

Long Covid at the crossroads: Comparisons and lessons from the treatment of patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

Journal of Health Psychology
1–15

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DOI: 10.1177/13591053221084494

journals.sagepub.com/home/hpq



Joanne Hunt¹ , Charlotte Blease² 
and Keith J Geraghty³ 

Abstract

Whilst parallels have been drawn between Long Covid and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), there is a well-documented history of negative stereotyping and marginalisation of patients with ME/CFS. A socio-politically oriented comparison of scientific, clinical and societal responses to Long Covid and ME/CFS is thus important to prevent similar harms arising among Long Covid patients. We identify four reasons for injustices in the treatment of ME/CFS patients, and discuss the risk of Long Covid following a similar trajectory. We conclude with policy and practice recommendations to help prevent such injustices arising again, including consideration of critical reflexivity in medical education.

Keywords

chronic fatigue syndrome, myalgic encephalomyelitis, health care, health inequities, Long Covid

Introduction

Within the first few months of the Covid-19 pandemic, increasing recognition of protracted signs and symptoms in some patients led to the emergence of a new condition termed ‘Long Covid’ (Callard and Perego, 2021). This term describes symptoms persisting 4 weeks or more post-infection with SARS-CoV-2 which cannot be explained by an alternative diagnosis (NICE, 2020). Comparisons and contrasts were quickly drawn within the chronic illness and scientific community to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), not infrequently triggered by a viral infection and presenting with strikingly similar symptoms (Komaroff and Bateman,

2020). Since then, a vigorous debate has emerged over whether and how the two conditions are related and to what extent research, clinical practice and patient advocacy might benefit or be hindered from comparative evaluation of the two conditions (Komaroff and Bateman, 2020; Perego et al., 2020).

¹University of Derby, UK

²Harvard Medical School, USA

³University of Manchester, UK

Corresponding author:

Joanne Hunt, College of Health, Psychology and Social Care, University of Derby, Kedleston Road, Derby DE22 1GB, UK.

Email: joannehunt@outlook.com

A considerable body of literature shows that patients with ME/CFS are treated negatively by healthcare professionals (HCPs) who question the existence of ME/CFS as a disease and/or lack understanding of the illness (Anderson et al., 2012; Blease et al., 2017). ME/CFS is often described as a ‘contested illness’, one that has given rise to considerable tension between patients and HCPs. Because of the similarities between ME/CFS and Long Covid, it is valuable to compare mainstream clinical, scientific and societal positioning of, and responses to, ME/CFS and Long Covid, with a view to learning from mistakes made and opportunities missed in the treatment of, and research into, ME/CFS. Our goal, drawing on historical evidence and current context largely in the UK, is to offer a constructive evaluation so lessons might be learned to benefit both patient groups.

The paper is structured as follows. After a brief overview of Long Covid and ME/CFS, we consider Long Covid through the lens of patient experiences, finding that currently there appears to be greater mainstream legitimisation of Long Covid relative to ME/CFS. Following this, we examine the roots of unjust treatment of ME/CFS patients and offer four reasons to explain greater mainstream legitimisation of Long Covid. We emphasise that the greater aetiological certainty around Long Covid relative to ME/CFS, alongside prevalence and dynamics associated with a public health crisis, may help ensure appropriate framing and ethical treatment of Long Covid patients. However, we also note that socio-political dimensions of health and illness have played a role in the psychologisation of ME/CFS, and we caution that Long Covid may be susceptible to a parallel process of politicisation. We argue that Long Covid can currently be conceptualised as sitting at a crossroads and that learning lessons from mistakes made with ME/CFS could ensure that Long Covid does not follow a similar path. Equally, vice-versa, the trajectory of ME/CFS could now be influenced by the degree to which learnings from Long Covid, and measures taken to accommodate this patient group, might be applied to ME/CFS. We close by offering

recommendations for how the scientific and clinical communities and policy makers might reduce the risk of injustices in the treatment of patients with Long Covid and ME/CFS.

