# Making space for disability studies within a structurally competent medical curriculum: reflections on long Covid

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### **ABSTRACT**

While critically informed approaches to medical education are increasingly advocated in literature, discussion of the potential role of disability studies in informing pedagogy and practice is largely lacking. The emergence of long Covid, alongside the strong possibility of a wave of covid-related disability, underlines an urgent need for medicine to develop more contextualised, nuanced and structurally competent understandings of chronic illness and disability. This article argues that the integration of thinking from disability studies into medical curricula offers a pathway to such understanding, informing a more equitable, holistic and patient-centred approach to practice. Further, a structurally competent, antiableist approach positions clinicians and patients as allies, working together within a structural context that constrains both parties. Such positioning may mitigate tensions within the clinical encounter, tensions that are well documented in the realm of marginalised chronic illness and disability. While the possibilities arising from a partnership between disability studies and medicine are numerous, the foci here are the social relational model of disability and the concept of psycho-emotional disablism, within a broader framework of critical disability studies. It is argued that inadequate healthcare provision and policy in the realm of long Covid can be understood as a form of structural and psycho-emotional disablism, arising from and reinforcing an ableist psychosocial imaginary permeated with neoliberal assumptions, and carrying a risk of furthering both disability and impairment. After considering long Covid through these particular lenses, the article concludes with a discussion of how a partnership between disability studies and a structurally competent approach to medical education might translate into practice.

### INTRODUCTION: STRUCTURALLY COMPETENT

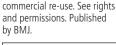
There are increasing calls in literature to draw

(Paradis et al. 2020; Sloan 2009). Critical perspectives are typically self-reflexive, interdisciplinary and share an explicit commitment to transformative practice and social change (Paradis et al. 2020). In 5 the field of medical education, critical approaches reach beyond acknowledgement of social determinants of health in curricula and training outcomes (see General Medical Council (GMC) 2018) in facilitating learners to recognise and challenge oppressive sociopolitical conditions that structure healthcare policy and practice, thus becoming socially accountable agents of change (Manca et al. 2020). However, critical approaches continue to be under-represented in undergraduate medical curricula within the UK and beyond (Campbell 2009a; Sandars 2016).

One such critical approach advocated for medical education and practice is the 'structural competency' paradigm (Metzl and Hansen 2014). Structural competency refers to an awareness of how health and healthcare are heavily influenced by social and institutional (structural) factors such as organisational policy, legislation, macro socioeconomic influences, dominant discourse and attitudinal contexts. While cultural competency recognises social categories such as race, ethnicity, disability, gender, sexuality and social class as forms of social inequity but typically focuses on individual (micro-level) interactions, a structurally competent approach recognises the structural (macro-level) context that constitutes and drives these forms of inequity (Metzl and Hansen 2014). In medical practice, and within the context of disability, this would mean understanding disability as being (at least partially) sociostructurally constructed: people are disabled predominantly or in part by social structures, not by their bodies or minds. There are clear parallels here with the social oppression which challenge the medical model's individualistic approach to disability by locating disability outside of the body, specifically within society responses to the non-normal disability of the body. disability studies-with the notable inclusion of the emerging subfield of critical disability studies (Goodley 2013; Meekosha and Shuttleworth 2009; Shildrick 2020)—is an interdisciplinary, critical and self-reflexive field of scholarship with an overt commitment to social justice, thus sharing the ethos of critical approaches discussed in medical education literature (see Paradis et al. 2020). Yet, with

## **CURRICULA AND DISABILITY STUDIES**

from social sciences and humanities in informing medical education, in particular advocating a greater emphasis on critical approaches (Paradis et al. 2020; Halman et al. 2017), and notably at undergraduate level (Manca et al. 2020). In this context, 'critical' includes but extends beyond the work of the Frankfurt School (see Geuss 1981) to encompass various theoretical approaches that interrogate dominant assumptions, norms and discourse, while problematising social structures that construct and reinforce power and oppression



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a few notable exceptions (see Campbell 2009a; Couser 2011) discussion of disability as a form of social inequity, and disability studies as a candidate for inclusion in medical curricula, appear under-represented in medical literature.

This article proposes that the field of disability studies has much to offer critical, structurally competent approaches to medical education and practice, in informing a more equitable, holistic and patient-centred approach to the social practice of medicine, in facilitating more nuanced and contextualised understandings of chronic illness and disability, and in guiding more constructive clinical interactions. Long Covid is drawn upon as a topical example and an emerging clinical entity that, it is argued, can be further elucidated through integrating disability studies and medicine. Equally, the strong possibility of a wave of covidrelated disability (Davis 2022), underscores the urgent need for a partnership between medicine and disability studies. Points raised in this article focus on subgroups of the long Covid population where demonstrable physical pathology is lacking. As such, the arguments forwarded are transferable to other chronically ill and disabled patient groups where medical uncertainty predominates and conditions are positioned as 'medically unexplained'. particularly where 'medically unexplained' is further understood as psychogenic (see O'Leary 2018; Geraghty and Blease 2019). While the possibilities arising from a partnership between disability studies and medicine are numerous, this article focuses on the social relational model of disability (Thomas 1999; Thomas 2007) and the concept of psycho-emotional disablism (Thomas 1999; Thomas 2007; Reeve 2020) as candidates for inclusion in medical curricula.

The structure of the article is as follows. After making a case to conceptualise long Covid from a structurally competent perspective, the social relational model of disability and the concept of psycho-emotional disablism are outlined, locating these ideas within the discipline of critical disability studies (Goodley 2013; Meekosha and Shuttleworth 2009; Shildrick 2020). Next, thinking from disability studies is situated in relation to concepts that are likely more familiar in healthcare settings, notably, patient-centredness and co-production. Long Covid is then discussed through a disability studies lens. The argument is made that inadequate healthcare provision and policy in the realm of long Covid can be understood as a form of structural (dis)ableism and psycho-emotional disablism, carrying a risk of furthering both disability and impairment (where disability and impairment are broadly understood as per the social model of disability). Finally, implications for education and practice are discussed, drawing on the structural competency paradigm for medical education (Metzl and Hansen 2014) and integrating thinking from disability studies. As a chronically ill researcher taking a pluralist approach with an underpinning commitment to the social model (Oliver 1990), the author uses the term 'disabled people' as opposed to person-first language, with an awareness of debates in this regard (see Shildrick 2020; Shakespeare 2014).

### A STRUCTURALLY COMPETENT APPROACH TO LONG COVID

Long Covid describes cases of protracted symptoms subsequent to infection with SARS-CoV-2 which cannot be explained by alternative diagnoses. In the UK, the National Institute for Health and Care Excellence (NICE) describes long Covid as encompassing both 'ongoing symptomatic COVID-19', with symptoms persisting 4 weeks or more postinfection, and 'post-covid-19 syndrome' which delineates cases of more than 12 weeks in duration (National Institute for Health and Care

Excellence (NICE) 2022). A burgeoning body of biomedical research indicates that pathogenic mechanisms include viral persistence, reinfection and/or postviral dysfunctional immune response, provoking autoimmunity, chronic inflammation, autonomic dysregulation and/or coagulation abnormalities (Proal and VanElzakker 2021; Grobbelaar et al. 2021). Further, studies demonstrate impairment in organs such as the lungs, heart and kidneys in both hospitalised and non-hospitalised patients (Dennis et al. 2021; Puntmann et al. 2020). While infection with SARS-CoV-2 as a proximal cause of long Covid is selfevident, critical inquiry reveals how structural influences play an important role. For example, indications that the pandemic is impacting disproportionately on the disabled community and racial and ethnic minority groups (Razai et al. 2021; Jumreornvong et al. 2020) demonstrate how pre-existing sociostructural disadvantage, entwined with other social determinants of health and structural discrimination, interact with biological triggers to (further) marginalise and disable. This underlines a need to integrate sociostructural influences into a holistic understanding of chronic illness and disability; in fact, the term long Covid arose from an appreciation that impairment and disability extend beyond biology (Perego et al. 2020).

Long Covid can be considered an umbrella term, with acknowledgement that different disease phenotypes exist within this umbrella, and that some patients may sit within more than one subtype (Maxwell and Poole 2021; Maxwell 2020). For example, Venturelli et al. (2021) proposed partitioning long Covid into postcritical illness syndrome, postviral chronic fatigue syndrome and post-traumatic stress disorder. Importantly for points raised in this article, some cases of long Covid are without detectable pathology and there are suggestions to categorise and treat subgroups accordingly (Yong et al. 2021). Lack of biomarkers renders application of a biomedical model challenging and opens the door to positioning subgroups of long Covid as 'medically unexplained symptoms'; a biopsychosocial model (Engel 1977) may thus be preferred. However, in the field of medically unexplained symptoms, a particular application of the biopsychosocial model has been critiqued for unduly psychologising chronic illness while dismissing patient narratives (Geraghty and Blease 2019) and it has been cautioned that long Covid may be susceptible to such influences (Hunt, Blease, and Geraghty 2022). While biomedical understanding and treatment of long Covid is crucial, and an ethically minded biopsychosocial approach may facilitate more holistic interventions, neither model can be described as holistic or structurally competent. That is, neither model acknowledges how structural factors influence health, healthcare encounters and the broader health system. The social relational model of disability and concept of psycho-emotional disablism, further positioned within the field of critical disability studies, arguably offer a structurally cognisant, complementary hermeneutical framework in this regard.

