighting, no one will do anything for us.
>
> I sleep poorly. Sometimes I have anxiety attacks; my brain doesn't work right anymore. I get confused and forget things all the time.
>
> At work, they look at me suspiciously, they think I'm faking it.
>
> The doctor says it's psychological, that I don't have anything, that this will soon pass.
>
> I'm not the same person anymore.

The testimonies that open this article come from women aged between 35 and 60 years old. They live with disturbing symptoms that emerged after COVID-19. There is still no formal diagnosis for the disease they complain about; however, all of them now identify it as long COVID.

Long COVID has become a new nosological entity that emerged in the wake of COVID-19. Its contours remain vague, but this novel development is driving research into its prevalence, symptoms, diagnosis, duration and treatment methods. While no precise definition yet exists, long COVID is gaining ground amidst the disparities and social injustices involved in this current complex, nebulous and uncertain zone that is often described as 'the end of the pandemic'. Pandemics, in fact, exceed linear narratives of beginning, peak and end. As historians of science Erica Charters and Kristin Heitman argue, they are experienced in cycles of intensity and temporality whose end, or ends, are not limited to the cessation of the pathogenic agent's circulation nor a reduction in contamination and death rates. In contrast to the idealistic hope of 'biological eradication', the end of a pandemic depends much more on an ongoing social, ethical and political negotiation of 'acceptable levels' that enable the 'administration of a normal social life' (Charters; Heitman, 2021).

This is the crux of the matter: for those living with long COVID, and for those still dealing with losses and rebuilding their lives, the COVID-19 pandemic is not over. More precisely, it is in the absence of diagnosis that the long COVID pandemic still awaits its beginning, amidst a scenario of uncertainty from which significant voices emerge, such as reports published by patients and those of women who shared their experiences of suffering, invisibility and struggle in the research that underpins this work. In the medical-biological context, these narratives can be interpreted as symptoms of a post-viral syndrome. However, from the perspective of the history of science and the anthropology of health argued here, they also represent a manifestation of epistemic injustice.[1]

Post-viral syndromes are defined in the medical-biological literature as a set of symptoms that may persist after an acute viral infection is considered resolved. Among the main manifestations are extreme fatigue and muscle weakness, joint and head pain, difficulty concentrating, memory problems, and sleep disorders. There are few indisputable facts regarding their aetiology and treatment, but it is believed that these syndromes may be related to the body's immune response to viral infection. In such cases, it is common practice to administer medications to relieve symptoms like chronic pain and recommend

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[1] This work is the result of research conducted by the Rede COVID-19 Humanidades MCTI [MCTI COVID-19 Humanities Network], within the Post-graduate Program in Social Anthropology at the Federal University of Rio Grande do Sul, based on a combined effort in four projects that qualitatively analyse the social impacts of the COVID-19 pandemic in Brazil. The first is a response to a technological order from the Ministry of Science, Technology and Innovation (MCTI) entitled *COVID-19 in Brazil 2: analysis and response to the social impacts of immunisation, treatment, practices and environments of care and recovery of those affected* (UFRGS-FINEP Agreement 1212/21, ethical approval CAAE 61966622.1.0000.5347). Two others, funded by the CNPq, deal specifically with long COVID: *Long COVID: the construction, recognition and social impacts of a post-viral syndrome* (CNPq/MCTI Call to Research 10/2023 Universal, Process 401752/2023-2); and *Long COVID in Brazil: an ethnographic study on the recognition and care policies of a post-viral syndrome* (MCTI/Health Ministry Call to Research 21/23, Process: 444326/2023-5). Finally, a partnership between the MCTI COVID-19 Humanities Network and the Science and Health Observatory of the Casa Oswaldo Cruz (COC-FIOCRUZ) developed the project entitled *Between visibility and invisibility: a historical and socio-anthropological approach to Long COVID among health workers in Rio de Janeiro and Porto Alegre* (INOVA-FIOCRUZ Decree). Jean Segata is a researcher registered with CNPq, Brazil (Productivity Grant, Process 309710/2021-9). Ilana Löwy is a researcher at the French National Institute of Health and Medical Research (INSERM). The authors express their gratitude to all the people who shared their experiences with long COVID during the research that resulted in this work. They are the legitimate protagonists of the history and knowledge of this disease. This gratitude also extends to Alfonsina Faya Robles, Jaqueline Ferreira, Eliza Teixeira de Toledo, Luiz Alves Araújo Neto, Juliara Borges Segata, Arlei Damo, Ceres Víctora, Ondina Fachel Leal, Handerson Joseph, Patrice Schuch and Paola Falceta for their collaboration in the research, generous readings and valuable insights.

good sleep hygiene combined with light exercise and a healthy diet to help strengthen the immune system (Camargo; Teixeira, 2002; Wessely *et al.*, 1989). Although post-viral syndromes can be debilitating and affect a person's quality of life, the same literature attests that the majority of patients recover completely over time. However, the lack of more precise explanatory structures for the patients' symptoms, combined with medical incredulity concerning patients' testimonies and the unequal power relations in the doctor-patient relationship, amplify and, in many cases, perpetuate situations of frustration and suffering. For this reason, the perspective taken in this article follows another direction. What patients with long COVID experience over time is not exactly recovery, but a process of transforming themselves and their world. It is the emergence of a new person, whose story becomes inseparable from the story of the disease itself in their body and in their life.

The article begins by dealing with the imprecise limits of long COVID, showing how patient reports were fundamental in driving the debate on the disease, challenging the initial perception that COVID-19 would be short-lived and revealing a complex reality of varied and prolonged sequelae. Activist groups, composed of academics and healthcare professionals, have played a crucial role in raising awareness and defining long COVID as a significant condition. Specifically in Brazil, AVICO – the Associação de Vítimas e Familiares de Vítimas da Covid-19 [Association of Victims and Families of Victims of COVID-19] – has emerged as a strong voice in the fight for justice and recognition of victims of the pandemic, including those affected by long COVID. Patients with this condition have faced significant challenges in the healthcare system, especially women, persons of colour, workers and the unemployed, who often find it difficult to be heard and believed by medical professionals. The scarcity of reports published by these groups highlights the disparity in access to treatments and recognition of the condition, transforming long COVID into an unrecognised pandemic of loneliness, rejection and social isolation.

The second part of the article introduces personal accounts of women affected by long COVID, highlighting how this condition transcends mere physical symptoms and permeates different aspects of life, including mental and emotional health, the reorganisation of domestic and professional routines, and changes in identities and social relationships. Furthermore, this section highlights the efforts of a state legislative coalition which conducted public hearings to collect testimonies on long COVID. These hearings emphasise the importance of recognising long COVID in health policies and the need to establish a link between the disease and the work environment, highlighting the impact of the condition on their capacity to work and social and professional dynamics of the people that long COVID has.

The third part of the article describes the complexity and challenges in defining and diagnosing long COVID. The World Health Organisation (WHO) defined post-COVID conditions as symptoms that persist for at least two months after SARS-CoV-2 infection. However, this definition is criticised for being too broad and based on the presence of symptoms that cannot be explained by other diagnoses. Medically unexplained symptoms are often overlooked and discredited, highlighting the persistent biomedical limitations in the field of 'uncertain diseases' that result in difficulties for patients in accessing adequate medical and social resources (Bransfield; Friedman, 2019).

The lack of objective diagnostic tests for long COVID further exacerbates this situation, obliging doctors to relay quasi-exclusively on the patients' subjective reports of their symptoms. Even with advances in the identification of physiological and structural anomalies in long COVID patients, there is still no consensus about specific diagnostic criteria of this conditions. This diagnostic uncertainty has significant implications for patients, such as difficulty accessing appropriate treatments and social support. This situation is intensified by 'epistemic injustice': the patients' credibility is often questioned and they are frequently classified as 'difficult'. This disbelief in the suffering of patients increases their anguish and frustration, especially among vulnerable social groups, highlighting the need to recognise and respect patients' experiential knowledge.

The fourth section of the article addresses the complexity and challenges in obtaining reliable data on long COVID due to the lack of objective diagnostic criteria. While COVID-19 has clear diagnostic criteria, long COVID suffers from a lack of consensus in both definition and diagnosis. Even with significant investments in research, difficulties persist, in part due to organisational issues and the complexity of defining precisely what long COVID is. Inconsistency in the definition of long COVID has led to varied and contradictory results in research. Differences in the type of population analysed, the symptoms explored and the methodologies used, led to divergent estimates of the prevalence and characteristics of the condition. Furthermore, the controversy over spontaneous recovery from long COVID illustrates the difficulty of obtaining reliable data.

The last part of the article explores the tensions between a perception of long COVID as a disease with primarily physiological causes and a view that suggest that psychological factors may play a significant role in the development of long COVID symptoms. This divergence reflects a broader debate concerning functional disorders, often perceived to lie at the intersection of the physical and the psychological. This complex nature of functional diseases creates challenges in both diagnosis and treatment, since many doctors are frustrated by the lack of clear physiological explanations of the patient's symptoms and the absence of effective therapies. Furthermore, the association of these diseases with psychiatric factors leads to a negative perception on the part of some healthcare professionals, who may see these conditions as less 'real' or less serious than diseases with more obvious biological causes. In this context, the association between long COVID and chronic fatigue syndrome (ME/CSF), another disorder with a higher prevalence in women, raises questions concerning the role of psychological factors in long COVID.