Background: Long Covid and ME/CFS

The term Long Covid was first used by social scientist Elisa Perego in May 2020 on social media to describe her experience of protracted symptoms subsequent to infection with SARS-CoV-2 (Perego, 2020). Long Covid is a capacious term encompassing all patients with protracted symptoms of 4 weeks or more, with recognition that sub-groups or different disease phenotypes exist and that some patients may fit more than one sub-group (Maxwell, 2020; Perego et al., 2020). There exists a burgeoning body of knowledge relating to symptomatology and pathophysiology of Long Covid, both independently and in comparison with ME/CFS (Altmann and Boyton, 2020; Davis et al., 2021; Komaroff and Lipkin, 2021; Proal and VanElzakker, 2021; Wong and Weitzer, 2021). Whilst we will not detail the findings here, it is important to note that the wide-ranging symptoms of Long Covid are, with a few exceptions, strikingly similar to ME/CFS (Davis et al., 2021; Wong and Weitzer, 2021). For example, the prominence of post-exertional malaise in both Long Covid and ME/CFS (Proal and VanElzakker, 2021) suggests that rehabilitative strategies might usefully draw on research and clinical experience across both conditions, to the benefit of both patient groups.

Prevalence and incidence of Long Covid are uncertain, in part owing to different definitions in data gathering. However, data indicate that at least 10% of those infected with SARS-CoV-2 experience at least one symptom for 12 weeks or longer; with a reported incidence (December 2020) in the UK of 301,000 people with symptoms lasting between 5 and 12 weeks; and a reported incidence (March 2021) of 1.1 million people with symptoms persisting past 4 weeks (Maxwell and Poole, 2021; ONS, 2021). In the case of ME/CFS, an estimated 135,000–270,000

people are affected in the UK (0.2%–0.4% of the UK population), although many people with ME/CFS may remain undiagnosed (CFS/ME Working Group, 2002).

Whilst Long Covid is in its infancy, ME/CFS has a long history, having been recognised as a disease of the nervous system by the World Health Organisation in 1969 (under the nomenclature ME) before the term ‘chronic fatigue syndrome’ gained prominence from the 1980s onwards (Holmes et al., 1988). This change of terminology emphasised subjective symptoms as opposed to biological markers and a biopsychosocial, as opposed to biomedical, conceptualisation of ME/CFS emerged within UK healthcare. The biopsychosocial model of ME/CFS places greater emphasis on psychosocial factors versus biological factors, whereby the illness is considered ‘medically unexplained’ (Deary et al., 2007). However, critics have maintained that biological findings are downplayed (Geraghty and Blease, 2019; Geraghty et al., 2019).

Mainstream responses to patients with Long Covid

In this section, we compare evidence pertaining to mainstream scientific, clinical and societal responses to patients with Long Covid. Since a considerable body of empirical literature has described evidence to show that patients with ME/CFS are often unfairly stereotyped and discredited by HCPs we will not review the findings here (see: Blease and Geraghty, 2018; Blease et al., 2017). In summary: while we note that some doctors may be sympathetic to patients with ME/CFS, many studies have captured evidence of highly prevalent negative attitudes among HCPs and trainees (Raine et al., 2004; Stenhoff et al., 2015). Consistent with these findings, further research demonstrates that people with ME/CFS report stigmatising responses in healthcare encounters, perceiving their moral character to be questioned and their concerns to be minimised (Anderson et al., 2012; Dickson et al., 2007). Such negative identity prejudice has also been reflected historically to some

extent in the UK press (Liddle, 2019; McKie, 2011), though it should be noted that in recent years some press coverage has been more sympathetic (Ryan, 2019). Some of this positive framing may be due to the emergence of Long Covid and a newfound appreciation of post-infectious syndromes (O’Neill, 2020).