# THE SOCIAL RELATIONAL MODEL AND PSYCHO-EMOTIONAL DISABLISM

Models of disability arising from disability studies coalesce around the idea of disability as social oppression, in contrast to medical understanding of disability as deviation from the 'norm', often conceptualised as individual functional impairment to be cured or rehabilitated (Thomas 2007; Couser 2011). The social relational model of disability defines disability as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being'

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(Thomas 1999, 3). According to this definition, chronic illness, including long Covid, is a form of impairment and, consistent with the social model (Oliver 1990), disability (or disablism) is a form of oppression imposed on people with chronic illness. However, the social relational model further develops the (materialist) social model of disability, acknowledging not only sociostructural barriers such as policy, legislation and infrastructure (macro-level and meso-level influences) but also interpersonal interactions (micro-level influences). These interactions can be understood as permeated with ableist and neoliberal ideology that can be discerned both in medicine and broader social practices (Cheshire et al. 2017; Hughes 2000). While neoliberalism can be understood as an economic policy model, prioritising the interests of private corporations and the market over respect for human rights in part via systematic retrenchment of health and welfare provision (Clifford 2020; Stewart 2016), it can also be understood as a biopolitical ideology. In this regard, neoliberalism is discernible in social practices and the collective consciousness through an emphasis on consumer-citizens, competition, free will and personal responsibility (Adams et al. 2019). Such ideology celebrates the abled, rational and productive individual, while positioning disability as deficiency, deviance or tragedy (Campbell 2009b). Neoliberalism is thus entwined with ableism, where ableism is understood as 'a cultural imaginary and social order centred around the idealised able-bodied and -minded citizen who is self-sufficient, self-governing and autonomous' (Goodley 2020, 367).

The 'socially engendered undermining' of disabled persons' well-being (Thomas 1999) that may ensue from expressions of ableist and neoliberalist ideology has been theorised as psychoemotional disablism (Reeve 2006; Reeve 2020). This concept describes how disablism impacts on psycho-emotional well-being through manifestations of oppression sustained by the psychosocial imaginary and cultural representations of disability (Reeve 2006; Reeve 2020). Psycho-emotional disablism may manifest as marginalisation and epistemically unjust treatment of chronically ill patient groups within healthcare (see Blease, Carel, and Geraghty 2017; Buchman, Ho, and Goldberg 2017), whereby the detrimental impact on patient well-being has also been documented (Bê 2016; Geraghty and Blease 2019; De Wolfe 2012). A notable argument from within disability studies literature, which will be explored later in the article, is that structural and psychoemotional disablism may impact detrimentally on physical as well as psycho-emotional well-being, exacerbating impairment and furthering disability (see Bê 2016; Hughes and Paterson 1997).

The social relational model of disability and concept of psychoemotional disablism sit comfortably within the broader discipline of critical disability studies, notably as regards challenges to the (materialist) social model of disability from a range of theoretical perspectives. Critical disability studies as a discipline is characterised by reflexive, transdisciplinary theorising through and beyond the social model, underlining the need to theorise impairment, integrate intersectional concerns, and attend to issues arising from representation of the Other, in particular through shifting the gaze from disablism to ableism and the ableist imaginary (Goodley 2013; Campbell 2009b; Shildrick 2020). Of particular relevance to medicine, the feminist emphasis on the body and need to theorise impairment (Morris 2007; Crow 1996; Morris 1996) highlight the need for appropriate medical treatment as well as social accommodations. Indeed, medical treatment could be considered a social accommodation for those disabled people who would benefit from such, suggesting that a social/ medical model binary is false and unproductive. In this respect,

some scholars have argued that the two models and associated paradigms can be considered complementary, and that disability studies can contribute to medical education by siting the medical model in a broader context (Couser 2011); this supports the argument that disability studies can help expand medical education in a structurally competent way. Critical disability studies is concerned with the interrogation and disruption of binaries, and thinking from this discipline may help to bridge the divide between medicine (and medical sociology) and disability studies (see Thomas 2007; Thomas 2022). Further, contributions from both feminism and phenomenology (see Hughes and Paterson 1997) foreground the lived experience of chronically ill and disabled people; this holds clear value for medicine since patient experience has historically been positioned as the lowest form of evidence (Schoemaker 2021; Goldenberg 2006). Finally, the poststructuralist recognition that both disability and impairment are shaped by discourse and the psychosocial imaginary (Shildrick 2020; Tremain 2001), holds relevance to the influence of medicine (particularly the act of diagnosis) in constructing some patient groups as legitimately chronically ill or disabled, while positioning others in a way that risks epistemic injustice and stigma (see Blease, Carel, and Geraghty 2017; Buchman, Ho, and Goldberg 2017). Such recognition is also relevant to how the term 'mild COVID-19' sits in the psychosocial imaginary, carrying implications for healthcare and social accommodations (see Callard 2020). While the discussion so far has been largely theoretical, the practical value of integrating disability studies into medical education can be further elucidated through considering how disability studies sits in relation to the concepts of co-production and patient-centredness.

### DISABILITY STUDIES, PATIENT-CENTREDNESS AND CO-PRODUCTION

Endeavours to draw on patients' values, preferences and lived experience in informing healthcare have been referred to by various terms; patient-centredness and co-production will be explored here. Despite the ubiquitousness of the term 'patientcentred', there is little consensus as to its precise meaning. In reviewing conceptual and empirical literature, Mead and Bower (2000) identify five dimensions: 'patient-as-person', 'doctoras-person', sharing power and responsibility, therapeutic alliance and biopsychosocial perspective. Here, the emphasis is on doctor and patient as whole persons engaging in an equitable, co-productive relationship, while acknowledging the broader context in which the therapeutic alliance is embedded. Here too, other concepts that emphasise participatory approaches to healthcare, such as shared decision-making (Barry and Edgman-Levitan 2012) and relationship-centred care (Beach and Inui 2006) are discernible. In fact, given the relational emphasis of patient-centred care, the term 'relationship-centred care' may be more appropriate; 'patient-centred' can be understood as a response to recognition that medicine has historically tended towards 'doctor-centredness' (see Beach and Inui 2006).

The 'biopsychosocial perspective' dimension of patient-centredness is of particular interest. That is, while the biopsychosocial model envisaged by Engel (1977) acknowledged the whole patient situated within their broader context, it has been argued that the model has been applied in ways which are far from patient-centred, notably in the field of conditions that may be framed as 'medically unexplained symptoms' (Blease, Carel, and Geraghty 2017; Geraghty and Blease 2019). Further, as previously alluded to, the biopsychosocial model also typically lacks the structural competency that Engel appeared to envisage,

in that it does not recognise or address structural influences in health and illness, nor does it acknowledge structural factors that have given rise to a particular application of the model dominant in UK health settings (Hunt 2021). In this respect, thinking from within disability studies can be drawn on both to support and expand the concept of patient-centredness in a structurally cognisant direction. The discipline of disability studies has its roots in the epistemic labour of disabled people (Union of the Physically Impaired against Segregation (UPIAS) 1976) and its political activist orientation ensures that the discipline demonstrates structural competency while emphasising the lived experience of the disabled community. In this regard, disability studies sits particularly well with the principles of co-production.

Co-production, a term with roots in public administration discourse, has more recently been applied to healthcare settings (Gregoire, Trager, and Blum 2021; Batalden et al. 2016; Palmer et al. 2019). Through this lens, clinicians and patients are positioned as co-producers of patient care within the wider context of the health system, community and society (Batalden et al. 2016), thus pointing towards a relationship-centred and structurally competent model. This approach stands in contrast to clinician-as-producer, patient-as-consumer models which, it has been argued, can hinder constructive clinician-patient relationships (Batalden et al. 2016). Co-production applies not only to healthcare encounters, but to all levels of the healthcare system, including design, commissioning, delivery and assessment of services. The pandemic has bolstered co-production in healthcare settings and within society more widely (Turk et al. 2021); in the healthcare arena, patients (including doctors-as-patients) have played a central role in influencing the clinical and societal positioning of long Covid, a patient-led term (Callard and Perego 2021). The ethos of co-production is also highly consistent with the ethos of the disability rights movement and the social model of disability, as symbolised by the banner 'nothing about us, without us' (see Barnes 2020). Indeed, the valuing of power sharing, lived experience and direct participation of persons in decisions that affect their lives underpins the emergence of disability studies and the disability rights movement (Barnes 2020), and medicine can learn from this tradition.

Principles of co-production have also been applied to medical education, where it has been observed that traditional top-down (teacher-as-producer; student-as-consumer) pedagogy models stand in stark contrast to the patient-practitioner partnerships that clinicians are expected to foster on qualification (Gregoire, Trager, and Blum 2021; Englander et al. 2020). A co-productive approach disrupts this top-down dynamic, emphasising partnerships between students, trainers, teaching institutions and the wider community in developing curricula (Gregoire, Trager, and Blum 2021). A contrast has also been noted between the formal (explicit) curriculum and what has been termed the 'hidden curriculum' (Hafferty 1998): implicit values and assumptions around practice that are internalised, sometimes unconsciously, by students and faculty. For example, while medical humanities components within curricula may explicitly emphasise patientcentredness and partnership, medical culture may implicitly devalue this through valorisation of objective detachment, hierarchy and competition (Lempp and Seale 2004; Coulehan and Williams 2001; see also Carel and Kidd 2014). It has been argued that co-production requires a supportive culture, one that values power sharing and diversity of perspectives (Turk et al. 2021), yet it could be contended that undergraduate students are socialised into a culture that is at odds with these values. Both (critical) disability studies and the structural competency framework, highlighting structural influences such as dominant

discourse, attitudinal context and policy, could illuminate the hidden curriculum and facilitate a structurally cognisant cultural shift within medical education and healthcare.