The imprecise contours of long COVID and the lack of objective diagnosis (disease signs) produces a frustrating reality that reshapes the biographies and life trajectories of people living with this condition. The COVID-19 pandemic did not end for those who suffer from invisibility of long COVID and the indeterminacy of its consequences. For this reason, long COVID is the unending pandemic.[2] The existence of a diagnosis means recognition of the disease and

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[2] To assert that long COVID is the unending pandemic is not strictly an epidemiological understanding, although its estimated repercussions are indeed alarming. When following the analyses of Diniz and Brito (2019) and Segata (2022) on the invisibility of the long-term social impacts in the zika epidemics and chikungunya outbreaks in Northeast Brazil, the statement that the pandemic is unending highlights the concrete experience of affected individuals in their search for treatments and care, and for respect for their right to health. The aim is to underscore the various losses and transformations that continue to cause significant changes in their lives, even after the epidemiological end of the pandemic. This includes mourning, job recovery, rebalancing their finances and quality of life, which are not always easy to address. Therefore, the struggles for recognition and care with long COVID manifest as the expression of a suffering that continues without answers – an unending pandemic, effectively.

provides concrete possibilities for relief from physical and mental suffering, but it also represents justice, reparation and a further step towards rebuilding their lives.

The fuzzy boundaries of long COVID

Long COVID emerged due to patients' stories. Even today, it exists mainly through these stories. The first reports of COVID-19 patients failing to recover appeared in the spring of 2020. At that time, the problem was associated only with severely ill, often hospitalised patients and was not presented as occurring in previously healthy people who had mild or moderate disease. In the early, dramatic phases of the pandemic, people who contracted COVID-19 were told they would fully recover after two or three weeks. Many discovered that this did not happen. Worse still, they began to experience strange, shifting syndromes, often unconnected to those they experienced during the infection episode. Thus, patients who were informed that their symptoms would not last more than three weeks, but continued to feel unwell, began to organise on social media saying that they continued to live with COVID-19, however, on a prolonged basis. Tellingly, the main French association of long COVID patients is called ApresJ20 [*lit.* After day 20]. In the spring and summer of 2020, highly effective groups of activists – many led by academics or healthcare professionals – managed to convey their views on the persistent and changing symptoms of COVID-19 to experts. In the fall of 2021, activists had already proudly stated that long COVID, the term they coined, was probably the first disorder initially defined by people experiencing it as a condition (Callard; Prego, 2021).[3]

In the first half of 2020, the majority of long COVID patients were relatively young, often female. They generally stated that they did not have serious health problems before contracting COVID-19 and were not hospitalised for this pathology. Their post-COVID symptoms sometimes appeared weeks or

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[3] This article refers to long COVID as a 'disorder' and 'condition'. The absence of a consensus on objective signs of 'syndromic' long COVID still causes resistance to its formal recognition as a disease. For a detailed analysis of the process of transitioning from symptoms to disease, see, for example, Aronowitz (2001).

even months after the supposed end of the infection and many of them were characterised as 'medically unexplained'. Felicity Callard, professor of human geography at the University of Glasgow, began posting tweets about her experience with long COVID in mid-April 2020, 27 days after the first outbreaks of COVID-19. Not only did she not improve after three weeks, she continued to develop new symptoms (Callard, 2020b). In May 2020, Callard began to reflect on the meaning of the term 'mild COVID' for patients who developed not-so-mild sequelae of this condition. Seven weeks after the onset of her COVID, she reported that she continued to suffer from severe fatigue, pain, brain fog, and difficulty concentrating. She was unable to take care of herself or perform basic household tasks. Fortunately, she received help from the people around her. She explained that 'mild COVID' can lead to long-term damage to the body and precipitate severe post-infectious fatigue syndrome (Callard, 2020a). In the winter of 2020, Callard, who remained severely disabled, compared her experience to that of patients with chronic fatigue syndrome and expressed hope that the recent attention to long COVID patients would end the invisibility of people with this syndrome (Callard, 2020c). However, in 2023, the reality is anything but.

Carla, 44 years old, a self-employed professional who lives in the interior of Rio de Janeiro, reported the anguish experienced after more than two years of illness, amid a lack of adequate care:

> I caught COVID more than once. This was in 2020, still, and then in 2021. At first, everything was fine, I thought I'd recovered. Then I began to feel confused and forgetful, and a weakness that never ends. Sometimes I'm even doing well. But suddenly, it's as if I shut down: an inexplicable tiredness comes. It's like a switch turns me off. The pain in my body starts and I feel I might die. Then I go to the doctor. [...] But I never found care for long COVID. I went to my usual doctor and he said it was normal. [...] Then I say it's long COVID, and he says it's difficult to know, that no one knows. So, he referred me to someone else, a psychiatrist: same thing; he pretends he didn't even hear me. So, we don't exist. For them, there is no long COVID. *We're invisible. Invisible. We're still sick and if we don't keep fighting, no one will do anything for us*. (Carla, 44 years old, July 2023).

Carla is a member of AVICO. Created in Porto Alegre, in April 2021, AVICO stood out as one of the first associations in Brazil that brought together people with the impetus to fight for justice in the face of what they described as inaction and criminal conduct in managing the pandemic by the government of former president Jair Bolsonaro. It was founded on the initiative of Gustavo Bernardes and Paola Falceta. He is a lawyer and activist for the health rights of the LGBTQIA+ population, who was hospitalised and intubated due to COVID-19. She is a social worker and human rights activist who lost her mother to COVID-19, due to a lack of adequate supplies at the hospital.

Initially, AVICO organised groups for bereaved people and groups that offered legal support to victims of the pandemic. These groups met weekly in online sessions through video conferencing applications, like Google Meet and Zoom. The sessions were mediated by volunteer professionals from different areas, including medicine, psychology, social work and law. These gatherings provided a space for participants to express their experiences of grief and the sudden loss of loved ones, often exacerbated by the impossibility of a proper ritual farewell due to pandemic restrictions. In addition to mutual support, strategies were discussed for rebuilding daily routines, reorganising school and professional life, and facing economic and bureaucratic challenges. This included navigating obstacles in administering inventories, managing debts and managing the assets of those departed, as well as the struggle to properly record deaths resulting from COVID-19. These difficulties, which were notable at the time, exposed the many strategies employed by certain institutions to minimise the scale of the tragedy.

From the onset, AVICO has also been involved in activities on social media, holding live streams and other initiatives to raise awareness among the population regarding the importance of individual and collective care policies. It emphasised the need to pay attention to fake news and denounced the widely reported failures and negligence of political and corporate authorities. By the end of 2021, the association was notably prominent in public demonstrations, demanding the population's rights to health and protection, in addition to supporting the impeachment of former president Jair Bolsonaro. In this context, it was quite evident how right-wing, neoliberal governments with fascist inclinations behaved as important pathogenic agents in the COVID-19 pandemic (Segata *et al.*, 2021As Ventura, Aith and Reis (2021, p. 26, our translation) summarised, Bolsonaro had already demonstrated a clear commitment 'in favour of broad dissemination of the virus in the national territory, with the declared objective of resuming economic activity as quickly as possible and at any cost'.

Not surprisingly, genocide was the expression often used in demonstrations to describe the then-president's stance during the pandemic.[4]

In 2021, AVICO also began to conduct activities that addressed long COVID, a condition that was beginning to gain global attention. Association members actively shared information and discoveries on the disease on social media and WhatsApp groups, many of which were found on the internet. These groups discussed the latest research, scientific articles and newspaper reports; many long COVID patients identified with the reported symptoms and after-effects. Due to the context of denialism of COVID-19 in Brazil, a large portion of this information came from abroad, since there were few incentives for research into long COVID in Brazil, or for the production of protocols or specific management guides for this condition.[5]

One of the first detailed descriptions of long COVID in the general press abroad was published in *The New York Times*, in April 2020. Fiona Lowenstein, a writer, producer and yoga teacher, who was briefly hospitalised for COVID-19 in March 2020, reported that three weeks after being discharged from hospital she was unable to answer the question 'how are you feeling now?'. Confused and distressed by her health problems, she started an online support group for people recovering from COVID. She discovered she was not the only person who was finding the post-COVID experience disconcerting and discovered that many of the people who came into contact with the infection had mental health issues:

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[4] On many occasions throughout the pandemic, former President Jair Bolsonaro advocated for denialist measures, in direct contradiction to health experts. One example of this was his support for 'herd immunity' instead of a policy of vaccination against COVID-19 (Matoso; Gomes, 2021).

[5] It is important to highlight that the discourses mobilised by social movements are well founded on the most recent publications in specialised medical journals. Much like the virus or the vaccines, such discourses play a crucial role in combating fake news on COVID-19 and its effects. As Camargo (2024) aptly noted in his analysis of disinformation and denialism concerning COVID-19 among physicians in Brazil, these issues also compose a broader set of extremes and disputes in determining who has genuine epistemic expertise in managing knowledge that intervenes in people's lives. Furthermore, as Rosenberg (1992) noted, the exceptional nature of catastrophic events like the pandemic, which require immediate responses, tends to suppress locally significant interpretations, favouring analyses and models of thought and intervention by global medical science. While this homogenisation could contribute to the nosological stabilisation of the disease by crystallising a 'universal template', once the 'long COVID black box' is established, it would not be surprising if new movements emerged to question such simplifications, seeking to include greater diversity and recognition in categorising the disease.

> The news is filled with uplifting stories of patients who have survived COVID-19 – including my own – but rarely do these narratives cover the long and jagged road to recovery that follows. The World Health Organization has stated that people with 'mild' cases can expect recovery to take two weeks, while those with 'severe' cases may take up to six weeks to recover, but the distinction between 'mild' and 'severe' cases is confusing, and many of us are experiencing symptoms for longer. Some of the young people in my online support group are struggling to get more time off from work – they are, after all, supposedly recovered. Almost all are experiencing mental health problems, including severe anxiety, panic attacks and depression, as they struggle to understand what's next for them. (Lowenstein, 2020).[6]

The mention of mental health problems in people who had COVID-19 sequelae as early as the spring of 2020 is noteworthy because the issue of links between long COVID and neurological/psychological/psychiatric problems subsequently became one of the main themes of controversies regarding this condition. Long COVID patients insist that their mental health difficulties are an unsurprising consequence of living with a chronic, debilitating and unpredictable condition, while some experts argue that pre-existing mental health difficulties could be a major cause of the development of long COVID.