Is there evidence that patients with Long Covid are subject to similar negative stereotyping? Early on in the pandemic some evidence indicated that many Long Covid patients reported healthcare experiences strikingly similar to people with ME/CFS, including HCP disbelief and psychologisation of their symptoms (Ladds et al., 2020; Maxwell, 2020). This reflects social media narratives (Lokugamage et al., 2020c) and media reports (The Telegraph, 2020). It is important to caveat that some of these reports of negative experiences were documented before Long Covid gained ground as a clinical entity. Of particular note are patient reports of HCPs attributing symptoms to anxiety and offering psychotropic medication (Kingstone et al., 2020; Ladds et al., 2020; Maxwell, 2020). However, the same studies demonstrate variation in responses from HCPs, with some participants noting HCP belief, willingness to acknowledge uncertainty and validation of patient testimony. This suggests that a stumbling block for some HCPs might be a lack of understanding around Long Covid, as opposed to not believing patients. Similarly, unsatisfactory healthcare for people with Long Covid as reported in the media often appears to derive from unpreparedness of health services as opposed to HCP disbelief (Jennings, 2020; Thomas, 2021). Whilst some Long Covid patients report having investigations refused, others report multiple investigations for other diseases (Maxwell, 2020); this again suggests that many HCPs are taking patients seriously, even if they are uncertain about how Long Covid might be treated. In other words, HCPs appear willing to revise their ideas about Long Covid in the face of emerging evidence. Certainly, there is no indication of negative identity prejudice in Long Covid with regard to collective moral character and personal qualities as evidenced in the case of ME/CFS, where the latter has been framed by some HCPs as a

'malingerers' last resort' (Chew-Graham et al., 2009: 4) and 'a certain personality trait that is chronic fatigue syndrome waiting to happen' (Raine et al., 2004: 2).

A more recent UK qualitative study (Razai et al., 2021) explored the experiences of 70 people with Long Covid vis-à-vis their experiences of symptoms, primary care services and their recommendations for service improvement. Whilst feelings of uncertainty and isolation were widely reported, it is notable that experiences of HCP disbelief and/or dismissal of patient testimony were not reported. Participants emphasised a need for regular follow-ups and on-going support, but there was no mention of a need for more empathetic or accepting responses from HCPs. It should however be noted that whilst the study's semi-structured topic guide included multiple questions around GP services, it did not include any specific questions on HCP (dis)belief or patient relationships with their GP. It is also noteworthy that the findings of this study – and thus patient experience – changed healthcare practice across the two GP surgeries involved. Razai et al. report how the GP practices involved in the study now offer Long Covid patients on-site social prescribing with signposting to community support services and on-going clinical support, whilst urgent consultations with on-going support are offered in the case of acute Covid symptoms. This willingness to change practice in response to research and patient experience in the case of Long Covid stands in contrast to ME/CFS, where even a change of direction within NICE guidelines (NICE, 2021) has failed to change the attitudes of some within the clinical and scientific community (Kmietowicz, 2021; Royal College of Physicians, 2021).

HCP acceptance and belief of patient testimony in the case of Long Covid, combined with recognition of clinical and scientific uncertainty, have largely been reflected by mainstream scientific and social structures. Both the UK and international press have produced numerous articles emphasising the severity and range of symptoms, alongside the detrimental impact on patients' lives, many of which feature or are written by medical doctors (BBC, 2020a; Herman, 2020; Mitchell, 2020). Scientific legitimisation of

patient narrative has been offered by, amongst others, the World Health Organisation which invited Long Covid patients and medical doctors to discuss concerns (Lokugamage et al., 2020b). The National Institute for Health Research (NIHR) reviews of evidence pertaining to Long Covid (Maxwell, 2020; Maxwell and Poole, 2021), both emphasise the need to listen to the lived experience of patients as experts by experience. Equally, well-established and reputable medical journals have published pieces, authored by people with Long Covid (many of whom are medical doctors) calling for patient testimonies to be heeded (Gorna et al., 2021; Lokugamage et al., 2020c). Finally, the fact that the patient-led term Long Covid has been adopted by scientific institutions, journals, scientists, academics and medical doctors (Nurek et al., 2021; Perego et al., 2020), albeit apparently more so in the UK than in other countries (Canino and Gainty, 2021), indicates some degree of recognition and acceptance of the patient narrative. This stands in contrast to ME/CFS, where the term 'chronic fatigue syndrome' (CFS) persists despite many patients finding this term reductive and misleading (Nicholson et al., 2016), whilst some research indicates that HCPs may consider the label CFS as a less serious diagnosis relative to ME (Jason et al., 2002).