### LONG COVID THROUGH A DISABILITY STUDIES LENS

Since the emergence of long Covid, people with this condition have reported disbelief and undue psychologisation from healthcare professionals (Ladds et al. 2020; Macpherson et al. 2022; Kingstone et al. 2020), although the referenced studies also demonstrate that not all (micro-level) healthcare encounters have been reported as negative. In fact, the barriers to understanding long Covid, and validation of patient narrative, appear predominantly structural; lack of adequate explanatory healthcare model, unpreparedness of health services to provide appropriate healthcare and a culture of privileging 'objective' markers and clinical expertise over patient narrative have all been discussed and challenged in this regard (see Maxwell and Poole 2021; Hunt 2020; Alwan et al. 2020). It has also been argued that ableist discourse—for example the 'recover or die' narrative—further embedded in the biopolitical ideology of neoliberalism, permeates healthcare and the social security system and negatively impacts on chronically ill and disabled people, including people with long Covid (Hunt, Blease, and Geraghty 2022). Associated binaries discernible in COVID-19 discourse, including 'mild infection or death' (Kingstone et al. 2020) and 'non-hospitalised (non-serious) or hospitalised (serious)' (Macpherson et al. 2022), are likely associated with reported difficulties accessing social security benefits, workplace accommodations, sick certification, disability insurance and broader social support, alongside appropriate healthcare (see Ladds *et al.* 2020; Davis et al. 2021; Kingstone et al. 2020). To determine whether such structural factors may be understood as facets of disability (oppression, disablism) as per the social relational model (Thomas 2007), a more detailed exploration of the experiences of people with long Covid is indicated.

Qualitative research indicates that people with long Covid experience significant difficulties navigating the healthcare system (Taylor *et al.* 2021; Ladds *et al.* 2020; Humphreys *et al.* 2021 Vi 2021; Kingstone et al. 2020). Patients report engaging in multiple strategies in an attempt to circumvent obstacles, with reports of fragmentary, compartmentalised care, alongside experiences of being passed between tiers of care, without satisfactory outcome (Ladds et al. 2020). A notable recurring motif in qualitative data is what might be described as patient experiences, needs and testimonies disappearing into the clinical, social and discursive vacuum between the poles of the ableist binary 'recover or die', frequently manifesting as 'mild cases resolving quickly at home' or 'serious cases requiring acute or intensive care' (see Maxwell 2020; Ladds et al. 2020). For example, non-hospitalised patients trying to self-manage from home report experiences of symptoms being minimised by clinicians (Ladds *et al.* 2020); such minimisation can be understood as a consequence of situating patients within the 'mild' ('recovery') binary category. Some people with long Covid have highlighted the lack of defined care pathways for persistent symptoms, as if the healthcare space between acute care and self-management has been overlooked (Maxwell 2020; Ladds et al. 2020). It has also been noted that public health information reinforces such binaries (Maxwell 2020); this may then impact on broader social attitudes to long Covid. Accordingly, (some, not all) people with long Covid report being expected to return to work before they are ready. being forced to take unpaid leave, resign or being made redundant due to disbelief and/or unaccommodating policy within the

workplace (Ladds et al. 2020; Davis et al. 2021; Macpherson et al. 2022). Similar experiences are reported among clinicians with long Covid (BBC 2020; Trueland 2020); here, the right to workplace compensation and classification of long Covid as an occupational disease in some countries remains uncertain (Tucker and Kenyon 2021). A picture thus emerges of restricted access to appropriate healthcare, social security support, disability compensation and/or workplace accommodations engendering a process of disablement (social disenfranchisement). Sociostructural barriers arising from and related to current healthcare provision and policy could thus be understood as a facet of oppression (structural disablism and ableism) as per the social relational model of disability.

It might be argued that structural barriers are more to do with lack of knowledge diffusion around long Covid than structural disablism and/or ableism. Certainly, long Covid is a nascent clinical entity, and there are notable demonstrations of epistemic humility, together with an increasing valorising of co-production, within the clinical and scientific communities (Hunt, Blease, and Geraghty 2022). However, it could also be contended that lack of health service preparedness for patients with complex postviral (or persistent viral) sequelae is partly a consequence of historical lack of co-production and patient-centredness in cases of other postviral conditions (see Blease, Carel, and Geraghty 2017), where such patient groups can be argued to have been subject to long-term structural ableism and disablism (Bê 2016; De Wolfe 2012). In the case of long Covid, it could be argued that clinicians, policy makers, educators and other social actors have had ample opportunity to learn from marginalised patient groups prepandemic with a view to creating a health system that is more accommodating of complex, multisystem and polysymptomatic presentations that may lack biomarkers. The failure to do so can be largely equated to the previously acknowledged historical tendency, at all levels of healthcare, to position patient testimony as the lowest form of evidence, and thus a failure to engage in the principles of patient-centredness and co-production (see Scheyett 2006; Schoemaker 2021; Goldenberg 2006). In these respects, current healthcare and broader social provision for people with long Covid, a legacy of existing provision for prepandemic marginalised patient groups, can be understood through the lens of both disablism and ableism, as the inheritance of social, clinical and epistemic 'landscapes of power and exclusion' (Kitchin 1998, 346).

Oppression has a psycho-emotional component and the concept of psycho-emotional disablism—including responses to sociostructural barriers, social interactions with others and internalised oppression (Reeve 2006; Reeve 2020)—is applicable here. In terms of social interactions with others, dismissive encounters with both clinicians and family and friends have been reported (Ladds et al. 2020; Kingstone et al. 2020); here, it may be that the invisibility of some symptoms, combined with the representation of 'serious illness' and emphasis on 'recovery' in the ableist social imaginary, results in disbelief. As regards structural barriers, experiences of navigating the system are described in literature as 'hard and heavy work' (Kingstone et al. 2020, 5, 6) and 'complex, difficult and exhausting' (Ladds et al. 2020, 6). It could be speculated that such hard, heavy work, alongside invalidating micro-level interactions, will take an emotional toll on people already struggling with a debilitating condition. Accordingly, people with long Covid describe feeling 'fobbed off', 'broken', 'heartbroken' (Ladds et al. 2020, 8), 'very, very alone and isolated' and 'really frightened, terrified' (Kingstone et al. 2020, 7, 8). Although it is important to recognise that not all clinical interactions are reported as negative, the concept of 'landscapes of power and exclusion' (Kitchin 1998, 346) is again evoked, whereby exclusionary policies and practices give disabled people the implicit message that they are 'out of place', different, and above all, unwelcome.

Qualitative research also suggests that internalised oppression, that is, the internalisation of negative attitudes, dismissive interactions and broader ableist ideology (Reeve 2006; Reeve 2020), may apply to long Covid. The 'disavowal of disability' (Hughes 2007), invalidating discourse or practices associated with the above-described exclusionary landscapes, can be internalised in a variety of ways (Reeve 2020). Some qualitative data have revealed the sense of being a 'burden' on others, with associated feelings of guilt (Taylor et al. 2021; Humphreys et al. 2021), while other findings depict the anxiety, notably among doctors with long Covid, of being positioned as a 'nightmare' or 'heartsink' patient (Taylor et al. 2021). The term 'heartsink' and the notion of being a burdensome patient group feature in mainstream social and clinical discourse around other marginalised conditions (see Raine et al. 2004); this suggests that internalisation of (dis)ableist attitudes may lead to people with long Covid invalidating themselves or seeking to distance themselves from invalidated groups (see Byrne 2022). In a study of the healthcare experiences of 114 people with long Covid, Ladds et al. (2020, 9), observe: 'Many of the narratives conveyed a sense of shame and blame consistent with stigma'. Shame and (self-)blame are also consistent with self-stigma, the internalisation of others' stigmatising attitudes and/or structural stigma, which has been noted in other qualitative data (Patient-Led Research Collaborative 2020) and more broadly discussed within the context of neoliberalism (Scambler 2018). Further, in observing the impact of chronic illness on sense of self, Ladds et al. (2020, 9), acknowledge the identity threat posed to 'healthy, independent and successful selves'. Good health, independence and success are positioned favourably in the neoliberal, ableist imaginary (Goodley 2020; Adams et al. 2019), suggesting that people with long Covid, like all social actors, risk internalising dominant yet oppressive ideology. Theoretical and empirical work from within the realm of other marginalised patient groups provides insight into the deleterious repercussions of internalised oppression for human flourishing (Thomas 1999; Reeve 2006; Reeve 2020). That is, the impact of internalised oppression can extend beyond restricting activity and impact on a profound ontological level (Thomas 2007; Reeve 2020) limiting who people can be and become.

A notable finding in long Covid qualitative data is that the experience of navigating structural barriers and dismissive social interactions within healthcare can be physically as well as psychologically exhausting (Ladds et al. 2020). This is consistent with the suggestion from within disability studies literature that both structural and psycho-emotional disablism can impact detrimentally on physical as well as psychological health. While the term 'impairment effects' has been applied to explicate of restrictions to activity associated with the body as opposed to socially imposed barriers (Thomas 2007), the term 'externally imposed impairment effects' describes impairment effects, such as fatigue and pain, that are generated or worsened by disconfirming, distressing interactions with agents or structures (Bê 2016). Long Covid can have a considerable functional impact, reverberating across physical, psychological, social, occupational and financial domains (Ziauddeen et al. 2022); while functional status (or functional impairment) is typically located within the person, a disability studies approach shifts the focus onto structural factors that shape impairment and further disability. Such an approach highlights the importance not only of timely

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and appropriate medical care but also social accommodations (enabling workplace practices, sick pay, disability benefits, etc) that would preclude externally imposed impairment effects, limit impairment effects (or disability as per the biomedical model) and prevent disability understood as per the social relational model. However, while revision of healthcare and social policy and provision is necessary for accommodating people with long Covid, particularly where biomarkers are lacking, thinking from critical disability studies suggests that such revision is not sufficient. Prejudicial attitudes towards disabled people, deeply rooted in the (ableist) psychosocial imaginary, will likely be resistant to change (Shildrick 2020), further highlighting the need for fundamental changes in medicine through structurally competent undergraduate medical education. It is to these issues the article now turns.

