



The contested meaning of “long COVID” – Patients, doctors, and the politics of subjective evidence

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ABSTRACT

In our article, we reconstruct how the patient-made term “long COVID” was able to become a widely accepted concept in public discourses. While the condition was initially invisible to the public eye, we show how the mobilization of subjective evidence online, i.e., the dissemination of reports on the different experiences of lasting symptoms, was able to transform the condition into a crucial feature of the coronavirus pandemic. We explore how stakeholders used the term “long COVID” in online media and in other channels to create their illness and group identity, but also to demarcate the personal experience and experiential knowledge of long COVID from that of other sources. Our exploratory study addresses two questions. Firstly, how the mobilization of subjective evidence leads to the recognition of long COVID and the development of treatment interventions in medicine; and secondly, what distinguishes these developments from other examples of subjective evidence mobilization. We argue that the long COVID movement was able to fill crucial knowledge gaps in the pandemic discourses, making long COVID a legitimate concern of official measures to counter the pandemic. By first showing how illness experiences were gathered that defied official classifications of COVID-19, we show how patients made the “long COVID” term. Then we compare the clinical and social identity of long COVID to that of chronic fatigue syndrome (ME/CFS), before we examine the social and epistemic processes at work in the digital and medial discourses that have transformed how the pandemic is perceived through the lens of long COVID. Building on this, we finally demonstrate how the alignment of medical professionals as patients with the movement has challenged the normative role of clinical evidence, leading to new forms of medical action to tackle the pandemic.

1. Introduction

The designation “long COVID” has gained increasing traction over the course of the ongoing coronavirus pandemic. However, both the name and the condition itself are controversial. Patients suffering from long COVID, usually in the aftermath of an infection, experience “a range of overlapping symptoms, including generalized chest and muscle pain, fatigue, shortness of breath, and cognitive dysfunction, and the mechanisms involved affect multiple system [sic] and include persisting inflammation, thrombosis, and autoimmunity” (Rajan et al., 2021: 5). It is difficult to detect with the usual diagnostic tools and parameters, such as laboratory values. Patients, especially those who are not acutely ill with COVID-19, are often not tested, and so, for want of evidence, find themselves in diagnostic limbo. Reliable and accurate diagnosis is a lengthy and often arbitrary process, as is receiving appropriate care and

rehabilitation. This particular configuration of problems in a society thrown into a state of emergency by the coronavirus pandemic has produced an unprecedented spillover in terms of patient experience and activity: the worldwide networking of those affected and the rapid dissemination of reports on the stubbornly enduring symptoms of COVID-19 infection has led to an impressive mobilization of subjective evidence online.

By giving a name to their suffering and spreading information about their individual conditions, patients have transformed their subjective experience into a collective one. The name “long COVID” has thus been able to establish itself as the widespread – albeit not universal – designation for a syndrome, even in public health discourses normally resistant to subjective evidence. Usually, diseases are named by medical scientists according to defined criteria. The World Health Organization (WHO) provides guidelines for naming new infectious diseases (World

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Health Organization, 2015). However, the patient-made term long COVID defies the common conventions for designating new diseases. Callard and Perego describe long COVID as “the first illness created through patients finding one another on Twitter” (Callard and Perego, 2021).

From the outset of the pandemic, there was both a lack of knowledge and an urgent need to know about the disease caused by the novel coronavirus. Researchers published early findings on acute COVID-19 in preprints without peer review and study protocols were relaxed to ensure quick results (Gadebusch-Bondio and Marloth, 2020). This lack of knowledge has also resulted in an openness to patient experience in the case of long COVID, which has been fed by sources on the internet and social media. In the following, we argue that under the circumstances of a global health crisis, the long COVID movement was able to fill crucial knowledge gaps in public health discourses with subjective evidence. We reconstruct how long COVID patients became a movement and how, by mobilizing their experiences of illness under the name long COVID, they anchored it in the public and professional discourses. We also shed light on the special role that health care professionals played as patients in this context.

The internet and social media have transformed how patient movements function and operate (Petersen et al., 2019; Schermuly et al., 2021). They have turned the actions characteristic of patient activism – campaigning for justice, rights, access to treatments, and a voice in research policy decisions (e.g., Epstein, 1996) – into the self-empowering construction of communities of shared medical identity, which curate and distribute their “narratives of illness, treatment and recovery” (Petersen et al., 2019: 481). As Schermuly and colleagues have suggested, the long COVID movement that formed during the pandemic exhibits traits of both the older patient activism *and* the newer Internet advocacy (Schermuly et al., 2021: 212). Taking our cue from this suggestion, we demonstrate how the awareness-raising and support functions of long COVID self-advocacy groups provided a crucial resource for patients in the online movement to influence clinical and social perceptions. In the case of long COVID, the curation and distribution of experiences has been doubly important since the lack of existing knowledge about the illness coupled with the pressures of a global public health crisis drastically elevated the role of patient-generated evidence in filling those knowledge gaps. Patient activists have succeeded in visibilizing the pandemic as defined by the morbidity of a non-mild disease with an open time course and a variety of manifestations, lending medicine and public health a space in which to act against it. At the same time, however, it has blurred the boundaries between the clinical and sociological understanding of long COVID.