One of the elements that tends to disappear in this debate is the possibility of worsening pre-existing mental health problems due to SARS-CoV-2 infection. The statement that this infection can worsen an already existing organic pathology, such as diabetes or circulatory problems, is not perceived as problematic. However, a parallel claim that this infection can worsen a patient's mental health problems is strongly rejected by long COVID patients, who are afraid of being labelled as 'hypochondriacs' and 'crazy' by some healthcare professionals. Indeed, one of the main problems faced by patients with long COVID is doctors' disbelief that their symptoms have a 'real' cause, that is, an organic cause, and

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[6] Lowenstein later became one of the leading long COVID activists in the United States and one of the founders of the group Body Politic Long COVID. In her book, *The Long COVID survival guide: how to take care of yourself and what comes next – stories and advice from twenty long-haulers and experts* (Lowenstein, 2022), she recounts her experience, along with that of other 'long haulers' – a term coined by activists to describe the long journey they face to recover from COVID-19, which has generated greater awareness concerning the lasting effects of the infection.

are not merely an expression of stress or anxiety. Hence the importance of the testimonies of healthcare professionals who published reports of their experience with long COVID in medical journals.

In an article in *Brazilian Archives of Neuropsychiatry*, a Brazilian neurologist who developed cognitive problems and severe migraines after a SARS-CoV-2 infection explained that she was fortunate to have specialised knowledge and access to medications that alleviated her symptoms. She added that, after speaking publicly about her experience, she received numerous emails from people with similar (or worse) symptoms who complained that most doctors do not understand long COVID and do not believe them when they describe post-COVID symptoms (Yasuda, 2022).

A Canadian global health expert recounted the story of her long-lasting and severely disabling symptoms on *eClinicalMedicine*. She wanted to encourage other long COVID patients whose doctors tended to ignore complaints, but also to draw attention to the potential role of long COVID in exacerbating inequalities. If a significant proportion of the millions of people who survive COVID-19 develop long-term disabilities, she argued, the burden of this condition will once again be heaviest among highly marginalised populations living in the Global South (Malta, 2020).

Affluent or well-connected patients are likely to encounter fewer obstacles to being heard and believed, probably due to the fact that they have access to competent medical experts and specialised long COVID clinics. A famous US conductor, who developed long COVID after an episode of COVID-19 in the spring of 2020, was treated at one of the most advanced specialised centres in the US for this condition, the Center for Post-COVID Care at Mount Sinai Hospital in New York. Doctors at the centre offered him a customised programme of adapted physical rehabilitation and a complex regimen of medications, including those for mood swings. This programme enabled him to gradually return to work (Otterman, 2022). A journalist leader who developed long COVID, in 2022, was also treated at the multidisciplinary centre at Mount Sinai Hospital. After seven months of experience with this condition, she reported that she divided her time between staying in bed and seeing numerous specialists: a neurologist, a cardiologist, an immunologist, a pulmonologist. She took several medications – pain blockers, antidepressants, anti-inflammatory medications – and simultaneously tried several alternative therapies (Senior, 2023). A renowned British scientist with long COVID was treated with an experimental hyperbaric oxygen therapy; she was placed in a high-pressure chamber while oxygen was forced into her lungs. The treatment relieved many of her symptoms, but unfortunately, she was reinfected with COVID-19, a frequent cause of the aggravation of long COVID symptoms (Blasdel, 2023).

‘Less prominent’ long COVID patients, such as those represented in Carla’s testimony, can face more problematic trajectories. Many go through a protracted medical odyssey until they find health professionals who take their complaints seriously – if they are lucky (Cha, 2022). Women of colour may have an especially difficult time persuading their doctors that they need professional help. A Black Baltimore teacher developed multiple neurological problems, but because she tested negative for specific anti-SARS-CoV-2 antibodies, her doctors refused to acknowledge that she had long COVID and classified her problems as psychosomatic. Unable to return to work, she described her experience as being gaslighted and dismissed by healthcare professionals (Silman, 2020). Her experience may be typical of many patients for whom failure to obtain adequate medical care is associated with serious material hardship. These patients tend to be of low visibility. The majority of people who told their long COVID stories in the media were between the ages of 25 and 55, middle class, white and educated.[7] The scarcity of published narratives on long COVID from workers, the unemployed, persons of colour or recent migrants is likely not a direct indication of the prevalence of this condition among different social groups. However, this lacuna can reveal the difficulties these people face in accessing specialists, receiving appropriate treatments and sharing their experiences. In the United States, a 2023 article suggested that long COVID was actually an unrecognised pandemic of loneliness, social isolation and rejection (Kwang, 2023).

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[7] Two recent books, the aforementioned *Long COVID Survival Guide: how to take care of yourself and what comes next* by Fiona Lowenstein (2022) and *The Long Haul* by Ryan Prior (2023), have collected numerous narratives from long COVID patients.

The people that long COVID has

'Is today Wednesday?' These were the first words of Maria, a 56-year-old retired civil servant from Brasília, during a Zoom conversation. When told it was Monday, she expressed surprise. It was May 2023, and Maria reported that for almost two and a half years she had been suffering from strange symptoms after COVID-19. 'I didn't even check. I always need to look at the calendar. For me, every day is Wednesday. Not today, right?' Maria shared that her husband is a healthcare professional and believes she was infected with COVID 'about eight times' at the beginning of the pandemic. According to her, each infection added a new layer of strange and debilitating after-effects and transformed who she is:

> It was on a Wednesday that I lost my brother. He was two years younger than me. He was a healthy person, very active. An inexplicable loss. I think that stuck with me, you know? [...]. I was deeply affected; here at home, the most affected [...]. Today I live confused. *I sleep poorly. Sometimes I have anxiety attacks; my brain doesn't work right anymore. I get confused and forget things all the time*. That's why I asked for retirement. I had already [done enough] years of service. If it weren't for COVID I would continue, but it's no longer possible. [...] So, I also stopped driving. After a while, when I took the car out of the garage, I felt like it wasn't going anywhere, because I forgot what I was going to do. [...] Look at these marks. Now, I burn myself all the time. I'm afraid to cook, you know? I forget that the pan is hot and I burn myself when I put my hand on it. I'm afraid of burning the house down. [...] I wash my clothes in the machine more than once, because I forgot I've already washed them. [...] Long COVID got me. After a while, the psychiatrist gave me a diagnosis, because I am undergoing treatment and some physiological changes were detected in my brain post-COVID. Yes, there was a hole in my brain. COVID caused demyelination of the myelin sheath, which we know leads to multiple sclerosis, right? So, the doctor says: 'How are you doing? How are you able to stand?' I don't know, because there were so many things, it caused this problem in the right frontal temporal lobe and so I've been taking humour stabiliser because it's like, sometimes I have outbursts, outbursts that I've never had. I've never been the calmest person in the world, but I've never been aggressive like that, and I've had two outbursts already. So, my life with long COVID is now different. [...] I'm still in this loop that never ends, because

> every day I need to readapt, it's like I'm reinventing myself every day. (Maria, 56 years old, May 2023).

In the text 'As pessoas que as doenças têm: entre o biológico e o biográfico' [The people that diseases have: between the biological and the biographical], which inspired the title of this section, anthropologist Waleska Aureliano (2012) suggests an approach that recognises illness not only as a biological condition, but also as a lived experience that intertwines with a person's biographical narrative. Influenced by the notion of biographical repositioning, which Michael Bury (1982) discusses in his study on chronic diseases, Aureliano (2012, p. 240, our tranlation) analysed how cancer can be thought of as a disease that can trigger 'forms of agency around diffuse and uncertain temporalities that are now marked by illness'. Her analysis of the chronicity of cancer helps reflect on how long COVID has transformed Maria:

> The biographical dimension involved in narratives on illnesses elucidates the specific stories and concrete strategies engendered by sick people in their experience with chronicity. This is not about considering the individualisation of the construction of meanings for the illness, but rather about observing how the biographical elements, inseparable from the experience of the disease (and fatefully relational), are activated in this process, constituting not only ways of attributing meaning to the disease, but also as an element that forms part of therapeutic actions, [...] from the construction of their clinical history to new forms of taking care of and attending to the body, as well as the subjective formulation of the experience of the disease and the emotional aspects involved therein. In all of them, the biographical narrative emerges as a way of engendering and legitimising actions and strategies in managing this experience and its consequences. (Aureliano, 2012, p. 241, our translation).

Maria is living biographical repositioning. Today, she is someone that has long COVID. In every conversation, Maria made it clear how the disease reshaped her routines, impacting everything from her physical limitations and emotional disorders to her social life. She explained that long COVID completely transformed her circle of friends. Friends from other times became less present, while new friendships, people who share the precarious life that long COVID has given them, became more frequent. In this new circle of friends, she can share experiences and be understood with no judgments about her mood changes, episodes of forgetfulness or discoveries related to her new brain physiology. Although it is possible to recognise the unique story that long COVID has constructed with Maria, the personal experiences and the very conception of illness that are modulated by this health condition are widely shared by patients who fight for the recognition of this disease.