#### IMPLICATIONS FOR TEACHING AND PRACTICE

From within the structural competency paradigm for medical education, five intersecting skill sets have been proposed to guide teaching and practice (Metzl and Hansen 2014). In what follows, these skill sets will be outlined and complemented with thinking from disability studies to provide further insight into, and practical examples of, conceptualising and working with long Covid and other chronic illness and disability. Recommendations made here are intended as a potential complement to, rather than replacement of, biomedical and ethically minded biopsychosocial approaches.

### **'RECOGNIZING THE STRUCTURES THAT SHAPE CLINICAL** INTERACTIONS'

This skill set (Metzl and Hansen 2014, 128) is further described as 'recognition of how economic, physical, and socio-political forces impact medical decisions' (Metzl and Hansen 2014, 128). In the context of long Covid, this would include clinicians acknowledging that clinical and societal discourse around poorly delineated health conditions and associated disability has been significantly influenced by sociopolitical agendas, for example, agendas associated with a particular application of the biopsychosocial model (Clifford 2020; Hunt 2021; Stewart 2016). Of particular note here is the argument, largely forwarded by disability scholars and activists, that biopsychosocial discourse around 'medically unexplained symptoms' has arisen from and is reinforced by sociopolitical interests coalescing around welfare reform policies in the UK and beyond (Jolly 2012; Berger 2014; Hunt 2022). That is, the positioning of certain chronic illnesses as primarily psychosocial in origin has allowed a narrative to be constructed whereby 'disability' (here, understood as per the medical model) is amenable to psychosocial health interventions and thus to 'recovery', ushering disabled people back into the labour market whether or not they are capable of work (Rutherford 2007; Faulkner 2016). This facilitates a reduction in state (biomedical) healthcare and welfare expenditure while creating new markets for private profit, notably for the disability insurance industry (Rutherford 2007; Stewart 2016). Such discourse, which legitimises some patient groups while marginalising others, partly through policing the boundaries between 'deserving and undeserving disability' (see Soldatic 2020; Shakespeare, Watson, and Alghaib 2016), is likely associated with the well-documented epistemic injustice and broader harms sustained by chronically ill and disabled people (see Blease, Carel, and Geraghty 2017; Geraghty and Blease 2019). Through a disability studies lens, this discourse, underpinned by individualist, ableist assumptions around recovery and productivity, can also be located within

a global context of neoliberalism, including state policies of retrenchment within health and welfare sectors that preceded, and were accelerated by, the 2008 global financial crisis and ensuing austerity measures (Clifford 2020; Stewart 2016). While it is clear how discourse generated by or associated with healthcare models can impact on clinical decision-making and patient health outcomes (see Geraghty and Blease 2019), neoliberalism exerts an effect of its own on clinical interactions. That is, neoliberalisation of healthcare, manifesting in practice through work-load intensification, pay-for-performance schemes, timelimited consultations and audit culture, has been associated with clinician burn-out and low morale (Cheshire et al. 2017) and this may be particularly true when working with complex, polysymptomatic presenting issues such as long Covid.

An important structural issue of relevance to the above discussion is the historical tendency in healthcare settings, notably in the UK, to recommend cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) for particular conditions that have been positioned as 'medically unexplained' and thus assumed to be largely psychosocial in origin. Most notable here is the case of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), where such an approach has been heavily critiqued as lacking in evidence base, ignoring a burgeoning body of biomedical research, and being associated with patient harms (Geraghty and Blease 2019; Geraghty, Hann, and Kurtev 2019). It has been argued that such harms have ensued not only through inadequate explanatory frameworks, but also through failure to accept patient testimony as a form of evidence (Blease, Carel, and Geraghty 2017); these harms could thus equally be understood as arising from a lack of co-production and patientcentredness at all levels of the health system. Although the US Centers for Disease Control and Prevention (Centers for Disease Control and Prevention (CDC) 2021) has for some years maintained that there is no effective approved treatment for ME/CFS, and despite NICE having dropped recommendations for a GET/ CBT approach to 'treating' ME/CFS owing to lack of evidence base (National Institute for Health and Care Excellence (NICE) 2020, 2021), support for such approaches continues (Kalfas et al. 2022; Flottorp et al. 2022). Importantly, the same or similar approaches can also be observed among proposed management strategies for long Covid, in particular for managing associated fatigue (Verveen et al. 2022; Sharpe 2021; National Health Service (NHS) 2021). However, in an echoing of ME/CFS, some (not all) people with long Covid report limited biomedical investigations alongside a clinical tendency to unduly psychologise symptoms (Lokugamage, Taylor, and Rayner 2020; Maxwell 2020). Further, postexertional malaise, a hallmark of ME/CFS, is also prominent among many people with long Covid (Davis et al. 2021), raising ethical questions particularly about graded exercise approaches (Décary et al. 2021). A structurally competent lens is helpful in understanding the persistence in applying psychosocial frameworks to poorly delineated, 'contested' and/or marginalised conditions. That is, the parrative of individual or marginalised conditions. or marginalised conditions. That is, the narrative of individualist, psychosocial interventions that emphasise personal hard work, motivation and determination in 'overcoming' chronic illness and disability is not only central to interests coalescing around welfare reform (Hunt 2021; Stewart 2016) but is also permeated with neoliberal ideology as previously defined.

In practical terms, clinical recognition of such structural factors constraining practice, and discussion with patients where appropriate, could significantly mitigate well-documented tensions within healthcare encounters, notably with patients with poorly treated or 'medically unexplained' conditions (Johansen and Risor 2017). Such tensions are argued to arise

from 'epistemological incongruence' or lack of fit between clinicians' (biomedical) training frameworks and the reality of the clinical encounter where biomarkers may be lacking, opening the door for (bio)psychosocial explanations which patients often reject (Johansen and Risor 2017). A structurally competent approach to chronic illness and disability, including long Covid, might offer a point of congruence between differing perspectives. That is, acknowledgement of structural factors that are constraining to both patients and clinicians positions both parties as partners or allies, promoting solidarity and collaboration as opposed to conflict and tensions. Through a lens of co-production, clinicians and patients would be positioned as co-producers of the patient's care, within the broader context of the health system, community and society (Batalden et al. 2016). Dominant (biopsychosocial) healthcare approaches to 'medically unexplained symptoms' have been demonstrated to be stressful and disempowering for clinicians as well as patients (see Geraghty and Blease 2019; Johansen and Risor 2017; Hunt 2022); explicit recognition that structural factors also impact on clinicians' health may thus encourage clinician self-care, maintaining fitness to practice and improving clinician-patient relationships. Such recognition of structural influences, of course, requires clinicians to be aware of them, pointing to the need for structurally competent medical curricula at undergraduate level and beyond. In terms of medical education curricula content, discourse and content analysis are recommended (see Ng et al. 2019) as a means of deconstructing and interrogating taken-forgranted narratives around disability, impairment and recovery. Further, politics, notably as it impacts on health and social policies, should also be considered as a component of training programmes (Goel and Kavanagh 2020). Encouraging clinician self-care may require a change of culture within medical training, towards a culture where expression of vulnerability is encouraged and valued (see Veal 2021); this again suggests a critical approach is required with a view to addressing the 'hidden curriculum' (Hafferty 1998).

# 'DEVELOPING AN EXTRA-CLINICAL LANGUAGE OF STRUCTURE'

Here, Metzl and Hansen (2014, 129) advocate drawing from social sciences and humanities to further understanding of what structure means and how structural factors impact on health. In fact, disability studies is briefly acknowledged, where the authors consider 'how structural assumptions about "healthy" body size and function implicitly stigmatize persons who fall outside of aesthetic norms' (Metzl and Hansen 2014, 129-130). This notion of othering of persons who are considered to deviate from 'normate' status (Garland-Thomson 1997) can be further developed through a critical disability studies lens in interrogating the modernist binary structures of 'normal', 'abnormal', ability/ disability, life (recovery)/death that permeate the psychosocial imaginary, where the second term in each binary pair is positioned as tragedy, deficiency, personal failure or deviance. Such binaries, pervasive in medical and dominant social discourse, are implicated in the othering of chronically ill and disabled people (Shildrick 2020). The 'recover or die' binary has already been discussed within the context of long Covid; this binary has been employed to position people with long Covid as responsible for their recovery, productivity and happiness (Garner 2021). Nevertheless, long Covid is disrupting these binaries, not least due to an increasingly large group of patients who have neither died nor recovered, encouraging medicine to focus on the space in between. Similarly, the clinician/patient distinction

is problematised as a considerable number of clinicians become patients (Taylor *et al.* 2021). While clinician-patients offer fresh clinical insight into the experience of chronic illness and disability, it may also engender discomfort, as some clinicians recognise their (unintentional) complicity in sociostructural injustices sustained by other disabled and chronically ill patient groups (Taylor *et al.* 2021; see also Rowland and Kuper 2018). Critical, notably postmodernist, approaches typically embrace uncertainty and harness the ensuing discomfort to galvanise change (Shildrick 2020); medical education and practice can follow this example.