Our analysis focuses on the programmatic work of patients within the online movement “long COVID” or “Long-Haul COVID”, as well as examining illustrative personal statements about the illness, and analyzing the contributions of a group of doctors and nurses as patients of COVID-19 long-term effects. Without claiming exhaustive representation, we examine different voices and perspectives, which have manifested themselves on websites and in blog posts, in articles in medical journals and preprints. In this context, the contributions of health care professionals as well as medically literate academics are central in bridging the discourses of subjective evidence in online communities and professional health care institutions. Their position has enabled them to employ the kind of language needed to enter into a dialogue with medical practice and therefore plays a key role in cultivating awareness and acceptance of long COVID as a recognized medical condition.

We explore how stakeholders use the term long COVID in online media and other channels to identify their illness and group identity, but also to demarcate personal experience and subjective evidence of long COVID from that of other sources (Atkinson et al., 2021). However, our concentration is on programmatic publications, and on how subjective evidence is politically employed, rather than on detailed accounts of

first-hand experience. The public usage of the long COVID concept by affected doctors and academics necessarily conflates the multiplicity of individual experiences of the illness in chat groups and online fora with expert opinion in order to enhance political impact and thus acceptance. Central concepts in public discourses are highly contested and ambiguous since many different actors are involved in their making (Kaldewey and Schauz, 2018). Key terms are employed to raise awareness and build consensus but can remain vague and produce fault lines in opinion (Bensaude Vincent, 2014, Roth and Bruni, 2021). Although, the term long COVID has also come to be used in non-anglophone countries (e.g., Lenzen-Schulte,), its contested meaning has mainly been shaped in anglophone discourses.

While the insufficiency of scientific evidence to date has meant that the condition has not (yet) been classified as a specific disease, patients’ “subjective evidence” (Gadebusch-Bondio and Hermann, 2021), i.e., the lived experiences of COVID-19 and long-term effects, provide proof of the condition’s existence, complexity and context outside the range of conventional diagnostic markers. We draw on the notion of “evidence-based activism” (Rabeharisoa et al., 2014), as a heuristic to comprehend the variety of ways in which patients, users, and especially activists engage in knowledge-generating activities. This framework allows us to understand how the knowledge generated by long COVID patients can function to simultaneously create facts and matters of concern, since knowledge here is taken to mean any “statements on the nature of patients’ and activists’ conditions or situations” (Rabeharisoa et al., 2014: 115). Matters of concern are issues that not only constitute given facts but also contribute to knowledge that is relevant to specific actors, since it refers to their problematic state as patients, for instance (Latour, 2004).

On this basis we address two questions. Firstly, how the mobilization of subjective evidence leads to the recognition of long COVID and the development of treatment interventions in medicine; and secondly, what distinguishes these developments from other examples of subjective evidence mobilization, particularly the case of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The latter is readily compared to long COVID because of a similar symptomatology and in terms of the lack of clinical specificity. To provide answers, we reconstruct the phenomenon long COVID, showing how patients made the long COVID concept by gathering different experiences that defied official classifications of COVID-19; following this, we compare long COVID and ME/CFS to set the stage for the question of how the clinical and social identities of the former became so widely and rapidly accepted, while the latter still struggles for recognition; subsequently, we shed light on the social and epistemic processes at work in the digital and medial discourses, in which academics affected by the illness have transformed how the pandemic is perceived by co-producing long COVID as a matter of fact and concern through evidence-based activism. The idea of co-production is used in the literature to describe the making of knowledge, goals, and practices in discursive interactions between the public, the state, and the scientific system (Jasanoff, 2004). Finally, we show how the alignment of medical professionals as patients with the movement has challenged the normative role of clinical evidence, leading to new forms of medical action in tackling the pandemic.

2. Between activism and advocacy – illness experience and the making of social identity in the digital age

To reconstruct how the long COVID group identity emerged through online advocacy, we can draw on the idea of a new form of individual and group identity, which Petersen et al. (2019) call “bio-digital citizenship”. The concept is a follow-up to the older idea of “biological citizenship”, which, from an anthropological and sociological perspective, defines identity based on biological features, particularly the susceptibility to disease associated with a specific genetic makeup (Rabinow, 1996). Bio-digital citizenship, in contrast, “is characterized by the entwining of biologically based identities and digital-based

practices" (Petersen et al., 2019: 481). Biological determinacy alone, in other words, does not make bio-digital citizens, whose identity is also formed through engagement with the online world. Recourse to the internet allows "those who self-identify on the basis of genetic or other biologically defined conditions" to construct online communities of shared medical identities (Petersen et al., 2019: 481).

The term "long COVID" as a signifier became available through the social media hashtag "#LongCovid" at the end of May 2020 (Perego and Callard, 2021). It allows the high variability of patient experiences to be qualified under a common denominator. Accordingly, the experience of patients suffering from long COVID span from interferences in their everyday routines to the fear of life-long impairment due to the illness. On Twitter, a user named "lindsay" gathered patient accounts through screenshots of private messages, offering a glimpse of the variability of experiences collected in online communities: they range from "I smell chemicals everywhere" through "brain fog" to the feeling of having "acid in my veins [,] couldn't move and now I have chest pains 6 months later" (Twitter, 2020a). On the UK-based website LongCovidSOS, a patient called Paula explains that "I've had headache where the pressure was so intense I felt as if my head was about to explode and I've had fatigue so bad I've barely been able to get out of bed and had to drag myself along the floor to the bathroom." (LongCovidSOS, 2020b).