Long Covid advocacy occupies a different space in mainstream social and scientific discourse compared with ME/CFS. Notably, the term activism has been largely used in Long Covid to commend the efforts of patient-led advocacy (Lokugamage et al., 2020b), contrasting starkly with mainstream responses to ME/CFS patient activism (Blease and Geraghty, 2018). Acceptance of the value of patients' lived experience has extended to a widespread recognition that patients should be involved in design of research (Alwan et al., 2020), notably as 'equal partners' (Maxwell and Poole, 2021). Of note is an acknowledgement that Long Covid patient-researchers can offer added value to research (Taylor et al., 2021); in the case of ME/CFS and to some extent more broadly pre-pandemic, the mainstream position on patient-researchers has historically been more cautious (David et al., 1988; Greenhalgh, 2019). In the

case of Long Covid, we see strategies aimed at including, rather than excluding, patient voices.

Such inclusivity appears to extend to policy development where doctors with Long Covid have recognised that existing explanatory frameworks require revision to accommodate people with Long Covid (Alwan et al., 2020; Lokugamage et al., 2020c). The need to take morbidity as seriously as mortality (which likely requires the development of a coherent chronic care model), the need for multi-disciplinary care services and the need to involve patients in clinical service commissioning have been strongly voiced by Long Covid advocates and discussed in medical journals and the UK press (Alwan et al., 2020; Herman, 2020). Further, medical and social discourse arguably underpinning inadequate chronic healthcare provision, such as the false dichotomy underpinned by the ‘recover or die’ narrative, are also being challenged (Alwan et al., 2020). Finally, rapid evaluation of alternative healthcare delivery models to meet the needs of Long Covid patients has been recommended by the NIHR (Maxwell and Poole, 2021).

In summary: we cautiously conclude, based on existing evidence, that patients with Long Covid appear to have sustained lower levels of negative stereotyping and discrediting relative to ME/CFS. There is also evidence that patients with Long Covid are more likely to have been included in medical knowledge formation activities. Although it may yet be too early to determine whether patients with Long Covid are, or will be, subject to similar discrimination in the longer term we examine the reasons as to why – despite similar symptomology – this emergent divergence appears to have arisen and what lessons we might learn.

Explaining differences in the treatment of patients with Long Covid and ME/CFS

Prevalence

We propose that the current and projected prevalence of Long Covid, as a chronic illness arising from a pandemic, is a considerable buffer to

negative patient stereotyping and provides a critical stimulus for taking the condition seriously. Owing to the scale of Covid-19 as a global pandemic, we can speak of a ‘tipping point’ of public and medical awareness about Long Covid, not experienced by ME/CFS patients. Partly because of the sheer numbers involved, Long Covid has affected numerous individuals across all walks of life, including those who are prominent in medicine, academia, politics and the media (Adams, 2020; Alwan, 2020; Herman, 2020). The social power of some of these high-profile Long Covid patients and advocates has facilitated greater legitimacy attributed to Long Covid as an illness and has raised the collective credibility of Long Covid patients as a group. For example, as previously alluded to, a published ‘manifesto’ authored by 39 doctors as patients (Alwan et al., 2020) made an epistemically weighty appeal for better recognition and treatment of Long Covid. Similarly, and more recently, a clinical toolkit comprising 35 recommendations for recognition, diagnosis and management of Long Covid was developed in the UK by 33 clinicians, 29 of whom have lived experience of Long Covid, termed ‘expert clinician-patients’ (Nurek et al., 2021).