Developing an understanding of 'structure' within a disability context can also be aided by application of the social relational model of disability and concept of psycho-emotional disablism. Here, as already outlined, structures are understood as infrastructure, policy, legislation and attitudinal contexts that disable. This theoretical lens also allows for recognition of how structures are internalised by individuals and (re)produced in social practices (Aragon and Jaggar 2018), manifesting from the 'micro' (disconfirming healthcare encounters) up to the 'macro' (retrenchment of health and welfare sectors). As previously discussed, disability studies has much to say about neoliberalism which can itself be considered an overarching structural factor that is internalised and (re)produced, notably in health and social policy where some chronically ill and disabled people are repositioned as 'not really disabled' (Soldatic 2020). In this regard, it is unclear how long Covid will be positioned in the long term, but it has been cautioned that actors and structures implicated in the marginalisation of other patient groups are also implicated in the positioning of long Covid (Hunt, Blease, and Geraghty 2022). Finally, as previously outlined, disability studies literature can be drawn on to theorise how structural factors can impact detrimentally on physical as well as psychological and social policy where some chronically ill and disabled people can impact detrimentally on physical as well as psychological health, understood as 'externally imposed impairment effects' (Bê 2016). Such theorising can be complemented by applying a biomedical lens, for example, drawing on the concepts of biological embedding and allostatic (over)load which describe how cumulative, often uncontrollable stressors (such as epistemic and broader sociostructural injustice) can, quite literally, 'get under the skin' (Heise et al. 2019; Aristizabal et al. 2020). In this way, integrating thinking from disability studies and biomedicine can provide fresh insight into how people with long Covid may sustain psychological and physical harms from sociostructural injustices, including those associated with healthcare. More importantly, it provides a framework by which clinicians can resist complicity with such injustices, as the following two skill sets demonstrate.

# 'REARTICULATING "CULTURAL" PRESENTATIONS IN STRUCTURAL TERMS'

Here, Metzl and Hansen (2014, 130) emphasise that, while this skill set does not eschew cultural considerations, the aim is to encourage clinicians to recognise broader structural forces that shape cultural representations. Through a disability studies lens, this skill set would involve clinicians acknowledging that disability, far from constituting individual deviance from a sociocultural norm, is largely to be located in disabling social structures, including the ableist psychosocial imaginary which shapes such norms. In a similar vein, psychological distress, typically conceptualised through the individualist lens of a biomedical or biopsychosocial model as arising from the patient's biology, behaviour or cognitions, might be understood as a downstream effect of structural (dis)ableism, including ableist discourse

associated with the healthcare models themselves. In fact, 'contested' illness research appears largely consistent with the suggestion that psychological distress ensues from disabling structures, notably where structures are understood as negative attitudinal contexts and discriminatory health and social policy (see Devendorf et al. 2020; Edwards et al. 2007; Blease, Carel, and Geraghty 2017; De Wolfe 2012), and the same might apply to long Covid. Qualitative data indicate that (some) people with long Covid experience anxiety partly as a response to persistent physical symptoms (as opposed to anxiety triggering physical symptoms) combined with lack of healthcare support targeting the space in between self-managed recovery and hospitalisation (see Maxwell 2020). Further, anxiety has been reported as a result of personal experience of 'recovery' being at odds with (ableist) mainstream expectations (Maxwell 2020). In both cases, ableist structures are demonstrated as contributing to psychological distress. Reimagining presenting issues through a structural lens may counter victim-blaming dynamics discernible in medical and broader social discourse around disability (Stanley, Salmon, and Peters 2002; Horton-Salway 2002; Shakespeare, Watson, and Alghaib 2016), reduce negative stereotyping and counter psycho-emotional disablism.

Through a critical disability studies lens, this skill set also involves recognising that intersectional concerns (see Turan et al. 2019) may contribute to how a person experiences both impairment and disability (Shildrick 2020; Sherry 2016) and may also influence the patient-clinician relationship, for example, impacting on patient trust. 'Cultural' presentations may arise as much from the social imaginary (and implicit biases of clinicians) as they do from any essential characteristic of patients, and reimagining such presentations through a structural lens may be particularly important where axes of oppression intersect. Research indicates that social disadvantage, notably on grounds of gender, race and socioeconomic status, is associated with marginalising (dismissive and unduly psychologising) encounters within healthcare (Hoffmann and Tarzian 2001; Diniz et al. 2020; Tait and Chibnall 2014); from this perspective, and given the varied healthcare experiences of people with long Covid, intersectional research in this area is indicated. The history of 'medically unexplained symptoms' is permeated with gender bias (O'Leary 2018), and it could be contended that the clinical trajectory of ME/CFS has been influenced by intersected sexism and ableism in (re-)positioning early viral outbreaks as mass hysteria (McEvedy and Beard 1970). A structurally competent approach to intersectionality demands that the lens of scrutiny extends beyond marginalised identities (an individual-level or cultural-level focus) to encompass the broader structural context within which marginalised identities, or socially constructed categories, interact (Gkiouleka et al. 2018; Campbell 2009b); this approach is crucial to prevent history repeating itself with long Covid. Such reimagining could encourage clinicians to resist complicity with oppressive structures, for example, through validating patients' attributions of distress to sociostructural factors, supporting patients in navigating hostile structures and considering structurally competent solutions. This latter suggestion leads onto the next skill set to be discussed.

## 'OBSERVING AND IMAGINING STRUCTURAL INTERVENTIONS'

This skill set (Metzl and Hansen 2014, 130) incorporates an awareness that 'structures are subject to various forms of intervention' (Metzl and Hansen 2014, 130), that is, since structural factors give rise to health, healthcare and broader social

inequities, any imagined solutions must address structural factors. Metzl and Hansen (2014) suggest that medical facilitators and students might observe how marginalised groups address structural health issues, recommending activist organisations as a potential resource. In the context of long Covid, it is noteworthy that some Disabled People's Organisations and chronic illness advocacy organisations, established prepandemic, are extending their advocacy work and research focus to include long Covid (see Chronic Illness Inclusion 2021; #MEAction UK 2022). Structural changes proposed by one such organisation include a coordinated, multidisciplinary healthcare approach for complex clinical issues that considers patients as equal partners in clinical decision-making and management, alongside enhanced integration of social care and welfare support (Hale *et al.* 2021). Importantly, a fundamental shift in attitudes towards chronically ill and disabled people is also advocated, including recognition of medical uncertainty (Hale et al. 2021). While these recommendations are echoed both by clinicians with long Covid and research bodies (Maxwell and Poole 2021; Alwan et al. 2020), it is noteworthy that similar proposals were made by disability activist and advocacy organisations prepandemic (Hale et al. 2020; Leary et al. 2019) and were accorded less mainstream attention.

Translating the above into training and practice, clinicians should acknowledge that the healthcare and social security system can be both a structurally disabling barrier and source of psycho-emotional disablism and commit to practising in a such a way that does not perpetuate such disablism. Examples include supporting social security applications and social care needs assessments where appropriate, signposting to organisations that provide further support in this regard and, once again, validating patient testimony (Altiery de Jesus et al. 2021). Further, while clinicians are typically trained to inspire confidence in patients, balancing this with recognition of professional and structural limitations (including medical uncertainty) may engender a more relational approach facilitative of patient trust and mutual respect (Beach and Inui 2006). In terms of coeducators, already suggested in the field of other marginalised chronic illness (Chew-Graham et al. 2010) ered. Central to critical approaches, including critical disability studies, is 'making (the familiar) strange' (Paradis et al. 2020, 843), that is, interrogating and/or problematising dominant assumptions and norms, typically with the aim of proposing counternarratives and imagining new, socially inclusive, possibilities. It could be contended that marginalised groups, drawing <u>a</u> on subjugated knowledges, are particularly well positioned to facilitate the construction of counternarratives and imagining of structurally competent, socially and epistemically just healthcare policy and practice. This is not to argue that disabled and chronically ill persons have an epistemic privilege per se, but that they have privileged knowledge vis-à-vis the lived experience of disability, including the negotiation of ableist and disabling structures (see Campbell 2009b; Carel and Kidd 2014; Blease, Carel, and Geraghty 2017). Finally, while activist organisations and disabled people outside of the medical profession can be a valuable resource for informing training and practice, it is important to acknowledge that there are valuable resources within the medical profession itself. That is, epistemic contributions from disabled medical students and clinicians should be actively sought out in informing education and practice, while measures are necessary to address the under-representation of disabled people within medical school intakes (Shrewsbury 2014).

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### 'DEVELOPING STRUCTURAL HUMILITY'

This skill set is described as 'the trained ability to recognize the limitations of structural competency' (Metzl and Hansen 2014, 131), which can be understood in various ways. First, as Metzl and Hansen (2014) highlight, it is important to be realistic about the remit of medical education. This may be understood as a recognition that structural competency is a process, not a tick box exercise; striving for structural competency will forever be work in progress. This is important in avoiding clinical overwhelm and burn-out: structural competency does not demand that clinicians are experts at everything 'structural' in addition to their intensive biomedical training, neither does it require that medical students become fully conversant with the canon of disability studies literature. Rather, structural competency encourages students and qualified clinicians to be aware of, and open to, epistemological and ontological positions beyond those espoused by the biomedical model, and disability studies offers a way of facilitating this (Couser 2011). Integrating different theoretical perspectives into medical curricula from the very beginning of training programmes would facilitate the fostering of structural competency in a manageable way. Further, given the previous outlining of theoretical challenges to the social model of disability, alongside divisions between medical sociology and disability studies (Thomas 2007), structural humility might involve recognising that overly focusing on structural disablement while downplaying bodily limitations and suffering would be counterproductive. The social relational model of disability, further embedded in thinking from critical disability studies, could offer balance and compromise between medical model and social model paradigms, recognising that people can be disabled by a complex interplay of structures, bodies and minds (Thomas 2022; Shakespeare 2014).

Structural humility may also be understood as taking a critically reflexive stance to structural competency, recognising the sociohistorical situatedness of such competency, and the need to develop and redefine competency as social conditions evolve. This involves creating a culture within medical education where students feel confident in asking 'difficult' questions, problematising the status quo and, where appropriate, challenging the assumed epistemic authority of educators (Halman et al. 2017). A dialogical, critical pedagogy approach (see Freire 1993) is necessary to foster openness and challenge power differentials within medical education. Questioning taken-for-granted norms and assumptions, acknowledging uncertainty, and reflexive interrogation are all central to critical approaches, including critical disability studies (Meekosha and Shuttleworth 2009; Shildrick 2020), again highlighting the potential value of a partnership between disability studies and medicine.