In order to understand the impacts of the COVID-19 pandemic on the organisation of the healthcare system in the State of Rio Grande do Sul, and on society and the healthcare sector in general, the Frente Parlamentar em Defesa das Vítimas da Covid-19 [State Legislative Coalition in Defence of COVID-19 Victims] was established on April 27, 2022. Over the course of the following three months, public hearings were held throughout the state.[8] At each hearing, an introduction detailed its objectives, followed by talks by entities and movements. After that, a space was opened for the population to express their opinions through statements. The central theme of these discussions was long COVID. Striking accounts highlighted the ways in which the disease had produced chronic debilitating conditions. Many of these conditions were evident, such as difficulties walking, balancing and even speaking. They embodied

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[8] The State Legislative Coalition was an initiative led by State Representative Pepe Vargas, a member of the Partido dos Trabalhadores [Workers' Party] in Rio Grande do Sul, and involved a broad range of supporting entities (including AVICO, which had been mobilising since 2021) in a process that culminated in a public hearing on the pandemic, when the Coalition was launched with the support of the presidency of the State Legislature (Ballejo, 2023; Rio Grande do Sul, 2022). A hybrid format was used for the hearings, which were held in the main cities of the seven health macro-regions and broadcast live on a specific YouTube channel: Atenção Integral do Estado às Vítimas da COVID-19 [Comprehensive State Care for Victims of COVID-19]. Invitations were sent to numerous municipal, state and federal institutions and public authorities, representative entities and organised movements. In addition, dissemination occurred on social media networks and in WhatsApp groups, including AVICO, seeking to promote broad participation. In the current geopolitical work of the government of the State of Rio Grande do Sul, the health macro-regions and their respective reference cities are: Metropolitana (Porto Alegre), Centro-Oeste (Santa Maria), Vales (Lageado), Sul (Pelotas), Missioneira (Santa Rosa), Norte (Passo Fundo) and Serra (Caxias do Sul) (Rio Grande do Sul, 2022). The public were able to watch and interact on YouTube by registering in advance or via chat; Pepe Varga's channel still contains the recorded sessions (see Atenção..., 2022).

a set of symptoms previously reported in the literature, highlighting the frightening dimension of the problem, which the available epidemiology is far from measuring accurately. In these narratives, the disease was often described as an agent occupying the body and identity of the deponents, most notably through expressions like 'COVID made of me', 'I am destroyed', 'the disease did this to me' or 'I'm a different person after I got sick', which align with the experience narrated by Maria concerning her new condition as a person. As argued by Kleinman (2020), such narratives and testimonies reveal how the experience of the disease transcends physical symptoms; it encompasses social, cultural and emotional dimensions, which are crucial to understanding the integrality of the disease in a person's life. Thus, these narratives act as a window into the patient's lived world, especially crucial in conditions that remain poorly defined, like that of long COVID, showing not only how the disease affects the body, but also how it impacts a person's identity, social relationships and position in society.

It is important to underline that both the testimonies from the audiences and many of the narratives of life with long COVID collected in this research have embodied the form and content of how the disease was represented in biomedical discourses. Many of the latter were driven by the organised social movements. Common to the dynamics of many social struggles for rights, audiences formed 'networks of distant suffering', to use an expression by Boltanski (1993), in which the biographies of concrete subjects unfolded in public spheres with the aim of producing cases, transforming them in political causes (Vianna, 2013). In this context, alongside the fight against fake news regarding the pandemic, the translation of individual experiences into biomedical language contributed to establishing a 'term reduction' of the 'truth' concerning long COVID. This process helped in the creation of 'abbreviated maps', which tend to favour legibility through standardisation and simplification, increasing the state's capacity to develop discriminatory interventions (Schuch, 2018; Scott, 1998). However, this operation also tends to simplify and even conceal the diverse experiences of long COVID, often not captured by the grammar of biomedicine, highlighting a significant loss that accompanies the discursive embodiment of medicalisation. Although this represents a challenge for biomedicine, the diversity of narrated symptoms, often obliterated in the standardisation process, can reveal a complex ontological multiplicity of long COVID, performed based on different practices, discourses and materialities, including an evolutive, cultural and syndemic history.[9]

In addition to collecting revealing testimonies from patients, the State Legislative Coalition also helped record other important elements for the construction and recognition of long COVID. At the end of the hearings, a report was published that contained several significant recommendations, of which two in particular stand out:

> 3. That, as a matter of urgency, joint efforts must be considered for the formulation and execution of all necessary public policies in order to guarantee *comprehensive and multidisciplinary care for patients affected by long COVID syndrome*, in compliance with the constitutional principles of the SUS [Unified Health System], notably those that regulate universal access and comprehensive treatment.
> [...]
> 17. That a *rehabilitation and social protection policy* be elaborated *for workers who experience COVID-19 or long COVID sequelae*. As studies indicate, symptoms can lead to physical, psychological and neurological changes that interfere with the ability to perform work. Following an established causal link between COVID-19 infection and the work environment, it is fair to recognise the resulting labour and social security rights. (Rio Grande do Sul, 2022, p. 9-10, our translation).

The report emphasises the use of 'long COVID syndrome' as a recommended operative category for the formulation and execution of public policies, aimed at comprehensive, multidisciplinary care for patients. This nomenclature represents an advance in relation to the more generic term 'post-COVID', which

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[9] Regarding the multiple ontologies of the body and health and disease processes, see Annemarie Mol (2002). For a temporal and historical perspective, see Amade M'charek (2014) and Fleck (1979). Regarding the cultural nature of diseases, Kleinman (2020) remains a seminal reference. For analysis on the syndemic character of diseases, including COVID-19, and how the adverse synergistic interaction between two or more debilitating conditions is promoted or facilitated by social and environmental conditions and the often hidden structures of violence and inequality, such as poverty, racism and discrimination, see mainly, Singer and Rylko-Bauer (2021). Additional contributions worth considering include Segata *et al.* (2021) and Segata *et al.* (2022).

was adopted in several municipalities in Rio Grande do Sul and other states in their management guides and protocols.[10]

It is also worth noting that the document is one of the first from a government entity in Brazil to emphasise the importance of recognising the possible causal link between long COVID and the work environment. The symptoms of long COVID, which include significant physical, psychological and neurological changes, directly affect work capacity. For this reason, this recognition is crucial to support public rehabilitation, social protection and reparation policies for affected workers. Furthermore, such recognition in Brazil aligns with a growing international agenda of the same nature, which claims COVID-19 – and, consequently, long COVID – as a 'work accident', even though it clearly remains more focused on how 'the potential economic impact is colossal' (Society of Occupational Medicine, 2022, p. 3) with regard to long COVID, rather than on the health and well-being of workers who suffer because of it.

In addition to the causal link, the relationship between work and long COVID is becoming increasingly complex. The debilitating and unpredictable conditions, combined with the lack of recognition of the disease, often lead to absences from work that are barely covered or not covered by labour rights. This was explained by Cristina, a 37-year-old nursing technician, who lives in Guaíba, in the metropolitan region of Porto Alegre:

> There are days when you simply can't work. The pain seizes my back, I can't even move properly. Then my menstruation got totally messed up. It was always like

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[10] The notable lack of qualified vertical information produced by the Ministry of Health during the Bolsonaro administration (2019-2022) contrasts with the historical role of the ministry since the creation of the Sistema Único de Saúde (SUS) [Unified Health System] in 1988. In previous critical events, the Ministry of Health acted as an essential source of guidance for the formulation and execution of public policies by states and municipalities. During the pandemic, however, a notable omission on the part of the ministry was observed. An evident example of this lacuna was the absence of a robust national vaccination campaign, compensated in part by the spontaneous initiative of the population who, through posting selfies on Instagram while getting vaccinated, thanked the SUS and encouraged others to do the same. Another point worth highlighting is the analysis of COVID-19 management guides and protocols. When analysing more than two dozen documents from states and municipalities in different regions of Brazil, the diversity and inconsistency in treatment and care approaches is evident. This analysis also reveals the virtually inoperative polysemy of the term 'post-COVID', the frequent omission of 'long COVID' and its simplification to that of mere sequelae to acute or post-hospitalisation forms of COVID-19.

> clockwork. Nowadays I feel really bad, and out of nowhere it's late, irregular, it comes out of step. [...] I didn't get migraines; I didn't get these things. [...] There are days when there's nothing you can do. I had to give up several projects, I couldn't handle everything anymore. *At work, they look at me suspiciously, they think I'm faking it*. (Cristina, 37 years old, June 2023)

Cristina's narrative points to a sad, but not uncommon, reality in 'end of epidemic' scenarios. Health emergencies end much sooner for epidemiological repercussions, based on acceptable numbers and scales, than in the bodies of those affected. A similar scenario was recently analysed among people who continue to suffer from chronic pain after falling ill from chikungunya in Northeast Brazil, between 2015-2016 (Segata, 2022). Persistent and poorly recognised symptoms often lead to the abandonment of jobs and careers, and compel the 'judicialisation of pain' in lengthy processes that directly contribute to the worsening and perpetuation of suffering.[11]

Finally, it is important to note that the state legislative coalition report is based on a study by the Oswaldo Cruz Foundation (FIOCRUZ), which indicates that the majority of people diagnosed with COVID-19 developed mild to moderate symptoms of the disease, but despite this developed sequelae that can persist for more than a year. Among these sequelae, chronic fatigue and mental disorders are specifically highlighted (Miranda *et al.*, 2022). The duration and symptoms observed in the study are crucial to underlining the chronicity of long COVID and revealing the extent of embodied suffering, facts that are fundamental to understanding the emergence of the new person that the disease produces.