Against this background, the impetus to take up digital tools in the face of illness ranges from the simple desire to be recognized for one's suffering by friends, family, or colleagues to the need of serious medical rehabilitation (e.g., Dumit, 2006). But the sheer quantity and range of different lasting illness experiences in connection with COVID-19 subsumed under a common name gave the long COVID movement leverage to legitimately confront the medical establishment and public health policies on their actions towards the pandemic. It helped these patients to overcome the lack of recognition by medical authorities as well as the fear of falling outside official perceptions of COVID-19. On LongCovidSOS, James describes his difficulties with having his illness recognized: "I tried to get advice from 111 and my GP surgery but was met with a lot of dismissal. Because I am young with no previous health issues, my symptoms were labelled as anxiety, something I have struggled with in the past. But this was different. I knew I was unwell" (LongCovidSOS, 2020b).

COVID-19 was visible to official eyes mainly in terms of its severity and with respect to mortality. Distinctions were quickly drawn between a severe or critical and mild or moderate progression with relatively fast recovery (World Health Organization, 2020). Although millions were infected (in the UK alone), reports focused on the severe cases, and many were left to manage their illness by themselves. "Their suffering was invisible" (LongCovidSOS, 2020a). Patients whose conditions defied the neat categorization into "mild" and "severe" cases felt they were falling through the cracks. Consequently, reports began to accumulate on Twitter, on websites like LongCovidSOS, or on blogs, that emphasized the range of long-lasting and debilitating effects of COVID-19 following so-called "mild" infection.

Felicity Callard, professor of human geography at the University of Glasgow, sufferer of long-term consequences, and long COVID advocate of the first hour, therefore contests the suggestion that those who have not been hospitalized due to COVID-19 are "mild" cases: "The mild is commonly construed as that which does not significantly impair one's existential equanimity", but "For many in the first, non-hospitalized Covid-19 cohort, our usual sense of agency and phenomenological fit with the world *has been* significantly disrupted" (Callard, 2020a: 4). The identity around which the Long COVID online advocacy originally formed was thus that of suffering from COVID-19 as a non-mild illness with a range of serious symptoms that persist and severely impair sufferers for an unspecified duration.

Furthermore, the initial invisibility of long COVID patients to medical and public health authorities resulted in an uncertainty about the biological side of their bio-digital identity – something long COVID shares with syndromes like ME/CFS. Since many sufferers of the

condition were not tested and usually had to overcome their illness at home, it was difficult to determine the individual infections with the SARS-CoV-2 pathogen (Altmann and Boyton, 2021; Greenhalgh et al., 2020). Consequently, the practice of sharing personal experiences of an unspecified condition that emerged during the pandemic was the primary marker of identity, without requiring a biomedical indication of having contracted the disease. For the group of sufferers this initially meant a lack of formal health records, since they were either not treated at all or only consulted with a general practitioner or family doctor. As one proponent reported on the *BMJ* blog on July 28, 2020: "I have no proof of my infection other than the accounts of thousands of people who are describing a similar experience of prolonged, fluctuating, and debilitating symptoms lasting for months" (Alwan, 2020b).

3. Maintaining fragile disease identities – long COVID and chronic fatigue syndrome

One crucial aspect which requires further investigation is the relationship between long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The illness of ME/CFS is characterized by symptoms that can affect multiple bodily systems. Sufferers usually experience severe mental and physical exhaustion. "The cause of ME/CFS remains unknown, although in many cases, symptoms may have been triggered by an infection or other prodromal event" (Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015: 1). Initially, ME/CFS was believed to be caused by nervous weakness (neurasthenia) and then later by inflammation (Murga and José-Vincente, 2019). Today, a large consensus sees the complexity of a heterogeneous etiology. Since the cause of ME/CFS is still not fully understood, diagnosis can be made only on the basis of symptoms, making it difficult to develop treatments (Karfakis, 2018). The disease first emerged in cases described as myalgic encephalomyelitis (ME) in the wake of polio outbreaks in the USA in the 1930s. In the 1980s, cases of lingering fatigue after suspected infection with the Epstein-Barr virus (EBV) became popular as "chronic fatigue syndrome" (Aronowitz, 1998). However, since EBV is one of the most common viruses in humans, it has been "difficult to attribute symptoms such as chronic fatigue to EBV infection on the basis of antibody tests because most adults have been exposed to the virus and thus have antibodies" (Aronowitz, 1998: 24). Today, patients and institutions refer collectively to ME/CFS as a condition that is hard to grasp biomedically, lacking a clear consensus on diagnosis and etiology (Barrett, 2004; Karfakis, 2018). Since long COVID and ME/CFS differ strongly in the official recognition they are receiving, but share many features socially, diagnostically, and ethically, it is worth sketching some of the most striking relationships.