Finally, although moving away from Metzl and Hansen's definition, structural humility might also be conceptualised as epistemic humility vis-à-vis the impact of structural factors on the well-being of each individual patient. Within a disability context, this requires recognition that each person's experience of disability and impairment is unique and will be impacted by, among other factors, intersectional concerns (Shildrick 2020; Sherry 2016). Critical disability studies, drawing from feminism among other disciplines, grapples with the ethical issues involved in representing the concerns of marginalised others (see Campbell 2009b) and provides a cartography for clinical practice in the realm of long Covid and other marginalised patient groups. While some clinicians with long Covid report that they now have an enhanced understanding of the experience of poorly treated chronic illness (Taylor *et al.* 2021), clinicians should also

be cognisant of how their social positionality intersects with and impacts on their experience. In other words, not all people within the long Covid and broader chronic illness community have the same or similar experiences of chronic illness and disability, and this is particularly important when representation of others proceeds from a position of relative social privilege. Falsely assuming homogeneity of experience may result in more marginally situated experiences and knowledges being 'co-opted and erased' (see Ruddock and Gkiouleka 2020). Epistemic humility, which involves valuing epistemologies other than one's own, has been proposed as a form of epistemic justice, and as an ingredient which may facilitate more collaborative care partnership, notably from within the realm of poorly delineated and difficult-to-treat health conditions (Buchman, Ho, and Goldberg 2017); the same might be argued of structural humility.

### CONCLUSION

Disability studies has much to offer medical education and practice, yet is currently under-represented in medical curricula and medical education literature. While possibilities from a partnership between disability studies and medicine are numerous, this article has focused on the social relational model of disability and the concept of psycho-emotional disablism, within a broader critical disability studies framework, as a pathway to a more nuanced and structurally competent understanding of chronic illness and disability. Long Covid, specifically those subgroups lacking biomarkers, has been discussed as a topical example of how knowledge from disability studies can be harnessed to facilitate more holistic, equitable and patient-centred healthcare for chronically ill and disabled persons. In particular, it has been argued that inadequate healthcare provision and policy in the realm of long Covid can be understood as a form of structural (dis)ableism and psycho-emotional disablism, carrying a risk of furthering both disability and impairment. These structural factors have been further located within an ableist psychosocial imaginary, imbued with neoliberal ideology and manifesting at every level of analysis, from micro-level encounters to macrolevel policies of retrenchment across health and welfare sectors. Prejudicial attitudes towards disabled people, deeply rooted within this psychosocial imaginary, suggest that changes to **\geq** policy are necessary but not sufficient, further highlighting the need for fundamental change through structurally competent, antiableist medical curricula. From a practical perspective, the possibility of integrating thinking from disability studies into a structural competency framework (Metzl and Hansen 2014) has been discussed. A structurally competent approach to chronic illness and disability also offers a pathway to mitigating welldocumented tensions within the clinician-patient relationship by positioning practitioner and patient as allies, working together within a sociostructural context that is acknowledged as constraining to both parties. Given the likelihood of a wave of covid-related disability, it is more important than ever to integrate disability studies into medicine.

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#### **BIBLIOGRAPHY**

- Adams, G., S. Estrada-Villalta, D. Sullivan, and H. R. Markus. 2019. "The Psychology of Neoliberalism and the Neoliberalism of Psychology." *Journal of Social Issues* 75 (1): 189–216.
- Altiery de Jesus, V., N. Alwan, F. Callard, and Z. Berger. 2021. "Listening to Long COVID: Epistemic Injustice and COVID-19 Morbidity." OSF Preprints. https://doi.org/
- Alwan, N. A., E. Attree, J. M. Blair, D. Bogaert, M.-A. Bowen, J. Boyle, M. Bradman, et al. 2020. "From Doctors as Patients: A Manifesto for Tackling Persisting Symptoms of Covid-19." BMJ (Clinical Research Ed.) 370: m3565. https://doi.org/
- Aragon, C., and A. M. Jaggar. 2018. "Agency, Complicity, and the Responsibility to Resist Structural Injustice." *Journal of Social Philosophy* 49 (3): 439–60.
- Aristizabal, M. J., I. Anreiter, T. Halldorsdottir, C. L. Odgers, T. W. McDade, A. Goldenberg, S. Mostafavi, et al. 2020. "Biological Embedding of Experience: A Primer on Epigenetics." Proceedings of the National Academy of Sciences of the United States of America 117 (38): 23261–69.
- Barnes, C. 2020. "Understanding the Social Model of Disability: Past, Present and Future." In *Routledge Handbook of Disability Studies*, edited by N. Watson and S. Vehmas, 14–31. Abingdon, Routledge.
- Barry, M. J., and S. Edgman-Levitan. 2012. "Shared Decision Making--Pinnacle of Patient-Centered Care." *The New England Journal of Medicine* 366 (9): 780–81.
- Batalden, M., P. Batalden, P. Margolis, M. Seid, G. Armstrong, L. Opipari-Arrigan, and H. Hartung. 2016. "Coproduction of Healthcare Service." BMJ Quality & Safety 25 (7): 509–17
- BBC. 2020. "I'm Not the First GP to Lose My Job over Long Covid I Won't Be the Last". BBC News." https://www.bbc.co.uk/news/av/uk-scotland-54897677.
- Bê, A. 2016. "Disablism in the Lives of People Living with a Chronic Illness in England and Portugal." Disability & Society 31 (4): 465–80.
- Beach, M. C., T. Inui, and Relationship-Centered Care Research Network. 2006.

  "Relationship-Centered Care. A Constructive Reframing." Journal of General Internal
  Medicine 21 Suppl 1.
- Berger, G. 2014. "Gordon Waddell's Biopsychosocial Attack on Disabled People".

  Disabled People Against Cuts (DPAC)." https://dpac.uk.net/2014/09/gordon-waddells-biopsychosocial-attack-on-disabled-people/#:~:text=Gordon%

  20Waddell%E2%80%99s%20biopsychosocial%20attack%20on%20disabled%

  20people.%20Atos%2C,in%20need%20of%20financial%2C%20moral%20and%

  20social%20support.
- Blease, C., H. Carel, and K. Geraghty. 2017. "Epistemic Injustice in Healthcare Encounters: Evidence from Chronic Fatigue Syndrome." Journal of Medical Ethics 43 (8): 549–57.
- Buchman, D. Z., A. Ho, and D. S. Goldberg. 2017. "Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain." *Journal of Bioethical Inquiry* 14 (1): 31–42.
- Byrne, E. A. 2022. "Understanding Long Covid: Nosology, Social Attitudes and Stigma." Brain, Behavior, and Immunity 99: S0889-1591(21)00556-0: 17–24. https://doi.org/
- Callard, F. 2020. "Very, Very Mild: Covid-19 Symptoms and Illness Classification". Somatosphere." http://somatosphere.net/2020/mild-covid.html/.
- Callard, F., and E. Perego. 2021. "How and Why Patients Made Long Covid." Social Science & Medicine (1982) 268: S0277-9536(20)30645-6.
- Campbell, F. K. 2009a. "Medical Education and Disability Studies." *The Journal of Medical Humanities* 30 (4): 221–35. https://doi.org/
- Campbell, F. K. 2009b. Contours of Ableism: Territories, Objects, Disability and Desire. London: Palgrave Macmillan.
- Carel, H., and I. J. Kidd. 2014. "Epistemic Injustice in Healthcare: A Philosophial Analysis." Medicine, Health Care, and Philosophy 17 (4): 529–40. https://doi.org/
- Centers for Disease Control and Prevention (CDC). 2021. "Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Treatment of ME/CFS." https://www.cdc.gov/me-cfs/treatment/index.html.
- Cheshire, A., D. Ridge, J. Hughes, D. Peters, M. Panagioti, C. Simon, G. Lewith, et al. 2017. "Influences on GP Coping and Resilience: A Qualitative Study in Primary Care." The British Journal of General Practice 67 (659).
- Chew-Graham, C., C. Dowrick, A. Wearden, V. Richardson, and S. Peters. 2010. "Making the Diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalitis in Primary Care: A Qualitative Study." *BMC Family Practice* 11: 16.