One year after the state legislative hearings, a new phase of the research that underpins this article obtained 1,282 valid responses to a questionnaire on long COVID. Participants included AVICO associates, students and healthcare professionals from all over Brazil and the data obtained corresponded with the testimonies of those affected at the hearings and with the FIOCRUZ research that supported the coalition's report. Among those who responded, 92% reported suffering from long COVID. Among this group, 87% indicated that they were living

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[11] The same can be said regarding diseases that are often considered to be eliminated but, in reality, they continue to exist below an epidemiologically relevant threshold, like leprosy (Fonseca, 2020).

with chronic fatigue and 82% with mental confusion, in addition to episodes of anxiety and depression. Respiratory problems (25%), cardiovascular problems (20%), weight gain (28%), changes in smell (8%), hair loss (8%) and more than 50 other symptoms were also reported, and recorded in the questionnaire[12] used to explore preliminary descriptive data.[13]

While all of the reported symptoms are debilitating, chronic fatigue and episodes of mental confusion, anxiety and depression are particularly perverse and alarming. The narratives obtained from the respondents, through in-depth interviews conducted following the questionnaire, revealed deep layers of suffering and invisibility. The majority of those affected by long COVID,

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[12] The research questionnaire was divided into three parts: personal and socioeconomic information, data on contagion, care and treatments, and questions on persistent symptoms. These results are still being studied, but they reveal that almost all the respondents self-declared as white, middle class, with a university degree. This suggests a very restricted profile not only of healthcare professionals, but also regarding the individuals capable of organising themselves into social movements to fight for health rights in the context of long COVID. It may also reflect the limited scope of a data collection instrument based on access to digital platforms. It is also important to mention that, among the participants who responded to the questionnaire, subsequent interviews identified that the majority of the COVID-19 infections, which gave rise to the current complaints of long COVID, occurred prior to vaccination and notably, among women. There is still no conclusive analysis on this; however, this preliminary finding helps to refute the allegations of two doctors who engaged in denialist discourses when interviewed during the research, stating that long COVID is a consequence of the vaccine. Regarding the suggested prevalence among women, indicated both by the profile of respondents to the questionnaire and by the exclusive willingness of women to share their experiences with long COVID in the collection of narratives in the research that forms the basis of this article, it is important to affirm that the available literature on the topic already suggests that the disease prevails among women (O'Mahoney *et al.*, 2023; Salari *et al.*, 2022). Nevertheless, this raises questions regarding how gender is implicated in health and illness processes, casting doubt on whether the disease is indeed more common among women or if men are less willing to seek care or to share their experiences, or even if men are attended to differently by doctors when they report their complaints, as has historically been recorded in diseases whose symptoms are not accompanied by evident signs.

[13] The questionnaire, applied using Google Forms, was distributed through WhatsApp groups. Its objective was to produce a non-probabilistic sampling for a broader qualitative study, including documentary analysis, interviews and the collection of life narratives. Participants were given the option of simply answering the questionnaire or being contacted for interviews and narrative collection. Among those who responded, 23% agreed to be contacted. The interviews have been taking place since mid-2023, via the Zoom application, and the narratives analysed in this work are derived from these interviews.

who are women, reported the indifference of doctors regarding these symptoms. Their severity was often minimised by expressions like ‘we are all going through a lot of difficulties, it’s just stress, remain calm’. These types of medical response reinforce stigmas concerning mental health and indicate disregard and negligence in relation to long COVID. According to these women, only complaints related to cardiac and respiratory changes, such as acceleration and palpitations or excessive shortness of breath after small activities, were ‘taken seriously’. However, even in these cases, the medical referral was often to specialists who treated them as cardiac or respiratory patients, at best relegating COVID-19 to a secondary differential diagnosis in their medical histories. Long COVID, in turn, was completely ignored in conversations and medical records. According to the reports of the women interviewed, in addition to medical considerations being reduced to physical symptoms, the principal post-COVID care available in the public health network is focused on post-hospital rehabilitation. For these women, this represents yet another way in which long COVID is made invisible. It is essential to differentiate the need for post-hospitalisation physiotherapy, which is more directly related to medical procedures like long hospitalisations and intubation in serious cases, from the treatment of COVID-19 sequelae, that is, determine whether the symptoms are due to the treatment or to the disease itself. In the absence of ‘obvious sequelae’, reports of fatigue and anxiety from these women were frequently underestimated compared with those requiring post-hospital rehabilitation. This disregard generated additional suffering, permeated by feelings of anger, disgust and frustration. The more restricted the access to appropriate medical treatment, the greater the suffering due to negligence, highlighting how experiences and living conditions, including issues of class, race and gender, impact health and well-being, particularly in the context of complaints of chronic fatigue (Ware, 1993).

As noted by Fassin (2007) in his research on HIV/AIDS in South Africa, the body is a space where social structures and personal experiences interact. The story that the pandemic inscribes on these women’s bodies does include the effects of a virus, but it goes beyond that. They embody layers of inequality, disrespect for health rights, and the arrogance and limitations of biomedicine, especially in relation to the diagnosis and treatment of functional disorders. It is not surprising that long COVID patients disproportionately suffer from living with debilitating symptoms – such as extreme fatigue, chronic pain or 'brain fog' – that cannot be explained by objectively displayed manifestations of a well-defined physiological disturbance.

Symptoms with no signs

So, what exactly is long COVID? The readily available answer is deceptively simple: an aggregate of disturbing symptoms that persist well beyond an episode of COVID-19 or, more precisely, those that follow a confirmed or strong suspicion of infection with SARS-CoV-2 virus.

In October 2021, the World Health Organisation (WHO), following a consensus procedure (the Delphi protocol), proposed the following definition for the 'post-COVID condition':

> Post COVID-19 condition occurs in individuals with *a history of probable or confirmed SARS-CoV-2* infection, *usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis*. Common symptoms include *fatigue, shortness of breath, cognitive dysfunction* but also others [...] which generally have an *impact on everyday functioning*. Symptoms may be *new onset*, following initial recovery from an acute COVID-19 episode, or *persist* from the initial illness. Symptoms may also *fluctuate* or *relapse* over time. A separate definition may be applicable for children. (World Health Organization, 2021, p. 1).

The WHO definition may seem straightforward, but that is far from the case. One complication is the difficulty of defining a pathological condition exclusively by exclusion – 'symptoms that cannot be explained by an alternative diagnosis' (Al-Aly, 2021). A second complication is the lack of distinction between medical problems caused by COVID-19, such as lung, heart or kidney dysfunction, which can be identified through standard diagnostic tests ('long COVID disease'), and the disabling symptoms seen in patients who are told that all their diagnostic tests are normal ('long COVID syndrome'). The first type of sequelae – a new onset of a well-identified chronic pathology – more often occur in people hospitalised for severe COVID-19. These sequelae are understood as a direct consequence of a severe viral infection. The second type of sequelae, the emergence of puzzling, ‘medically unexplained’ symptoms, can occur in people who have been hospitalised and in those who have had mild or moderate onset of COVID-19. Since the number of people with mild or moderate COVID-19 was much greater than those who were hospitalised for a severe form of the disease, it is not surprising that the initial descriptions of long COVID were made mainly by patients with ‘medically unexplained’ sequelae of coronavirus infection (Callard, 2020c).

> *The doctor says it’s psychological; that I don’t have anything, that this will soon pass*. [...] I did several tests. Everything normal. It was the one for liver and kidney function, I did the one for D-Dimer to find out if I might have thrombosis, cholesterol, everything, everything. Everything came up normal. [...] I still had a cough, I had a bit of a headache and I treated it with syrup, with other medications that he prescribed for me. [...] The thing is that every now and then I began to feel some pain, out of nowhere. A strange thing. I had a consultation and nothing. Everything normal. He didn’t know what I had. So, when I said that I still wasn’t feeling well, that I was different, that my head wasn’t feeling well either, he told me ‘It’ll pass, it’s psychological’. (Bety, 60 years old, May 2023).

The experience of Bety, a 60-year-old retired teacher who lives in the Northeast of Brazil, illustrates one of the central problems in the WHO’s definition of ‘post-COVID condition’. The key term here is ‘medically unexplained’. People who develop medical problems that can be visualised through standard diagnostic tests following an episode of COVID-19 are classified as having a ‘real disease’ and, whenever possible, have access to appropriate medical and social resources. They are perceived as suffering from heart disease respiratory disease or some other type of well-defined pathology. In contrast, individuals like Bety, with medically unexplained symptoms, are often denied this access. Furthermore, if they continue to seek medical help with new and equally unexplained symptoms, they are sometimes labelled as ‘problematic’. Some experts have therefore proposed to define patients with demonstrable damage to vital organs induced by COVID-19 as suffering from ‘long COVID disease’ and those with medically unexplained symptoms following an episode of COVID-19 as suffering from ‘long COVID syndrome’. According to this definition, the vast majority of non-hospitalised patients may 'only' have 'long COVID syndrome', while hospitalised patients may have 'long COVID disease', 'long COVID syndrome', or both (Goldenberg; Dichter, 2023).

The WHO definition 'post-COVID condition' is problematic, because it is very broad and imprecise. It does not distinguish between 'medically explained' and 'medically unexplained' symptoms, between severe and less severe manifestations of 'post-COVID syndrome' or between symptoms that persist for a few months and gradually disappear and those that lead to the development of chronic disability. Despite the WHO's efforts, as of 2023 there is no consensus definition for this condition. Scientists have not even been able to agree on the name of this new pathological entity. This article uses the term 'long COVID', initially proposed by patients (Callard, Prego, 2021); however, more than three years after the first descriptions of the persistent sequelae of COVID-19, alternative names continue to be used in scientific and lay literature: 'long-term COVID', 'post-COVID condition', 'post-COVID syndrome', 'chronic COVID syndrome' (CCS) or 'post-acute sequelae of COVID-19' (PASCS). All names include the term 'COVID', some use the term 'syndrome', others 'condition' or 'sequelae', but none of them use the term 'disease'.

The main reason why the boundaries of long COVID remain blurred is the absence of objective diagnostic tests for this condition, that is, tests that demonstrate pathological changes in the body that are independent of the information provided by the patient. The three elements – the medically unexplained symptoms, the ill-defined limits of a pathological condition and the absence of consensual objective 'diagnostic signs' (elements that differentiate a given condition from other similar pathologies) – are interdependent and, at least in part, consubstantial. In the absence of objective signs of long COVID, patients' descriptions of their symptoms remain a key source of information on the new condition.