Perhaps less evidently but importantly, the prevalence and public health implications of Covid-19 have been cited as a reason for taking Long Covid seriously (Perego et al., 2020). For example, it has been suggested that appreciating the potential long-term consequences of infection with Covid-19 might assist in encouraging the general public’s compliance with government public health directives (YouTube, 2021) and this can be observed to some extent in UK government communications (DHSC, 2020). The urgent need to understand covid-19 and, by extension, Long Covid, is perhaps reflected in the amount of research published in this field. A PubMed search in November 2021 of papers on Long Covid (search string ‘Long Covid or post Covid or chronic Covid or Post-acute Covid-19 syndrome or post covid-19 condition’) within the previous 12 months returned 13,287 papers, with ‘Sars-cov-2 or covid-19 or

coronavirus' returning 122,429 papers. The same search on 'chronic fatigue syndrome or myalgic encephalomyelitis or myalgic encephalopathy' returned 611 papers. In fact, according to PubMed, more papers have been published in the last year on Long Covid than have been published on ME/CFS in the last 70 years combined (9958 papers since 1950). It seems likely that the volume of findings on Long Covid reflects the prevalence of the illness, and global urgency to address it.

Aetiology of illness

A second reason for the contrasting experiences between the two patient groups is the more salient grasp of illness aetiology. The proximal cause of Long Covid appears self-evident – namely, the SARS-CoV-2 virus. Even while the vulnerabilities to the illness are still the subject of early investigations, and poorly understood, this stands in marked contrast to ME/CFS. In what might be described as a vacuum of medical understanding, the influence of the biopsychosocial model of ME/CFS (Sharpe et al., 1997) unduly de-emphasised biological explanations and more strongly emphasised a range of hypothesised psychological and social causes for the illness. Some of the moralising and stigmatising attitudes towards persons with ME/CFS appear to originate, or at least to be exacerbated by, (bio)psychosocial theorising. For example, ME/CFS has been conceptualised as a 'meme', a cultural phenomenon, a possible way of avoiding personal responsibility or a form of somatisation with secondary gains (Huibers and Wessely, 2006; Stanley et al., 2002). Clearly, such ideas around aetiological factors may increase negative identity prejudice towards ME/CFS patients and patient advocacy groups. The extent to which the narrative of psychosocial aetiology in ME/CFS has become engrained within the clinical, scientific and social imaginary is arguably reflected in the resistance of certain actors and groups to the recently published NICE guidelines on the diagnosis and management of ME/CFS, as previously noted.

It is worth noting that the biopsychosocial healthcare narrative of aberrant illness beliefs and fear-avoidance, as promulgated in the case of ME/CFS and medically unexplained symptoms (Deary et al., 2007; Sharpe et al., 1997) might sit uncomfortably with Long Covid given the high numbers of HCPs with Long Covid. It has also been suggested that mental health stigma might discourage medical doctors from seeking help for psychological issues (Taylor et al., 2021). It might thus be speculated that a collective desire among HCPs with Long Covid to maintain respect and secure support from colleagues may lead to a foregrounding of the biological underpinnings of this condition (BMA, 2020; Herman, 2020) which in turn may buffer undue psychologisation and epistemically unjust framing of Long Covid. However, whilst the proximal cause of Long Covid is ostensibly self-evident, lack of community testing early on in the pandemic, together with the possibility of false negatives (Alwan et al., 2020), introduce elements of causal uncertainty in some cases of Long Covid that may leave the condition (or at least subgroups thereof) open to unjustified psychologisation in a way that echoes ME/CFS (Devine, 2021). In addition, lack of understanding of underlying vulnerabilities for Long Covid might also engender suspicion about illness legitimacy on a case-by-case basis.