Regarding their pathophysiological mechanisms, both illnesses remain unexplained. Accordingly, just like long COVID, ME/CFS initially did not have strong support within the medical profession but had to rely on a strong patient base. Those affected were compelled to occupy "more dominant roles in the movement" in order to generate publicity and acquire legitimacy (Barrett, 2004: 157). We can describe both long COVID and ME/CFS in terms of a subjective "emerging illness" (Packard et al., 2004). These illnesses have epidemiological characteristics, but usually lack clear diagnostic descriptions and etiologies – "communities of sufferers" therefore need to negotiate their "experiential knowledge" with different actors and institutions in order to "transform individual illness experience into recognition of a wider collective health problem" (Packard et al., 2004: 10). Dumit has additionally pointed to the social character of illnesses like ME/CFS as "biomental", meaning that there is no consensus on whether a condition is primarily caused by mental, psychiatric, or biological factors; as "therapeutically diverse"; and as having "fuzzy boundaries", since they are "crosslinked to other emergent illnesses as subsets, mistaken diagnosis, and comorbid conditions" (Dumit, 2006: 578). A main reason for patients who suffer from newly emerging illnesses not being fully

recognized by the medical system is that the condition is not sufficiently expressible in the “codes” or protocols of contemporary biomedicine, e. g., in the form of a diagnosis lending it legitimacy.

Another striking similarity is the epidemic/pandemic context. ME/CFS became known in different epidemic waves, including during the AIDS epidemic in the USA. Some proponents even sought to associate the illness with the immune deficiency disease. In attempts to make their condition credible, activists have emphasized how it is debilitating “and framed CFS as ‘AIDS junior’ and even a ‘non-HIV positive AIDS’”. Since the illness was understood primarily as an infectious disease, however, “it shared a scientific niche with AIDS and therefore competed with it for resources and attention” (Barrett, 2004: 160). Thus, while ME/CFS was considered distinct from the viral disease causing the AIDS epidemic, which disadvantaged its status within the health care system, long COVID, despite the lack of biomedical evidence, retains an advantageous connection to the ongoing pandemic and to investigations into its pathogen.

Since a lack of specificity and a lack of therapy options characterize the two syndromes, there appears to be a need to keep the two illness conceptions demarcated socially in a form of boundary work (Gieryn, 1999). Accordingly, proponents of long COVID as well as of ME/CFS maintain a clear distinction between the two conditions on the basis of either credential knowledge or lived experience. Long COVID advocates argue against enfolded their condition within other diagnoses and keeping the illness identity of long COVID separate (Perego et al., 2020: 5). Because of the fuzzy boundaries that characterize them, proponents of ME/CFS and long COVID try to avoid crosslinks to mistaken diagnosis and to the condition as merely a subset of other illnesses. Thus, while ME/CFS patients and caregivers emphasize the chronicity of their illness, long COVID patients are concerned foremost with the novelty of the condition, emphatically keeping the temporal course open. One Twitter user, who self identifies as a long-time sufferer of ME/CFS and long COVID, suggests: “I don’t think long-haul covid should be automatically regarded as ME. Sometimes it may fit the criteria, but for the most part, I think not. All the ME + Covid people I’ve been in touch with says [sic] the long-haul covid feels distinctly different from the ME ...” (Twitter, 2020b). However, over the course of the pandemic, medical professionals have observed striking similarities between long COVID and ME/CFS (e.g., Paul et al., 2021).

How this form of boundary work between long COVID and ME/CFS ensues can be drawn from an entry by Paul Garner on the *BMJ* blog and the comments that were left on the post. A professor of infectious disease at the Liverpool School of Tropical Medicine, he has been a public voice for lasting symptoms of COVID-19 by regularly publicizing his case on the *BMJ* blog. On January 25, 2021, he made his final blog entry about his “recovery from long covid”. In the blog post, Garner explains that what helped him find his path to recovery was his consultation with ME/CFS specialists and guidelines, thereby crosslinking long COVID and ME/CFS. After having acquainted himself with material on “pacing” and ME/CFS, “and listening to the CFS/ME community” (Garner, 2020), Garner reports on September 29 how he formed his own little self-help group with friends that applied a practice common within ME/CFS communities consisting of daily scheduled routines of rehabilitation and rest. He emphasizes that his recovery hinged on “listening to people that have recovered from CFS/ME, not people that are still unwell”. As a consequence, he quit the “constant monitoring of symptoms” and avoided “reading stories about illness and discussing symptoms, research or treatments by dropping off the [long COVID] Facebook groups” (Garner, 2021). Crucially, he explains how his path to recovery drew on the remarkable insight that “our unconscious normal thoughts and feelings influence the symptoms we experience”, thereby pushing his experience of long COVID as “post-viral fatigue” in the supposedly psychological corner of ME/CFS; that viral infections can sometimes provoke “unconscious defense mechanisms”, which become established as dependent neural marks “giving false fatigue alarms” (Garner, 2021). He learned from people who have overcome ME/CFS that he “could

change the symptoms” that he was experiencing, “by retraining the bodily reactions with my conscious thoughts, feelings, and behaviour” (Garner, 2021).