- Chronic Illness Inclusion. 2021. "Chronic Illness Inclusion." https://chronicillnessinclusion. orq.uk/.
- Clifford, E. 2020. The War on Disabled People: Capitalism, Welfare and the Making of a Human Catastrophe. London: Ze Books Ltd.
- Coulehan, J., and P. C. Williams. 2001. "Vanquishing Virtue: The Impact of Medical Education." *Academic Medicine* 76 (6): 598–605.
- Couser, G. T. 2011. "What Disability Studies Has to Offer Medical Education." *The Journal of Medical Humanities* 32 (1): 21–30. https://doi.org/
- Crow, L. 1996. "Including All Our Lives: Renewing the Social Model of Disability." In Exploring the Divide: Illness and Disability, edited by C. Barnes and G. Mercer, 55–72. Leeds: The Disability Press.
- Davis, N. 2022. "Long Covid Could Create a Generation Affected by Disability, Expert Warns." The Guardian." https://www.theguardian.com/society/2022/mar/23/long-covid-could-create-a-generation-affected-by-disability-expert-warns.
- Davis, H. E., G. S. Assaf, L. McCorkell, H. Wei, R. J. Low, Y. Re'em, S. Redfield, J. P. Austin, and A. Akrami. 2021. "Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact." *EClinical Medicine* 38.
- De Wolfe, P. 2012. "Reaping the Benefits of Sickness? Long-Term Illness and the Experience of Welfare Claims." *Disability & Society* 27 (5): 617–30.
- Décany, S., I. Gaboury, S. Poirier, C. Garcia, S. Simpson, M. Bull, D. Brown, and F. Daigle. 2021. "Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." *The Journal of Orthopaedic and Sports Physical Therapy* 51 (5): 197–200.
- Dennis, A., M. Wamil, J. Alberts, J. Oben, D. J. Cuthbertson, D. Wootton, M. Crooks, et al. COVERSCAN study investigators. 2021. "Multiorgan Impairment in Low-Risk Individuals with Post-COVID-19 Syndrome: A Prospective, Community-Based Study." BMJ Open 11 (3): e048391.
- Devendorf, A. R., S. L. McManimen, L. A. Jason, S. L. McManimen, and L. A. Jason. 2020. "Suicidal Ideation in Non-Depressed Individuals: The Effects of a Chronic, Misunderstood Illness." *Journal of Health Psychology* 25 (13–14): 2106–17.
- Diniz, E., P. Castro, A. Bousfield, S. Figueira Bernardes, P. Castro, and A. Bousfield. 2020. "Classism and Dehumanization in Chronic Pain: A Qualitative Study of Nurses' Inferences about Women of Different Socio-Economic Status." British Journal of Health Psychology 25 (1): 152–70.
- Edwards, C. R., A. R. Thompson, A. Blair, C. R. Edwards, A. R. Thompson, and A. Blair. 2007. "An 'Overwhelming Illness': Women's Experiences of Learning to Live with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis." *Journal of Health Psychology* 12 (2): 203–14.
- Engel, G. L. 1977. "The Need for A New Medical Model: A Challenge for Biomedicine." Science (New York, N.Y.) 196 (4286): 129–36.
- Englander, R., E. Holmboe, P. Batalden, R. M. Caron, C. F. Durham, T. Foster, G. Ogrinc, et al. 2020. "Coproducing Health Professions Education: A Prerequisite to Coproducing Health Care Services?" Academic Medicine 95 (7): 1006–13.
- Faulkner, G. 2016. "'In the Expectation of Recovery': Misleading Medical Research and Welfare Reform." Sheffield: The Centre for Welfare Reform.
- Finkelstein, V. 1980. Attitudes and Disabled People: Issues for Discussion. New York: World Rehabilitation Fund.
- Flottorp, S. A., K. G. Brurberg, P. Fink, H. Knoop, V. B. B. Wyller, and V. B. B. Wyller. 2022. "New NICE Guideline on Chronic Fatigue Syndrome: More Ideology than Science?" Lancet (London, England) 399 (10325): S0140-6736(22)00183-0: 611–13.
- Freire, P. 1993. Pedagogy of the Oppressed. 20th anniversary ed. Continuum.
- Garland-Thomson, R. 1997. Extraordinary Bodies: Figuring Disability in American Literature and Culture. New York: Columbia University Press.
- Garner, P. 2021. "Paul Garner: On His Recovery from Long Covid. BMJ Opinion." https://blogs.bmj.com/bmj/2021/01/25/paul-garner-on-his-recovery-from-long-covid/.
- General Medical Council (GMC). 2018. "Outcomes for Graduates." https://www.gmc-uk. org/-/media/documents/outcomes-for-graduates-2020\_pdf-84622587.pdf?la=en& hash=35E569DEB208E71D666BA91CE58E5337CD569945.
- Geraghty, K. J., and C. Blease. 2019. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and the Biopsychosocial Model: A Review of Patient Harm and Distress in the Medical Encounter." *Disability and Rehabilitation* 41 (25): 3092–3102.
- Geraghty, K., M. Hann, and S. Kurtev. 2019. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients' Reports of Symptom Changes Following Cognitive Behavioural Therapy, Graded Exercise Therapy and Pacing Treatments: Analysis of a Primary Survey Compared with Secondary Surveys." Journal of Health Psychology 24 (10): 1318–33.
- Geuss, R. 1981. *The Idea of a Critical Theory: Habermas and the Frankfurt School*. Cambridge, England: Cambridge University Press.
- Gkiouleka, A., T. Huijts, J. Beckfield, and C. Bambra. 2018. "Understanding the Micro and Macro Politics of Health: Inequalities, Intersectionality & Institutions - A Research Agenda." Social Science & Medicine (1982) 200: S0277-9536(18)30025-X: 92–98.
- Goel, R. R., and N. M. Kavanagh. 2020. "Beyond Structural Competency: Why Politics Should Be Taught During Medical Education." Academic Medicine 95 (11): e10.
- Goldenberg, M. J. 2006. "On Evidence and Evidence-Based Medicine: Lessons from the Philosophy of Science." Social Science & Medicine (1982) 62 (11): 2621–32.
- Goodley, D. 2013. "Dis/Entangling Critical Disability Studies." *Disability & Society* 28 (5): 631–44.

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- Gregoire, B., L. Trager, and J. Blum. 2021. "Coproduction in Medical Education during the COVID-19 Pandemic: Critical Components of Successful Curricular Reform." *International Journal for Quality in Health Care* 33 (Supplement\_2).
- Grobbelaar, L. M., C. Venter, M. Vlok, M. Ngoepe, G. J. Laubscher, P. J. Lourens, J. Steenkamp, et al. 2021. "SARS-CoV-2 Spike Protein S1 Induces Fibrin(Ogen) Resistant to Fibrinolysis: Implications for Microclot Formation in COVID-19." Bioscience Reports 41 (8): BSR20210611.
- Hafferty, F. W. 1998. "Beyond Curriculum Reform: Confronting Medicine's Hidden Curriculum." *Academic Medicine* 73 (4): 403–7.
- Hale, C., S. Benstead, J. Lyus, E. Odell, and A. Ruddock. 2020. "Energy Impairment and Disability Inclusion: Towards an Advocacy Movement for Energy Limiting Chronic Illness". Centre for Welfare Reform." https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/energy-impairment-and-disability-inclusion.pdf.
- Hale, C., J. Brough, A. Allam, S. Lydiard, F. Springfield, A. Fixter, N. Wright, V. Clutton, and K. Bole. 2021. "Submission to the Department of Health and Social Care's Inquiry into Women's Health and Wellbeing in England". Chronic Illness Inclusion." https://chronicillnessinclusion.org.uk/wp-content/uploads/2021/06/CII.DHSC-Womens-Health-England-June-2021.pdf.
- Halman, M., L. Baker, S. Ng, L. Baker, and S. Ng. 2017. "Using Critical Consciousness to Inform Health Professions Education: A Literature Review." *Perspectives on Medical Education* 6 (1): 12–20.
- Heise, L., M. E. Greene, N. Opper, M. Stavropoulou, C. Harper, M. Nascimento, D. Zewdie, et al, and Gender Equality, Norms, and Health Steering Committee. 2019. "Gender Inequality and Restrictive Gender Norms: Framing the Challenges to Health." Lancet (London, England) 393 (10189): S0140-6736(19)30652-X: 2440–54.
- Hoffmann, D. E., and A. J. Tarzian. 2001. "The Girl Who Cried Pain: A Bias against Women in the Treatment of Pain." *The Journal of Law, Medicine & Ethics* 29 (1): 13–27.
- Horton-Salway, M. 2002. "Bio-Psycho-Social Reasoning in GPs' Case Narratives: The Discursive Construction of ME Patients' Identities." *Health* 6 (4): 401–21. https://doi.org/
- Hughes, B. 2000. "Medicine and the Aesthetic Invalidation of Disabled People." Disability & Society 15 (4): 555–68.
- Hughes, B. 2007. "Being Disabled: Towards a Critical Social Ontology for Disability Studies." *Disability & Society* 22 (7): 673–84.
- Hughes, B., and K. Paterson. 1997. "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment." *Disability & Society* 12 (3): 325–40.
- Humphreys, H., L. Kilby, N. Kudiersky, and R. Copeland. 2021. "Long COVID and the Role of Physical Activity: A Qualitative Study." BMJ Open 11 (3): e047632.
- Hunt, J. 2020. "Why Is the NHS III-Equipped to Care for Long Covid Patients? Lessons from MUS and Chronic Illness." Healthcare Hubris, 29 October. https://www. healthcarehubris.com/post/why-is-the-nhs-ill-equipped-to-care-for-long-covidpatients-lessons-from-mus-and-chronic-illness.
- Hunt, J. 2021. "Structural Dimensions of the Biopsychosocial Model (Full Series of Blogposts)." Healthcare Hubris, 5 June. https://www.healthcarehubris.com/post/ with-references-structural-dimensions-of-the-biopsychosocial-model-full-series-ofblogposts.
- Hunt, J. 2022. "Towards a Critical Psychology of Chronic Fatigue Syndrome: Biopsychosocial Narratives and UK Welfare Reform." Journal of Critical Psychology, Counselling and Psychotherapy 22 (1): 18–28.
- Hunt, J., C. Blease, and K. Geraghty. 2022. "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. https://doi.org/
- Johansen, M.-L., and M. B. Risor. 2017. "What Is the Problem with Medically Unexplained Symptoms for GPs? A Meta-Synthesis of Qualitative Studies." Patient Education and Counseling 100 (4): S0738-3991(16)30542-0: 647–54.
- Jolly, D. 2012. "A Tale of Two Models: Disabled People vs Unum, Atos, Government and Disability Charities". Disabled People Against Cuts (DPAC)." http://dpac.uk.net/2012/ 04/a-tale-of-two-models-disabled-people-vs-unum-atos-government-and-disabilitycharities-debbie-jolly/.
- Jumreornvong, O., L. Tabacof, M. Cortes, J. Tosto, C. P. Kellner, J. E. Herrera, and D. Putrino. 2020. "Ensuring Equity for People Living with Disabilities in the Age of COVID-19." *Disability & Society* 35 (10): 1682–87.
- Kalfas, M., A. Smakowski, C. Hirsch, F. Simiao, and T. Chalder. 2022. "Generalized Worry in Patients With Chronic Fatigue Syndrome Following Cognitive Behavioral Therapy: A Prospective Cohort Study in Secondary Care." Behavior Therapy, January.
- Kingstone, T., A. K. Taylor, C. A. O'Donnell, H. Atherton, D. N. Blane, and C. A. Chew-Graham. 2020. "Finding the 'Right' GP: A Qualitative Study of the Experiences of People with Long-COVID." BJGP Open 4 (5): bjgpopen20X101143: .
- Kitchin, R. 1998. "'Out of Place', 'Knowing One's Place': Space, Power and the Exclusion of Disabled People." *Disability & Society* 13 (3): 343–56.
- Ladds, E., A. Rushforth, S. Wieringa, S. Taylor, C. Rayner, L. Husain, and T. Greenhalgh. 2020. "Persistent Symptoms after Covid-19: Qualitative Study of 114 'Long Covid' Patients and Draft Quality Principles for Services." BMC Health Services Research 20 (1): 1144.
- Leary, S., J. Sylvester, E. Shorter, and E. Moreno. 2019. "Your Experience of ME Services: Survey Report by #MEAction UK." http://y9ukb3xpraw1vtswp2e7ia6u-wpengine.