Biological markers of symptoms

Patients with Long Covid and ME/CFS experience many symptoms that are subjective in nature and lack 'objective' diagnostic biomarkers. On the other hand, as previously noted, some people with Long Covid have organ impairment that can be objectively diagnosed. Such objective findings may have contributed to recommendations of full investigations for Long Covid patients, notably by doctors with Long Covid (Lokugamage et al., 2020a; Nurek et al., 2021). Greater openness to consider and search for biological markers of Long Covid in clinical practice, at least from some HCPs, is reflected in research where large portions of public funding have been allotted to research

foregrounding a biomedical understanding of Long Covid. For example, the NIHR announced a £18.5 million investment in February 2021, followed by a £19.6 million in July 2021, in predominantly biomedical research seeking to better understand Long Covid (NIHR, 2021a, 2021b). Such openness to ‘not knowing, but willing to find out’ can be observed in increased recognition, in published literature and in the media, of scientific uncertainty (BBC, 2020b; Koffman et al., 2020; Rutter et al., 2020). It is thus feasible that the scale of the pandemic and the unpreparedness of clinical and scientific structures have enforced a form of epistemic humility.

In the case of ME/CFS, greater medical uncertainty and emphasis on biopsychosocial theorising is accompanied by recommendations that clinicians limit biomedical investigations (Sharpe et al., 1997) on grounds that this would risk colluding with purported aberrant illness beliefs (Stanley et al., 2002), despite cases of patient harm from under-investigation (Gilje et al., 2008) and concerning misdiagnosis rates (Newton et al., 2010). Such focus on psychosocial factors extends to public funding of research; prior to June 2020, when the NIHR and Medical Research Council (MRC) announced £3.2 million funding for DecodeME, the NIHR had never funded biomedical research in ME/CFS.

Despite suggestion of less medical uncertainty, or greater openness to uncertainty, in Long Covid relative to ME/CFS, there are also indications that Long Covid may be subject to similar attempts at psychosocial hegemony as have been evidenced in ME/CFS (Garner, 2021; Miller et al., 2021).

Socio-political dimensions of illness

The psychologisation of ME/CFS might be traced to, or be understood as being reinforced by, the political, professional and corporate interests of a complex of socially powerful agents and structures. Whilst the biopsychosocial model in healthcare literature and discourse is largely associated with Engel (1977), it is

often maintained that the model as it is applied to chronic illness and disability may have been motivated on economic grounds, notably in the context of UK welfare reform, and driven by associations between the UK government, certain academics, and the private disability insurance industry (Rutherford, 2007; Shakespeare et al., 2017). Health conditions that can be positioned as predominantly psychosocial in nature, lacking objective biomarkers and allegedly receptive to psychosocial interventions, may be subject to welfare and disability insurance exemptions, cutting state expenditure and increasing private profits (Rutherford, 2007). In the UK, some psychiatrists who are strong proponents of a psychosocial conceptualisation of ME/CFS and developers of rehabilitative interventions such as cognitive behavioural therapy and graded exercise therapy, have also been involved in both government advisory positions and disability insurance consultancy (Select Committee on Health, 2007). Further evidence of potential conflicts of interest in the UK is the establishment of a Centre for Psychosocial and Disability Research at Cardiff University, sponsored for some time by Unum, with a former medical advisor to the Department of Work and Pensions (DWP) as director, which produced papers drawing on the work of prominent UK psychiatrists favouring a biopsychosocial understanding of ME/CFS (Waddell and Aylward, 2005, 2010). Some of the Cardiff centre’s papers, commissioned by the DWP, went on to form the intellectual framework for further welfare reforms and it was envisaged that the work of the centre would also significantly change medical practice in the UK (Rutherford, 2007). In fact, UK welfare reform and disability policy appears to have been largely derived from biopsychosocial literature on ME/CFS as an analogue of so-called ‘medically unexplained symptoms’ (Faulkner, 2016; Rutherford, 2007; Waddell and Aylward, 2010).