Many answers to Garner’s interpretation of his former long COVID suffering as ME/CFS are characterized by disbelief and the need to repudiate his report. For instance, based on an assessment of Garner’s description of his engagement with ME/CFS treatments, a user named Dr. Richard Ramyar points out that Garner was most likely not suffering from ME/CFS: “While the science is incomplete, and widely underfunded, the repeated corroboration of related findings does lead to a consistent menu of questions and research avenues. Which are apparently not compatible with your account being one of ME/CFS” (Garner, 2021). Another user, probably a sufferer from ME/CFS, notes: “[COVID] Longhauers seem to show a peak in recovery at around 9 months, I’m glad Dr Garner is in the group but it is important to differentiate his experience from true ME/CFS” (Garner, 2021). A further user, likely a long COVID patient, complains: “It’s a great shame that Prof Garner, who was a beacon in the early days of covid last Spring, when no-one of any note was validating the experience of ‘long covid’ sufferers, has chosen now to suggest it can all be cured by positive thinking” (Garner, 2021). A long COVID caregiver comments that s/he is “certainly surprised to hear how easily sufferers can get over this dreaded disease. [...] I’m curious if you had damage to your organs like so many Long Covid patients have discovered. How would you advise those Long Covid patients who have damage to their heart, kidneys, lungs and brains or those with blood clots throughout their body?” (Garner, 2021).

The comments on the blog entry cast Garner’s experiences into an indeterminate or overlapping space between long COVID and ME/CFS. They reveal the ambiguity of the clinical identities, which can be explained by the lack of specificity and the unknown pathophysiological causes in both cases. Although both illnesses have been associated with similar epidemic/pandemic contexts and with viral infections, and exhibit clinical similarities, the question remains how long COVID was able to become a disease concept widely accepted amongst medical scientists and public health officials, compared to ME/CFS, on the basis of patient online advocacy. Aronowitz has suggested for the case of ME/CFS that “social factors” underlying its acceptance, “its spread among select populations, its declining interest for doctors, and the influence of its determined lay advocates have all contributed to the syndrome’s incidence and distribution, that is, its epidemiology” (1998: 37). Consequently, we need to look at how the underlying social factors in the case of long COVID have been made to contribute to its acceptance.

4. Mobilizing “subjective evidence” – co-producing the long COVID concept in the pandemic

Because of the similar clinical and social ambiguities of long COVID and ME/CFS, we need to ask why the former was able to achieve widespread recognition so quickly, compared to the latter with its decades of struggle. We argue that the online mobilization of subjective evidence for long COVID has enabled a rapid co-production of the illness as a matter of fact and concern, which included contributions by affected doctors and health care professionals to reform clinical practice. The general attention to COVID-19, and the fears of suffering from long term effects, has provided a favorable condition for co-producing the understanding of long COVID with its blurred clinical and sociological boundaries. The level of publicity and public sympathy it has received – especially among the media, policy makers, and many medical professionals – has contributed to creating an audience for the many different sufferers of long COVID, which ME/CFS patients (still) lack. Putting the spotlight on them and their subjective evidence allowed making a social illness identity as a matter of general concern, despite still lacking facts that lend it a thorough scientific basis. In the process, long COVID was clearly linked to the pandemic and COVID-19, however, in a way that does not classify it merely as a subset. Instead, the activism of long COVID patients succeeded in transforming the

condition from initially invisible to the public eye into a prominent feature of the coronavirus crisis.

Rabeharisoa and colleagues have introduced the concept of evidence-based activism in order to comprehend “modes of activism that focus on knowledge production” and the mobilization of knowledge “in the governance of health issues” (Rabeharisoa et al., 2014: 112). In evidence-based activism, the mobilization of experiential knowledge is understood as a reframing of “what is at stake”, leading to the destabilization of “existing understandings of conditions and problems and resulting in the identification of zones of ‘undone science’” (Rabeharisoa et al., 2014: 115). As a result, the possibilities of the Internet and social media mean that co-production can be seen to operate between what is known (or still unknown) about a disease and the issues that are at stake for those afflicted by an illness.

A significant success of long COVID patients, in contrast to those suffering from ME/CFS, was to frame what is at stake for them as a matter of the pandemic currently holding the globe in its grip, which was achieved by the unconventional naming. While long COVID satisfies the international WHO standards for brevity and neutrality in labelling emerging diseases, it deliberately departs from the recommended terms for time course: “the WHO suggests using ‘[a]cute, sub-acute, chronic, progressive, transient’. ‘Long’ does not impose an end (‘post’) nor implies chronicity; it does not divide the illness into COVID-19 and what comes after” (Perego and Callard, 2021: 6). The significance lies in the unwarranted evidential claims made by calling the illness either “post-COVID” or “chronic COVID-19”. The scientific evidence is neither clear on the duration nor the chronicity of long COVID (Gadebusch-Bondio and Münch, 2022); and patient experiences clearly suggest a continuation between (suspected) infection and lasting symptoms. Moreover, distinguishing the concept from alternative terminologies employing the “post-” or “chronic” prefixes also ensured that the condition would not simply be seen as a subset to the disease caused by the coronavirus.