Scientists have dedicated important efforts to uncovering physiological and structural anomalies in long COVID patients and have reported numerous such anomalies. However, thus far, none of these, alone or in combination, are specific enough to determine with certainty whether an individual has long COVID (The Lancet, 2023). Many experts argue that the absence of diagnostic signs of long COVID merely reflects the fact that this is a very new disorder. Three years have not been sufficient to discover specific causes and develop diagnostic tests for this condition. However, it is highly probable that the pathological mechanisms of long COVID will be unravelled soon (Berger, 2023). It may indeed happen quickly – or it may not.[14] In the meantime, the absence of a firm diagnosis for this condition has important and sometimes dramatic implications for patients.

In his seminal text, 'The tyranny of diagnosis', medical historian Charles Rosenberg (2002) explained how the 'diagnostic revolution' in the field of medicine in the nineteenth century radically changed patients' trajectories and experiences, the organisation of health care, and has had broad social consequences in other areas, such as labour laws, social security, insurance and public health. Paraphrasing Rosenberg, it could be argued that people with long COVID are faced with the material and social consequences of 'the tyranny of non-diagnosis'. They may face difficulties in accessing medical resources and social support, difficulties that, not surprisingly, are greater for patients from lower social strata.

The patients' plight may be aggravated by 'epistemic injustice' resulting from disbelief in their claims. This injustice takes two forms: 'testimonial injustice' – a negative stereotyping of patients that systematically undermines their credibility – and 'hermeneutical injustice' – a consequence of the lack of explanatory framework for the patients' symptoms and suffering (Blease; Carrel; Geraghty, 2017; Carrel, 2016; Fricker, 2007). The latter form of epistemic injustice is often magnified by doctors' frustration at being unable to help these patients and the consequent labelling of patients with unexplained symptoms as 'difficult' (Sarradon-Eck; Dias; Pouchain, 2020). Epistemic injustice is magnified by unequal power relations between doctors and patients. In Brazil, they can be further amplified by the persistence of medical paternalism, including among doctors who work in the private sector. The issue is not a contestation of the epistemic privilege of professionals, based on their superior specialised knowledge, but rather a systematic denial of the existence of a different type of epistemic privilege – the patient's experiential knowledge, which deserves to be recognised and respected, including when dealing with patients from vulnerable social strata.

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[14] A programmatic article outlining the challenges of long COVID highlighted that there are no 'currently accepted objective diagnostic tests or biomarkers' for this condition (Phillips; Williams, 2021).

For the latter category of patients, the failure to recognise their suffering is an additional source of frustration and anguish (Segata, 2022).

The difficult search for reliable epidemiological data

One important consequence of the lack of objective diagnostic criteria (signs of a recognized disease) for long COVID is the difficulty in obtaining reliable epidemiological data. Past and present controversies remain concerning the prevalence of COVID-19 in the population and the number of deaths attributed to this disorder, but these controversies have reflected debates on the reliability and diffusion of specific diagnostic tests, classifications of people with asymptomatic infection, or methods used to produce mortality statistics. However, the general consensus is that COVID-19 is an infection by the SARS-CoV-2 virus that can be confirmed by a laboratory test, ideally a well-executed polymerase chain reaction (PCR) test.[15] There is no similar agreement regarding the definition of long COVID, its diagnosis or the causes of this disorder.[16]

In March 2023, an editorial in *The Lancet*, the most renowned British medical publication, entitled 'Long COVID: 3 years in', reported that the two main barriers to advancing the understanding and treatment of long COVID were insufficient investment in research into this condition and the lack of consensus regarding its definition. However, the first claim may not be entirely accurate. During the period when COVID-19 was officially described as an international emergency (March 2020 to May 2023), investments in research into long COVID were much lower compared with the resources allocated to acute COVID-19, but they were far from negligible. In Western Europe and especially the United States, government bodies invested significant amounts of money for research

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[15] This does not mean that the laboratory diagnosis of COVID-19 is obvious and simple. On the complexities of testing for SARS-CoV-2, see, for example, Löwy (2020), Beaudevin *et al.* (2021) and for a classic study on the pitfalls and problems of a diagnostic test for an infectious disease, see Fleck (1979).

[16] To obtain reliable epidemiological data, it may not be sufficient to obtain agreement on the diagnostic criteria for a given condition and the diagnostic tests capable of detecting it. It is also important to be able to implement reliable testing on a large scale. See, for example, Kameda, *et al.* (2021).

into long COVID/ post-COVID condition. In December 2020, the US Congress allocated $1.15 billion to study the late consequences of SARS-CoV-2 infection (Collins, 2021),[17] though how efficient the use these resources was remains unclear. In March 2022, the National Institutes of Health (NIH) initiative was described as 'a slow-moving glacier' (Cohrs, 2022). While part of this prolonged wait can be attributed to organisational difficulties and bureaucratic obstacles, it seems reasonable to assume that at least some of the long COVID research difficulties are related to the second point evoked in *The Lancet*'s editorial: the complexity of defining precisely what long COVID is.

One of the main aims behind the WHO definition of 'post-COVID condition' was to homogenise research on this topic and facilitate comparisons between studies conducted in different locations. This did not happen. It is true that after October 2021 many publications on long COVID stated that they used the WHO definition of post-COVID condition as participant inclusion criteria, but their interpretation of this definition was highly variable.[18] Consequently, some studies only studied people hospitalised for COVID-19, others only studied non-hospitalised individuals and many combined both populations; certain studies explored up to 200 different symptoms, while others focused on a much smaller number of 'typical symptoms'; some took into account the severity and

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[17] In 2022, Brazil launched a public call for research on long COVID through the CNPq, with total funding of 27 million reals (US$ 5.2 M) – Call to Research CNPq/MCTI/CT-Saúde no. 53/2022 – 'Research, development and innovation in long COVID'. A surprisingly small investment in research given the monstrous catastrophe that led Brazil to occupy second place in the number of contaminations and deaths due to COVID-19. Furthermore, mentions of long COVID are still very rare in official Brazilian government documents, including those from the Ministry of Health. One exception, though no less confusing than the 2021 WHO definition, can be found on the Secretaria de Atenção Primária [Secretariat of Primary Care] website, in a section entitled 'Understanding long COVID', which reads: 'according to the definition currently used by the Ministry of Health, a person with post-COVID condition is someone who presents new, recurrent or persistent clinical manifestations after acute SARS-CoV-2 infection, when these are not attributed to other causes' (Brasil, 2022, our translation).

[18] The problem was not the heterogeneity of the manifestations of long COVID. Many diseases, including COVID-19, present highly variable expression. Patients may present mild, moderate or severe symptoms, and diverse trajectories. However, in order to decide that a given set of symptoms is a 'disease', it is crucial to be able to determine objective signs of that disease: the presence of an infectious agent, specific changes in the tissues, unique images produced by medical imaging, or, in some well-studied pathologies, the presence of characteristic clinical symptoms.

duration of patients' symptoms, while others merely recorded the presence of all patients' symptoms, whatever they may be. Not surprisingly, these studies have produced divergent and, not infrequently, contradictory results.[19]

Research that focused exclusively on long COVID in patients hospitalised for severe COVID-19, in principle a more homogeneous population than the totality of people infected by SARS-CoV-2, have already shown significant variability in results. Thus, a large collaborative UK study of hospitalised patients highlighted muscle pain, limb weakness and fatigue (Evans *et al.*, 2022). An Austrian study of these patients found a predominance of neurological symptoms, including forgetfulness, 'brain fog', sleep disturbances and post-traumatic stress disorder, while a Chinese study of people hospitalised for severe COVID-19 showed a predominance of respiratory failure and depression (Huang *et al.*, 2022; Rass *et al.*, 2022). Moreover, studies on post-COVID condition in hospitalised patients show no indication that women are more prone to this disorder, probably because more men than women have been hospitalised for severe COVID-19. In contrast, one study reported that women composed the majority of patients treated in specialised long COVID clinics (Salmon-Céron *et al.*, 2022).

The results of research on non-hospitalised patients showed even greater variation. A Swedish study that analysed patient records and separated records of hospitalised and non-hospitalised individuals reported that only 1% of non-hospitalised COVID patients, 6% of hospitalised patients, and 32% of patients treated in intensive care units received a diagnosis of post-COVID condition (Hedberg *et al.*, 2023). Other studies on non-hospitalised patients with COVID-19 have reported a much higher proportion of individuals – up to 15% – who developed persistent symptoms (Tran *et al.*, 2022; Van der Maaden *et al.*, 2023). There were also important divergences in estimates of the role of factors like age, sex, previous medical conditions and lifestyle elements in the propensity to develop long COVID.

One of the main sources of disparity between the results obtained was the differing definitions of 'symptoms' – recall that the WHO definition of post-COVID condition does not specify what counts as a symptom of long COVID. Another important reason for this disparity was the length of patient follow-up.

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[19] For an example of a large study that does not make such distinctions, see Fernández de-las-Peñas *et al.* (2022).

One issue that has become particularly controversial is the proportion of patients who spontaneously recover from long COVID. A widely quoted Israeli study argued that claims regarding the high prevalence of long COVID may be exaggerated, based on analysis of a large volume of patient records. According to this study, nearly all the patients who presented multiple symptoms a few months after a mild episode of COVID-19 were symptom-free one year after the onset of the disease. The paper suggests that the perception of a long COVID pandemic in non-hospitalised patients may be largely an artefact, attributing this to the inadequacy of the WHO definition, which does not consider variations in the duration of convalescence from COVID-19 (Mizrahi *et al.*, 2023). This text was strongly criticized by COVID experts and patient associations. They argued that the study confounded the absence of medical appointments with complete recovery and ignored the reality that many individuals continue to suffer from debilitating symptoms even without seeking medical help. This situation can be attributed to several factors: people may have adapted to reduced functional capacity, sought alternative therapies or adopted self-help approaches, and, crucially, many may have lost trust in conventional medical care. This last point may be a reflection of the scarcity of clinics specialising in the treatment of long COVID.