Although our analysis has focussed largely upon the UK, it is important to locate the above discussion within a broader global context of state policies of retrenchment across health and welfare sectors. That is, disability scholars and

disabled activists have argued that successive welfare reforms in the UK and beyond are associated with a neoliberal capitalist agenda to prioritise market forces and the interests of private corporations over respect for human rights, in part via a shrinking of the welfare state and creation of opportunities for private profit within the welfare arena (Clifford, 2020; Stewart, 2016). Such global structural adjustment programmes preceded, but were accelerated by, the 2008 global financial crisis and subsequent austerity measures (Clifford, 2020; Sakellariou and Rotarou, 2017). Neoliberalism extends beyond an economic policy model in constituting a biopolitical ideology that underlines personal responsibility in matters of health and broader ‘success’, whilst othering marginalised persons for creating their own misfortune (see: Hughes, 2015; Sakellariou and Rotarou, 2017). Such ideology can arguably be discerned in cases where psychologising narratives around Long Covid have arisen (see: Garner, 2021). It has been argued that disabled and chronically ill people have historically been among the most affected by neoliberal retrenchment policies (Hughes, 2015; Sakellariou and Rotarou, 2017), carrying potential implications for people with Long Covid who fail to ‘recover’ as per mainstream society’s expectations.

To date, there are few indications as to whether Long Covid will be subject the same politicisation as ME/CFS. It is, however, noteworthy that some influential actors in the politicisation of ME/CFS are involved in the emergent clinical conceptualisation and management of Long Covid (Sharpe, 2021; Willis and Chalder, 2021). Further, the potential economic implications of a tidal wave of Long Covid chronic illness and disability are now becoming apparent (Hansard, 2021), raising questions about how this will be addressed in the long-term. Some Long Covid advocates have for example raised concerns regarding a possible political impetus to downplay the seriousness of Long Covid to prioritise an expedient ‘return to normal’ for the sake of the economy (Perego et al., 2020), and the same impetus might be speculated with a view to reducing welfare spending. It could thus be argued that Long Covid is susceptible to

treating a path that is similar to ME/CFS. On the other hand, social media has a powerful influence in the socio-political domain and has galvanised Long Covid advocacy (Callard and Perego, 2021), facilitating co-ordinated responses to epistemic and social injustices and platforming patient experience in a way that was not possible for much of the history of ME/CFS, prior to digital social networking.

Long Covid at the crossroads: Recommendations for practice and policy

In terms of its trajectory as a clinical entity, Long Covid can be conceptualised as sitting at a crossroads, and the same might be said of ME/CFS. Clinical and scientific communities can learn from mistakes made with ME/CFS and can take an approach to Long Covid which is more cognisant and inclusive of the needs of both Long Covid and ME/CFS (and other ‘contested’ illness) patients.

Firstly, research, policy development and practice for Long Covid can and should draw from the body of knowledge that exists in ME/CFS, including the lived experience of ME/CFS patients. This knowledge base suggests caution around blanket recommendations for graded exercise therapies. To date, there has been notable resistance from certain mainstream (UK) agents and structures towards drawing on findings in ME/CFS when developing policies towards Long Covid (ME Association, 2020a, 2020b). On the other hand, expert-clinician-patient led guidelines for Long Covid (Nurek et al., 2021) emphasise the importance of pacing, that is, remaining within one’s energy envelope, suggesting that lessons from the past (with ME/CFS) are being learnt. Within the field of ME/CFS and more broadly ‘medically unexplained symptoms’, some researchers have proposed alternatives to the ME/CFS biopsychosocial model that are more patient-centred and humanistic (Geraghty and Blease, 2019) rather than a one-size-fits all model; such approaches may hold utility in conceptualising and clinically managing Long Covid.

Secondly, whilst understanding of ME/CFS can inform Long Covid, the reverse can also apply. Strategies of inclusion observed in Long Covid, including patient-led research and involving patients in the commissioning of services, should be extended to ME/CFS. Broader structural changes to the health system in terms of policy, provision and discourse that are being discussed in the case of Long Covid should also accommodate other patients groups. Recommendations include the development of biomedically-informed multi-disciplinary clinics, alongside broader disruption of narratives within healthcare (e.g. 'recover or die') which construct and reinforce ableist policy and practice. Whilst it is important to acknowledge Long Covid as a clinical entity separate to other virally induced conditions, it is equally important to avoid creating a form of 'Long Covid exceptionalism' (Khan, 2021), whereby one diagnosis is positioned as more 'complex' or 'serious' than others (BMA, 2020; Herman, 2020).