Thus, long COVID patients have reframed how the pandemic itself is officially perceived. The historian Charles Rosenberg has argued that “a true epidemic [...] is highly visible”, featured in the visibility of the sick, the dying and dead (Rosenberg, 1992: 279). While this holds for the incidence and mortality numbers of victims of COVID-19, long COVID deals not with the acute, contagious infection, but with direct or no (longer) provable consequences of it. By sharing and collecting their different experiences of long-term effects online, patients have provided a resource to politically transform the pandemic from as concerned only with mortality to concerning both mortality and morbidity. In distinguishing their experience of (suspected) COVID-19 from the official statements on severity and mortality they have made visible to public actors dimensions of the disease that have not been informing the emergency public health actions. “What becomes clinically or sociologically visible often depends on multiple actors, tools, and media: to make something visible often requires political struggle and brings political consequences” (Callard, 2020b: 729).

Early in the pandemic, clinicians had already observed persisting symptoms in a large portion of patients who had overcome the acute COVID-19 phase. These early observations show the interest of clinicians in post-acute care needs of recovered patients. Carfi and colleagues remarked in this regard: “Clinicians and researchers have focused on the acute phase of COVID-19, but continued monitoring after discharge for long-lasting effects is needed” (Carfi et al., 2020: 605). However, their focus was initially only directed toward the group of survivors, i.e., people who had contracted acute COVID-19, received clinical care and, at best, were monitored after hospitalization. To co-produce long COVID as a morbidity concern in non-hospitalized patients of the ongoing pandemic, activists drew on different practices available to them through online possibilities. Given the urgent need for clinical knowledge, and the contested meaning of long COVID, they mobilized their subjective evidence to fill crucial gaps in the pandemic discourse. One practice was to simply quantify and characterize those non-hospitalized

patients with lasting-symptoms. Proponents feared that as “long as ‘long COVID’ is labelled anecdotal”, that is, not quantifiable in a scientific manner, it will remain difficult to take the illness seriously “and public communication will neglect it” (Alwan, 2020a: 170). Another practice concerns tapping the rich sources of subjective evidence, which have been extensively collected on social media platforms (e.g., Banda et al., 2020), or generating data on the condition by patient-led research (Patient-Led Research Collaborative, 2021).

This “engagement in knowledge-related activities” can be seen as a “multidimensional exploration” of the conditions that constitute the experience of illness, “whose definition is at stake over the process, and whose political implications proceed from this process rather than the other way around” (Rabeharisoa et al., 2014: 120, s. also Petersen et al., 2019: 4179). Through these social practices patient activists provide a knowledge basis on which to make visible the morbidity of a non-mild disease with an open time course and a variety of manifestations. Thereby long COVID patients have succeeded in identifying “zones of undone science”, which is evident in the large-scale funding programs issued for the study of long COVID as well as in the acknowledgement of its existence by governments. Today, research on long COVID is being generously supported by national agencies such as the National Institutes of Health in the USA, the National Institute of Health Research in the U.K., or the German Ministry for Education and Research (e.g., Subbaraman, 2021).

5. “From doctors as patients” – institutionalizing new clinical practices

The co-production of the concept of long COVID by patient advocates has also impacted the institutions of clinical medicine. A central demand of long COVID proponents is to establish “a clinical case definition of COVID-19, which does not solely rely on laboratory confirmation; and a sophisticated definition for recovery that accounts for relapsing illness” (Perego et al., 2020: 3). The large number and heterogeneity in the group of sufferers from long-term consequences of COVID-19 also includes numerous medical professionals and others working in the health sector. This sub-group plays a crucial role in the discussion because of their double position. Being experts contributing to clinical medicine, they could engage in a form of co-production that allowed them to discuss and critique the particular clinical approaches to COVID-19 and its long-term effects. On the basis of the notion of patient-centeredness that is central to long COVID, they have been able to move the role of subjective evidence within clinical COVID-19 medicine to the forefront.

In September 2020, a group of thirty-nine physicians, all themselves affected by long-term consequences, called for “persistent symptoms of Covid-19 to be treated with a scientific methodology without bias” (Alwan et al., 2020). In their appeal (“From doctors as patients: a manifesto for tackling persisting symptoms of covid-19”), the authors present themselves as advocates for all patients affected by “persistent symptoms of suspected or confirmed Covid-19” on the basis of, first, their shared experience, and then of medical competency and authority: “We write as a group of doctors affected by persisting symptoms [...]. We aim to share our insights from both a personal experience of the illness and our perspective as physicians” (Alwan et al., 2020). The four principal issues presented in the letter are: 1. Research and Surveillance – persistent symptoms of COVID-19 should be dealt with using a scientific methodology and without bias. People experiencing them should be counted; 2. Clinical services – services need to be timely, tailored to individuals’ presentations, and involve investigating and treating pathology, as well as the functional recovery of individuals; 3. Patient involvement – patients must be involved in the commissioning of clinical services and the design of research studies (“no decisions without me”); 4. Access to services – clinical services commissioned should not unfairly discriminate against those with negative tests and a clinical diagnosis should be adequate for accessing any appropriate services.