The controversy over the proportion of long COVID patients who recover spontaneously is just one expression of a more general difficulty in obtaining reliable data on this condition. A synthetic report by the European Centre for Disease Prevention and Control (ECDC), from October 2022, concluded that

> there was high variability in symptom prevalence estimates between individual studies. This is the result of considerable heterogeneity in cohort study designs developed to investigate post COVID-19 condition, which often lack the control groups necessary to compare symptoms reported among SARS-CoV-2 infected individuals and non-infected individuals. Consequently, symptom prevalence estimates must be interpreted with caution [...]. (European Centre for Disease Prevention and Control, 2022, p. 1).

A systematic review and meta-analysis of multiple articles on long COVID that included 194 studies, totalling 735,006 participants, published in early 2023 reached a similar conclusion to the ECDC report:

> Current understanding is limited by heterogeneous study design, follow-up durations, and measurement methods. [...] there is no unified consensus on the definition of Long Covid, in particular with time components of continuing symptoms ranging from 4 to 12 weeks following infection onset. [...] Even when excluding studies with less than 100 patients and those in specialist populations, variability in estimated prevalence between studies remained high, particularly in the non-hospitalised cohort. In addition to varying study designs, different follow-up measurement tools and a wide range of follow-up durations, observed heterogeneity between studies may be explained by the lack of standardised data collection tools, particularly in studies of non-hospitalised populations. (O'Mahoney *et al.*, 2023).

The stark difference between the large number of publications on long COVID and the scarcity of reliable data on the prevalence of this condition and patient trajectories is a striking illustration of the consequences of 'the tyranny of non-diagnosis'.

A 'real disease' or a functional disorder?

Numerous long COVID experts are firmly convinced that this disorder has a purely physiological cause, whether it is the persistence of viral RNA in tissues, an anomaly of the immune system, the reactivation of latent viruses, like the Epstein-Barr Virus (EBV), an inflammation in the brain, or the presence of microclots in the blood.[20] These experts also argue that the psychological and psychiatric difficulties faced by numerous long COVID patients are a predictable outcome of coping with a chronic, disabling and unpredictable disease, especially one with an uncertain prognosis and no efficient cure. Patient associations strongly support a purely biological understanding of long COVID. In Western Europe and North America, patients and experts also support the association between long COVID and one of the most frequent – but also highly

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[20] See the interview with the leading long COVID expert in the US, Akiko Iwasaki (2023).

controversial – functional disorders, chronic fatigue syndrome, often referred to by the acronym ME/CFS.[21] This association firmly links long COVID to disorders strongly suspected of having psychological/psychiatric roots.

The term 'functional disorder' refers to a physiological dysfunction that can be visualised through objective tests (laboratory tests, medical imaging) and/or presents a typical, unambiguous clinical picture.[22] Thus, theoretically at least, it is a value-free description. Functional disorders are defined as a group of medical conditions that result from modifications in the functioning of body systems, rather than being caused by a disease that affects the structure of the body (Camargo, Teixeira, 2002; Wessely *et al.*, 1989).[23] However, in practice, some clinicians view functional disorders as a subcategory of 'somatic symptom disorders' – which, unlike 'real diseases', that is, pathologies induced by the presence of a lesion – are often perceived as closely related to psychiatric pathologies.[24]

Many doctors, particularly general practitioners, are reluctant to treat patients with functional disorders, because they are frustrated by the absence of

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[21] The term 'chronic fatigue syndrome' is used mainly in the US, while the term 'myalgic encephalomyelitis' is used mainly in the UK. Patients with this condition have a strong preference for the term 'myalgic encephalomyelitis' because it describes a pathological condition and not just being fatigued. Currently, scientific publications on this topic generally use the term ME/CSF, while the media often talks about chronic fatigue.

[22] Regarding the importance of objective signs of disease, see Cambrosio *et al.* (2006), and regarding the increase in clinical knowledge based on clinicians' experience, Lawrence (1985).

[23] Some researchers seek to restrict the term 'functional disorder' to 'functional neurological disorder' (FND), a more restrictive definition that includes only conditions in which the brain fails to correctly process signals from the body. However, FND is a controversial diagnosis and some experts claim that it is identical, or at least partially overlapping, with 'conversion disorder', 'somatoform disorder' or 'functional somatic syndrome'. It also has troubling links to past diagnosis of hysteria (see Kwon, 2020).

[24] The history of 'somatisation' as a psychiatric/psychosomatic disorder, which primarily falls under the jurisdiction of a psychiatrist, is closely linked to the history of the different names for this condition and debates over its name in consecutive editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the 'bible' of US psychiatrists. In the past, somatisation was called 'conversion disorder'. Recently, the preferred name is 'functional neurological symptom disorder', a category that falls under the general category of 'somatoform disorders' (currently also called 'somatic symptoms and related disorders'). For the classification of somatoform disorders by psychiatrists, see Young (2014).

medical explanations for their symptoms and the lack of efficient therapies (Sarradon-Eck; Dias; Pouchain, 2020). Furthermore, the observation that the majority of long COVID patients are women has reinforced the suspicion that, at least in some cases, the roots of patients' suffering are psychological rather than organic: women continue to be seen as more affected by stress, more suggestible and more prone to hypochondria. They also compose the majority of patients affected by other functional disorders. Although few physicians describe themselves as committed reductionists interested only in molecular mechanisms of pathology, or as unwilling to pay attention to the whole patient, in practice they often present negative attitudes toward patients with unexplained medical complaints (Goutte; Cathébras, 2021; Uclés-Juárez *et al.*, 2020). These negative attitudes could be described as 'public secrets' – uncomfortable knowledge recognised by many people, but seldom spelled out (Giessler, 2013).[25]

Scientific publications reflect the persistent dichotomy between a purely physiological and an at least partially psychosomatic perception of long COVID. In May 2022, an important review article published in *Nature Medicine* characterised long COVID, from the perspective of post-COVID syndrome, as one of several post-viral syndromes. In this category, the author of the review also included other functional diseases with suspected viral origin, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CSF) (Choutka *et al.*, 2022). The main message of this article was that although the precise biological mechanisms of the long-term damage caused by infection with the SARS-CoV-2 virus are not yet fully understood, the existence of such harm is neither mysterious nor surprising.

Other publications propose a very different picture. Two articles from May 2022 stated that the main risk factors for developing long COVID are female sex and anxiety (Sneller *et al.*, 2022; Weldon; Aslibekyan, 2022). The same risk factors – female sex and prior history of anxiety – have been described as key risk factors for other functional disorders. A study published in late 2022 stated that although the majority of long COVID patients recover completely after

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[25] Other terms to describe such suppressed knowledge are 'uncomfortable knowledge' and 'unknown knowns' (Marris; Jefferson; Lentzos, 2014).

12 months or have mainly cardiopulmonary symptoms that marginally affect their quality of life, a subgroup of patients, the vast majority of whom are women, continue to experience multiple symptoms that negatively affect their daily life and mental health. These patients also had elevated somatisation scores and exhibited a pattern characteristic of psychosomatic conditions, such as a marked proportion of relapse of symptoms closely associated with somatisation (Sahanic *et al.*, 2022). The suspicion that patients (often women) somatise and do not have a 'real disease' ('It's all in your head', 'It's psychological and soon passes') is indeed the elephant in the room when dealing with long COVID. It is probably one of the main reasons why so many long COVID patients struggle to be believed by their doctors (Löwy, 2021).

The assumption that an infection with SARS-CoV-2 could lead to the development of chronic fatigue syndrome, which is a 'classic' functional disorder, was raised as early as the beginning of April 2020, that is, at the very beginning of the COVID-19 pandemic. This assumption was based on the observation that people who recovered from previous coronavirus epidemics, such as the 2003-2004 SARS epidemic, often suffered from chronic fatigue (Wilson, 2020). In the summer of 2020, one of the United States' leading COVID-19 experts, Anthony Fauci, noted that 'it's extraordinary how many people have a post-viral syndrome that's very strikingly similar to myalgic encephalomyelitis/chronic fatigue syndrome' (see Jackson, 2021).

The parallels between long COVID and chronic fatigue syndrome were later reinforced in two distinct ways. One of these was the application of lessons learned in ME/CSF studies to patients with long COVID, for example, the recommendation not to offer rehabilitation techniques like graded exercise therapy (GET). This is because much like patients with ME/CSF, patients with long COVID often suffer from post-exertional symptom exacerbation (PESE), a syndrome aggravated by GET. Another way to link these two conditions is to present ME/CFS as one of the main manifestations of long COVID, present in some but not all patients with this condition (Davis *et al.*, 2023). A multi-centre study distinguished two subgroups of patients with long COVID, those with long COVID alone (about 2/3 of patients in this subgroup were women) and those with long COVID and ME/CSF (almost all patients in this subgroup were women). The authors of this study observed that patients with long COVID and ME/CSF presented more severe symptoms, and few of them showed improvement after 18 months. They concluded that diagnosing ME/CSF in patients with long COVID helps identify those who present a more severe prognosis and require more intensive treatment and support (Legler *et al.*, 2023).[26]

Finally, some experts have proposed that the controversy over whether long COVID is a 'real disease' (i.e. organic in origin) or an 'imagined' disorder (non-organic in nature) with no discernible cause is a fruitless discussion. In September 2023, long COVID activist Steven Phillips and Harvard University epidemiologist Michelle Williams argued that long COVID is not a new disease, but rather a manifestation of ME/CFS and similar post-viral conditions:

> Long Covid is really not new. It is virtually indistinguishable from the condition long known in the medical lexicon as post-infectious syndrome or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). (Phillips; Williams, 2023).