Thirdly, medical education needs to reflect the needs and narratives of patients with illnesses who lack diagnostic biomarkers in a way that is epistemically just (Blease et al., 2017). This process requires an appreciation of power relations and how social power shapes knowledge. We therefore suggest consideration of greater emphasis on critical reflexivity in medical education, where this is understood as 'a process of recognizing one's own position in the world in order both to better understand the limitations of one's own knowing and to better appreciate the social realities of others' (Ng et al., 2019: 1123). It has been argued that the fostering of critical reflexivity in medical education can promote epistemic justice by encouraging epistemic humility, and through acknowledging epistemologies other than those that privilege biomedical knowledge above other kinds of evidence, such as empirical evidence about patients' experiences (Thomas et al., 2020). Further, since dominant discourse around health and illness is historically as well as socially contingent, the history of medicine should be considered an important component of the medical syllabus (Jones et al., 2015). In this

regard, teaching could include discussion of conditions that were once medically unexplained (and often subject to psychologisation and dismissal of patient testimony) before becoming medically accepted. Examples include epilepsy, asthma and multiple sclerosis (Ackerknecht, 1982; Jacob et al., 2015; ME/CFS Skeptic, 2021; Richman et al., 2000); in some cases, attempts at psychosocial interpretation, notably in the context of 'perpetuating disability', persist (Bol et al., 2010). We caution that when public and media attention gradually move away from the pandemic and Long Covid, the risk of negative stereotyping may increase. Therefore, to neutralise the possibility that patients with conditions lacking biomarkers succumb to discrediting, training of today's and tomorrow's HCPs must encompass education about respecting the epistemic legitimacy of patient contributions to their care, and acknowledgement of the lived experience of their illness.

Finally, considering the broader disability policy context as previously outlined, fundamental revisions of state social security systems and employment practices should be considered, revisions that underline a social model of disability whilst recognising the lived experience of chronic illness and thus importance of appropriate medical care (Hale et al., 2020, 2021). As regards employment, flexible and/or reduced working hours and remote/home working practices (the latter measure introduced on a large scale due to the pandemic) should be considered as a reasonable adjustment for chronically ill and disabled persons who would benefit from such (Hale et al., 2021). Disability assessing should move away from the disability assessment medicine model towards a humanistic model grounded in the lived experiences of disabled and chronically ill people, whilst social security systems should support those who are unable to work due to ill-health (Hale et al., 2021).

Conclusion

We have argued that, to date, people with Long Covid appear not to have experienced the same level of negative stereotyping, discrediting and

exclusion from epistemic activities within medicine, compared with people living with ME/CFS. We have proposed that these differences can be traced to various factors, notably: prevalence of Long Covid and social power of the collective patient voice, with many Long Covid advocates being HCPs who have fallen victim to lingering symptoms after contracting Covid, clearer proximate aetiology and high incentive to research pathogenic mechanisms, and a notable demonstration of scientific and clinical epistemic humility, combined with desire to learn, in the face of absence of diagnostic biomarkers. On the other hand, there are indications that Long Covid may be susceptible to a parallel process of politicisation as has been the case in ME/CFS, particularly around the best way to manage and treat patients. Lessons must be learnt from ME/CFS to ensure that Long Covid does not follow the same path. It is now essential that patient narratives are foregrounded in Long Covid, and that this foregrounding is extended to other illnesses that might be considered medically ‘contested’, including ME/CFS. Long Covid offers a unique opportunity to work collectively, cohesively, and inclusively for the benefit of people with Long Covid, ME/CFS, and other illnesses with unexplained or medically contested symptoms. Long Covid can be a conduit to progress in these domains.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Joanne Hunt  <https://orcid.org/0000-0003-3868-5765>

Charlotte Blease  <https://orcid.org/0000-0002-0205-1165>

Keith J Geraghty  <https://orcid.org/0000-0001-5060-5022>

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