In a related case, a similarly constituted group of physicians – also

sufferers of long-term consequences – promptly published a critique of the first guidelines that were issued for the management of COVID-19 long-term effects. In a significant move, on October 5, 2020 – characteristic of the rapidness of developments in the coronavirus pandemic – the U.K.'s National Institute for Care and Health Excellence (NICE) announced its intention to quickly develop guidelines on the diagnosis and treatment of long COVID patients, to be published on December 18. On the day of their publication, a critique of the recommendations with the title “Long COVID guidelines need to reflect lived experience” was published in *The Lancet* by concerned clinicians (Gorna et al., 2020). In a programmatic paragraph at the start of the text, they describe their current situation, drawing, too, on the aspect of subjective suffering to lend legitimacy to their claims:

“We have lived experiences of long COVID, with a range of symptoms lasting for more than 6 months. Staff in the UK National Health Service (NHS) have been variously supportive or disbelieving of our ongoing, often worsening, symptoms. Before our illness we were fit, healthy, and working in demanding roles, including as doctors, nurses, and other health professionals. Our symptoms of acute COVID-19 included dyspnea, dry cough, fever, anosmia, and debilitating fatigue. Throughout 2020 we also experienced other symptoms and conditions, never experienced before our acute illness [...]; we all share difficulties accessing adequate health-care services [...]. We share these experiences with thousands of people we engage with in rapidly growing online support groups” (Gorna et al., 2020).

The disappointment in the face of the guidelines is great and brings to the fore their role as certified medical experts in the co-production of long COVID: The characterization of symptoms in their intermittent nature, and the associated consequences – when it comes to patients' clinical stays or discharges – are not considered accurate. Too much emphasis is put on self-management rather than on the actual clinical care of patients with lasting symptoms. Most importantly – and this is a central point in the critique – previous findings on pathology are not considered. In respect of the three main theories – namely, the persistence of the virus in immune-privileged sites, an aberrant immune response, and autoimmunity – rather than considering these, the guidelines overemphasize aspects of “self-management, psychological support, and rehabilitation”, impeding the provision of thorough physical assessments of patients as well as the psychological components. The lack of consideration of the apparent relapsing-remitting nature of the condition exacerbates the risk that patients might be discharged from clinics during a time of remittance of symptoms but before resolution of the condition. It might have been better to wait for the upcoming WHO decision to change the nomenclature. However, it appears that WHO has already decided to change the designation, and on Feb 8, 2021, it published recommendations for systematically gathering clinical information on “Post-Covid-Conditions”.

The lack of participation and inclusion of people “with lived experience” points to the tensions that characterize the initial perception of the pandemic in the medical system and after the establishment of long COVID as a recognized condition. Critics accused the guideline authors of employing a new designation, which has profound implications. Instead of the patient-made term “long COVID”, they introduce “post-covid syndrome”. However, this term contains an unfounded non-evidence-based assumption about the pathology of COVID-19. It suggests that the syndrome manifests itself only after disease and recovery has to some degree already occurred. It therefore tries to force the deliberate openness of temporal course of long COVID into biomedical “codes”, similar to medical professionals who opt for adopting conventional classifications like “post-covid syndrome”, “post-acute COVID-19”, or “chronic COVID-19” and call for “an appropriate medical terminology” to standardize the experiences of “Long-COVID and COVID Long-Haulers” (Baig, 2020).

The problem of the lack of clinical evidence for doctors, who

themselves are affected, is crucial for co-producing long COVID in the clinic. In this regard, the experience of Jeffrey Siegelman, emergency medicine physician, is exemplary. In a concise paper published in *JAMA* in November 2020, he emphasizes how he experienced the problem of a lack of objective data associated with persistent, severe symptoms of COVID-19. All examinations – tests, imaging, lab results – went well and yielded “normal values”, but a constellation of troublesome symptoms such as fever, headache, dizziness, palpitations, tachycardia, and others persisted. The crucial finding for the physician was that a myriad of unpleasant, real symptoms that are unimaginable and invisible from the outside are experienced as distressing and limiting from the inner perspective: “There is a marked difference between tests being within normal limits and a patient being well” (Siegelman, 2020: 2031). Siegelman describes the anxiety he felt at each new examination yielding negative results and an unchanged condition. The lack of clinical evidence finally forced him to adopt a new attitude, focusing on the symptoms rather than on the examination results. The central insight of this experience is that, with all the uncertainties of an illness that have not yet been fully explored, a “symptom-based approach” is the only viable way forward because it allows the affected person to be treated with respect and understanding on the one hand, and on the other, allows them to be treated fairly even in the face of their inability to work (Siegelman, 2020: 2032).

Finally, we would like to mention a development within the challenges of dealing with long-term consequences in the face of insufficient clinical evidence, which exemplifies an institutional form of clinical action and co-production between doctors and patients. It is a paper on the “Management of post-acute covid-19 in primary care” published in August 2020 (Greenhalgh et al., 2020). It shows how the idea of patient-centeredness and subjective evidence can function to reform the conventional format in which medical research is published and create clinical responses to COVID-19. In its design, the paper represents a new genre of medical publication. It is an evidence- and experience-based handout to facilitate the management of “post-acute COVID-19” patients in primary care. The information laid out addresses the process of assessment and primary care of patients with persistent symptoms (Greenhalgh et al., 2020). On the very first page of the text, where Trisha Greenhalgh and coauthors give their definition of “post-acute COVID-19”, there is an account about a 40-year-old, originally healthy patient, which serves as subjective evidence. Moreover, at the end, the text also explains how the article was conceived – as a pragmatic contribution that came about when no definitive evidence on the subject was available. Therefore, a pragmatic method was adopted, based on studies of SARS and MERS; various sources and media were used in addition to clinical experience. One patient authored the report published in the article. Four other laypersons with experience of COVID-19 (either direct or indirect, e.g., through ill relatives) critically read the text, and it was heavily modified – according to their feedback – before submission. Peer reviewers also involved patients with “post-acute COVID-19” in the review process. The largest corrective processes that occurred in response to patient-provided critiques were related to the management of fatigue. This is an example of successful participation in the development of clinical recommendations and in the design of publications based on the subjective evidence of long-term effects.