Given that this appears to be the case, treatment of long COVID should benefit from long experience in the therapeutic treatment of post-viral symptoms. A false dichotomy between 'real' and 'imagined diseases' must also be avoided, since scientific evidence shows that post-infectious fatigue syndromes (including long COVID) can have a spectrum of inseparable pathobiological and psychological components.

The association between long COVID and chronic fatigue syndrome and, to a lesser extent, with other functional disorders, may favour the comprehension of long COVID symptoms and expand the circle of professionals and lay people interested in the new condition. The close association with other pathological conditions of uncertain status may also complicate the efforts of people with long COVID to be recognised as having a 'real disease' and to gain access to effective medical treatment, social support and respect.

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[26] The authors of this study employed a widely accepted set of diagnosis criteria for ME/CFS, the Canadian Consensus Criteria. The diagnosis of ME/CFS is made after ruling out all the other diseases that could explain the symptoms presented. Thus, like the WHO definition for post-COVID-19 syndrome, it is diagnosis by exclusion.

Conclusions: one more illness you have to fight to get

> Every day is a struggle. Sometimes you have to fight the pain, because life doesn't stop; there's the house, the kids, you have to work. There are days when your breath doesn't come, when sleep doesn't come. Just a tiredness, a tiredness that doesn't even let you rest. [...] A strange thing. You don't turn off; your body doesn't turn off. [...] *I'm no longer the same person*. But that's okay, I've gotten used to doing things the way I can. I'm getting on with my life, what can I do? [...] Most doctors don't care. None of them are capable of saying: 'You have long COVID, and we're going to do this and that to help you'. That doesn't exist. You talk, talk, complain, and it's as if the disease doesn't exist, we don't exist. [...] You don't see a debate about long COVID. You don't see policy on long COVID, some treatment, nothing. That's why we keep fighting. We exist, we're here. (Joana, 59 years old, July 2023).

The testimony of Joana, a nurse from the interior of Rio Grande do Sul, together with the testimonies of other women described in this article, reveals the way in which long COVID operates a complex process of existential transformation. New scripts are mobilised daily to deal with bodily sensations, experiences and identities that are repositioned to the extent that the symptoms become part of these people's daily lives (Seppola-Edvardsen; Risør, 2017). For many of them, it becomes difficult to distinguish between 'everything's fine' and 'suffering', especially in chronic contexts (Hay, 2008). In addition to the biographical repositioning, these women's narratives also show that the struggles for recognition of their illness are essential for the production of treatment and care policies, are often hampered by state and corporate interests in the field of health. Directly echoing the concerns raised by Dumit (2006) in his study on uncertain and contested diseases, like many functional diseases and rare syndromes, long COVID thus emerges as another one of those diseases that people need to fight to get.

Titled 'Illnesses you have to fight to get: facts as forces in uncertain, emerging illnesses', Dumit's (2006) article examines the crucial issues related to emerging and contested illnesses, offering an in-depth analysis of the challenges faced by patients and the complexities involved in the search for the diagnosis, treatment and recognition of these conditions, including social legitimacy.

Dumit (2006) emphasises that patients suffering from emerging illnesses often face an uphill battle for recognition of their conditions. This is due to the ambiguous and difficult-to-diagnose nature of these illnesses, which can manifest a wide range of varied and persistent symptoms. This uncertainty generates tension between patients' narratives concerning their symptoms and the search for medical objectivity that, in many cases, fails to adequately capture the complexity of these conditions. In this context, the importance of patient narratives stands out, since they play a fundamental role in the comprehension and construction of a knowledge base on these diseases. Since doctors may not be familiar with these emerging conditions, patients take the lead in constructing an understanding of their own illnesses. This scenario accurately portrays the complexities faced by people affected by long COVID today, summarised throughout this article as epistemic injustice.

In the absence of diagnosis, the epidemiological repercussions and consequent social impacts of the disorder are impaired, while projections that affirm more than half of COVID-19 cases developed long COVID articulate that, at this very moment, this is a pandemic experienced in silence. The fact is obtaining a definitive diagnosis is not yet a reality for those living with long COVID, due to the uncertainties of this tumultuous scenario of controversies and uncertainties with regard to the varied and unpredictable symptoms, which challenge the modern belief in objectivity that still prevails in medicine. It is at this point that the tyranny of non-diagnosis reveals its cruellest face in the context of long COVID. A medicine whose central infrastructure is objective diagnosis creates an irreconcilable fissure between signs and symptoms. In other words, the narrative that the affected person offers to the doctor is always at a disadvantage to that which their own biology is saying to the instruments they rely on. This turns into even more layers of suffering. Thus, the search for validation of their condition and public understanding becomes a fundamental part of the long journey for people with long COVID.

This challenging process also exposes the limitations of the current technocratisation of health policies, particularly in contexts of global health crises. A significant exaltation of biosecurity has revived the recalcitrant conversion and militarisation of health as a question of security, rather than one of care. In this context, precision instruments for virus mapping and surveillance are often presented as 'combat weapons' against 'invisible enemies' (Segata, 2020).[27] However, the shameful management of the pandemic in countries like the United States and Brazil has shown that these technologies are not yet sufficiently calibrated to control the behaviours of populations governed by ultra-radical and denialist leaders, frequently described as genocidal (Ventura; Aith; Reis, 2021).

Indeed, to a greater or lesser degree of efficiency, the central concern of many governments seems to have been much more about combating the virus than caring for the sick, especially those with persistent symptoms, who were neglected even further following proclamations of the ‘end of the pandemic’. It is not surprising that the pandemic is often described as a time of war rather than care (Segata, 2020). This scenario also clearly reflects the criticism of Arthur Kleinman (2020, p. xviii-xix), who argues that the desire for fast, efficient, technological solutions, often with a market focus, has increasingly supplanted care:

> No one today can doubt that medical care is profoundly destabilized by the most powerful bureaucratic, commercial, and governmental influences. Nor is there a lack of critical awareness that the culture of biomedicine, the hegemony of an economic language, and the fetishism of technology distort the purposes and objectives of care. Together these forces substitute indirect measures of efficiency for direct measures of the quality of care. They contribute significantly to poor care, to frustrated and mistrustful patients and families, and to physician burnout.

Echoing Kleinman (2020), the long COVID recognition and care policies described and analysed in this article are not solely limited to the issue of physical health, but also encompass justice and reparation for patients who are ignored, discredited or who receive inadequate support due to a lack of understanding of the disease. To combat this epistemic injustice, it is crucial that society, the medical community, and policymakers recognise the seriousness of long COVID and invest in research to fully understand the disease. Moreover, promoting public awareness of the challenges faced by long COVID patients is required in

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[27] Similar fears are also observed in reference to migrants, often compared to pests and mistakenly associated with terrorists, as well as border security with regard to animal and plant products in global food systems (Segata, 2020).

order to eliminate stigma and ensure they receive the support they need. Therefore, recognising and treating it in this manner is an important step in ensuring that patients receive the care and support they need despite the complexities associated with this often disenabling condition, alleviating their suffering, advancing in our understanding and treatment of the disease, and favouring the reconstruction of their lives with greater dignity.

Long COVID is a pandemic awaiting recognition. Stating this means saying that there is no doubt that people affected by long COVID may still face an uphill struggle. The biases of doctors, together with considerations regarding to class, race, gender, and a lack of funding, especially after the pandemic ends, can significantly complicate the situation for patients. In the US, an article published in October 2023 in the *New England Journal of Medicine* highlighted the situation:

> Now from a political standpoint 'Covid' is a bad word. People don't want to talk about it. People don't want to think about the pandemic. It connotes government overreach, and people believe that we should just get past this. There's not the political will to say, 'Look, we are dealing with millions of people who have these symptoms [...].' So, I think there's a political non-will to do anything and to think we're past this and ignore the societal implications of a very difficult and unusual condition. And on top of that, we don't have any treatments. So, when you don't have any treatments and you have a primary care provider who can't elucidate exactly what's going on and do not have treatment options, that becomes extremely difficult. (McComsey; Rosen, 2023).

For those experiencing long COVID, the lack of an accurate diagnosis often results in a prolonged period of uncertainty and anxiety. Clearly, a formal diagnosis is not always the answer to the problem. In the US, for example, the NIH provided formal recognition of long COVID (a number for the official classification of pathology and diagnostic criteria), but as the article in *The New England Journal of Medicine* attests, patients' needs often continue to be unmet (McComsey; Rosen, 2023). Some doctors (especially general practitioners) reject a diagnosis by exclusion and, more crucially, patients need not only a diagnosis, but also access to appropriate expertise (for a complex illness, ideally in a multidisciplinary centre), social provisions, and the recognition on their experiential knowledge about their condition. Waiting for a full recognition of long COVID is an active process, of struggle, but also of hope for a future horizon. Without a medical label to explain their persistent symptoms, patients may feel that they are navigating uncharted waters without a map to guide them. Not infrequently they end up facing accusations of faking or exaggerating their symptoms, and disbelief on the part of healthcare professionals and employers, creating significant barriers to obtaining appropriate treatments and social support. This can negatively affect their mental and emotional health, increasing stress and feelings of isolation.

The struggle for the diagnostic of long COVID represents much more than an ongoing battle against suffering and invisibility. It is a demonstration of the strength, resilience and active role of patients in the health, disease and care processes. The people affected who demand a full recognition are the legitimate protagonists of the construction of long COVID as a new nosological entity, offering to the history of science an essential testimony of the concrete experience of the disorder inscribed in their bodies and in their lives.

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