6. Conclusion

As we have seen, the digital interconnectedness of sufferers of long-term consequences during the pandemic allowed them to exchange their experiences quickly in a heterogeneous and global community. Although their experiences vary, these patients became a movement out of the collective gathering of subjective evidence of COVID-19 that fell outside of the official classifications of severity and time course, which they called long COVID. As we argued, the long COVID movement acted unlike other forms of patient online self-advocacy, since it succeeded in introducing a patient-made term as a widely accepted disease concept.

In its clinical and conceptual identity, long COVID is marked by fuzzy boundaries, just like contested illnesses such as ME/CFS. Not only does this make it necessary for proponents to keep the social identity of long COVID distinct, in order to avoid crosslinking to illness subsets or mistaken diagnoses. The blurred boundary between its clinical and sociological understandings also enabled long COVID to become widely accepted as a serious and debilitating illness, despite the lack of a thorough scientific basis.

As we have demonstrated, the long COVID movement was able to fill crucial knowledge gaps in public health discourses. Thrown into crisis by the ongoing coronavirus pandemic and in urgent need of knowledge about COVID-19 and long COVID to ground its actions, health care systems were more open to acknowledging and learning from patient experience. By mobilizing subjective evidence in online fora, the activism of long COVID patients transformed the illness from initially invisible to the public eye into a central feature of the pandemic. In many different media, actors began to co-produce the knowledge about the illness between what was known about COVID-19 and what was at stake for patients, namely the morbidity of a range of long-lasting and recurring symptoms as well as strategies for dealing with these in clinical medicine. Thereby they were able to define a disease concept beyond the conventional channels of medicine. In this respect, the naming of long COVID as distinguished from alternative terminologies employing the “post-” or “chronic” prefixes, also ensured that the condition would not simply be seen as a subset to the coronavirus disease, which secured for it a strong social legitimacy status, as compared to ME/CFS, for instance. For those clinicians who were also sufferers of long COVID, and additionally adhered to the patient-made term, it allowed them to devise new forms of medical action to address the pressing issue of long-term consequences, which circumvented the requirement of scientific evidence.

Our paper has shown that in the digital age the co-production of knowledge can be understood in broad terms as the interconnectedness between what is known (or still unknown) about a disease and the issues that are at stake for those afflicted by an illness as the complex entanglement of matters of fact and matters of concern. However, further investigations will have to show how this form of co-production is impacting existing medical institutions. For instance, Dumit has pointed out how diagnosis is crucial in the case of contested illnesses, since it grants sufferers access to the medical system through “social recognition of their very suffering” (Dumit, 2006: 578). Both long COVID and ME/CFS lack clear clinical evidence to enable a thorough diagnosis but differ crucially with regard to acceptance and recognition. While in the case of ME/CFS patients still struggle for recognition, long COVID was successfully established as a feature of the current pandemic and thereby receives the attention of doctors, scientists, and politicians. How stable this acceptance is in the long term remains to be seen, though, since this “success” was not due to the recognition of the disease’s specificity, which would also enable a clear diagnosis. Rather, the situation of the pandemic did not allow the opportunity for people to rely on biomedical confirmation to consider themselves as part of the patient group. As a result, patients could provide their subjective evidence to the co-production of knowledge about long COVID only on the suspicion of having contracted the disease, which makes it difficult to draw clear boundaries to other illnesses (as the case of Garner shows).

This points to two possible consequences: first, in the digital age and in the context of a pandemic, the political power of patients can make the requirement of diagnosis to establish recognition for a newly emerging illness virtually obsolete by generating broader interest in the condition merely through the buzz of online resources (Bensaude Vincent, 2014; Roth and Bruni, 2021). However, this means that although the subjective evidence base was sufficient to establish the disease publicly, it does not by the same token suspend the requirements of clinical evidence. Second, and in relation to this point, online patient advocacy has demonstrated the potential to change perceptions of disease states. It has also shown that the supposedly insurmountable

asymmetries between medical expertise on the one hand and affectedness on the other can be overcome productively and creatively. Not only have new collaborative study designs been realized on this basis (Greenhalgh et al., 2020). The documentation of symptoms initiated by the WHO is also directed at physicians as well as patients (World Health Organization, 2021b). Both are addressed as an equal source of data and information on the basis of which new insights are to be gained.

Credit author statement

Phillip H. Roth: Conceptualization; Writing – original draft preparation, Mariacarla Gadebusch Bondio: Validation; Writing – review & editing.

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