- netdna-ssl.com/wp-content/uploads/2019/11/Your-experience-of-ME-services-Survey-report-by-MEAction-UK.pdf.
- Lempp, H., and C. Seale. 2004. "The Hidden Curriculum in Undergraduate Medical Education: Qualitative Study of Medical Students' Perceptions of Teaching." BMJ (Clinical Research Ed.) 329 (7469): 770–73.
- Lokugamage, A. U., S. Taylor, and C. Rayner. 2020. "Patients' Experiences of 'Longcovid'
  Are Missing from the NHS Narrative. BMJ Opinion." https://blogs.bmj.com/bmj/2020/
  07/10/patients-experiences-of-longcovid-are-missing-from-the-nhs-narrative/.
- Macpherson, K., K. Cooper, J. Harbour, D. Mahal, C. Miller, and M. Nairn. 2022.
  "Experiences of Living with Long COVID and of Accessing Healthcare Services: A Qualitative Systematic Review." BMJ Open 12 (1): e050979.
- Manca, A., G. J. Gormley, J. L. Johnston, N. D. Hart, A. Manca, G. J. Gormley, J. L. Johnston, and N. D. Hart. 2020. "Honoring Medicine's Social Contract: A Scoping Review of Critical Consciousness in Medical Education." Academic Medicine 95 (6): 958–67.
- Maxwell, E. 2020. "Living With Covid 19: A Dynamic Review of the Evidence Around Ongoing Covid 19 Symptoms (Often Called Long Covid)". National Institute for Health Research." https://evidence.nihr.ac.uk/themedreview/living-with-covid19/.
- Maxwell, E., and R. Poole. 2021. "Living with Covid19 Second Review: A Dynamic Review of the Evidence around on Ongoing Covid19 (Often Called Long Covid)". National Institute for Health Research." https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/.
- McEvedy, C. P., and A. W. Beard. 1970. "Royal Free Epidemic of 1955: A Reconsideration." British Medical Journal 1 (5687): 7–11.
- MEAction UK. 2022. "About #MEAction UK." https://www.meaction.net/countries/uk/.
  Mead, N., and P. Bower. 2000. "Patient-Centredness: A Conceptual Framework and Review
  of the Empirical Literature." Social Science & Medicine (1982) 51 (7): 1087–1110.
- Meekosha, H., and R. Shuttleworth. 2009. "What's So Critical About Critical Disability Studies." Australian Journal of Human Rights 15 (1): 47–75.
- Metzl, J. M., and H. Hansen. 2014. "Structural Competency: Theorizing a New Medical Engagement with Stigma and Inequality." Social Science & Medicine (1982) 103: S0277-9536(13)00377-8: 126–33.
- Morris, J., ed. 1996. Encounters with Strangers: Feminism and Disability. London: The Women's Press.
- Morris, J. 2007. "Personal and Political: A Feminist Perspective on Researching Physical Disability." *Disability, Handicap & Society* 7 (2): 157–66.
- National Health Service (NHS). 2021. "Getting Moving Again: Why Is Getting Moving Again Important." https://www.yourcovidrecovery.nhs.uk/your-wellbeing/getting-moving-again/.
- National Institute for Health and Care Excellence (NICE). 2020. "Myalgic Encephalomyelitis (or Encephalopathy) / Chronic Fatigue Syndrome: Diagnosis and Management. Evidence Reviews for the Non- Pharmacological Management of ME/CFS." https://www.nice.org.uk/guidance/GID-NG10091/documents/evidence-review-7.
- National Institute for Health and Care Excellence (NICE). 2021. "Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome: Diagnosis and Management NICE Guideline [NG206]." https://www.nice.org.uk/guidance/NG206.
- National Institute for Health and Care Excellence (NICE). 2022. "COVID-19 Rapid Guideline: Managing the Long-Term Effects of COVID-19.V.1.13." https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742.
- Ng, S. L., S. R. Wright, A. Kuper, S. L. Ng, S. R. Wright, and A. Kuper. 2019. "The Divergence and Convergence of Critical Reflection and Critical Reflexivity: Implications for Health Professions Education." Academic Medicine 94 (8): 1122–28.
- Oliver, M. 1990. The Politics of Disablement. Basingstoke: Macmillan.
- O'Leary, D. 2018. "Why Bioethics Should Be Concerned With Medically Unexplained Symptoms." *The American Journal of Bioethics* 18 (5): 6–15.
- Palmer, V. J., W. Weavell, R. Callander, D. Piper, L. Richard, L. Maher, H. Boyd, et al. 2019. "The Participatory Zeitgeist: An Explanatory Theoretical Model of Change in an Era of Coproduction and Codesign in Healthcare Improvement." Medical Humanities 45 (3): 247–57.
- Paradis, E., L. Nimmon, D. Wondimagegn, and C. R. Whitehead. 2020. "Critical Theory: Broadening Our Thinking to Explore the Structural Factors at Play in Health Professions Education." *Academic Medicine* 95 (6): 842–45.
- Patient-Led Research Collaborative. 2020. "Report: What Does COVID-19 Recovery Actually Look like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team." https://patientresearchcovid19.com/research/report-1/.
- Perego, E., F. Callard, L. Stras, B. Melville-Jóhannesson, R. Pope, and N. A. Alwan. 2020. "Why the Patient-Made Term 'Long Covid' Is Needed." Wellcome Open Research 5.
- Proal, A. D., and M. B. VanElzakker. 2021. "Long COVID or Post-Acute Sequelae of COVID-19 (PASC): An Overview of Biological Factors That May Contribute to Persistent Symptoms." Frontiers in Microbiology 12: 698169.
- Puntmann, V. O., M. L. Carerj, I. Wieters, M. Fahim, C. Arendt, J. Hoffmann, A. Shchendrygina, et al. 2020. "Outcomes of Cardiovascular Magnetic Resonance Imaging in Patients Recently Recovered From Coronavirus Disease 2019 (COVID-19)." JAMA Cardiology 5 (11): 1265–73.
- Raine, R., S. Carter, T. Sensky, N. Black, R. Raine, S. Carter, and N. Black. 2004. "General Practitioners' Perceptions of Chronic Fatigue Syndrome and Beliefs about Its Management, Compared with Irritable Bowel Syndrome: Qualitative Study." BMJ (Clinical Research Ed) 328 (7452): 1354–57.

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### Original research

- Razai, M. S., H. K. N. Kankam, A. Majeed, A. Esmail, and D. R. Williams. 2021. "Mitigating Ethnic Disparities in Covid-19 and Beyond." BMJ (Clinical Research Ed) 372: m4921.
- Reeve, D. 2006. "Towards a Psychology of Disability: The Emotional Effects of Living in a Disabling Society." In *Disability and Psychology: Critical Introductions and Reflections*, edited by D. Goodley and R. Lawthom, 94–107. London: Palgrave Macmillan.
- Reeve, D. 2020. "Psycho-Emotional Disablism: The Missing Link?" In Routledge Handbook of Disability Studies, edited by N. Watson and S. Vehmas, 102–16. Abingdon, Routledge.
- Rowland, P., and A. Kuper. 2018. "Beyond Vulnerability: How the Dual Role of Patient-Health Care Provider Can Inform Health Professions Education." *Advances in Health Sciences Education* 23 (1): 115–31. https://doi.org/
- Ruddock, A., and A. Gkiouleka. 2020. "I Feel Forgotten.' A Submission by the Chronic Illness Inclusion Project to the Women and Equalities Committee Inquiry into the Impact of Coronavirus (Covid-19) on People with Protected Characteristics". Centre for Welfare Reform." https://citizen-network.org/library/i-feel-forgotten. html.
- Rutherford, J. 2007. "New Labour, the Market State, and the End of Welfare." *Soundings* 36 (36): 40–55. https://doi.org/
- Sandars, J. E. 2016. "Critical Theory and the Scholarship of Medical Education." International Journal of Medical Education 7: ijme.7.246247: 246–47.
- Scambler, G. 2018. "Heaping Blame on Shame: 'Weaponising Stigma' for Neoliberal Times." *The Sociological Review* 66 (4): 766–82. https://doi.org/
- Scheyett, A. 2006. "Silence and Surveillance: Mental Illness, Evidence-Based Practice, and a Foucaultian Lens." Journal of Progressive Human Services 17 (1): 71–92.
- Schoemaker, C. G. 2021. "The Patient Voice: A Biased or Valuable Source of Information." https://blogs.bmj.com/pmj/2021/05/17/the-patient-voice-a-biased-or-valuable-source-of-information/.
- Shakespeare, T. 2014. *Disability Rights and Wrongs Revisited*. 2nd ed. Abingdon: Routledge.
- Shakespeare, T., N. Watson, and O. A. Alghaib. 2016. "Blaming the Victim, All over Again: Waddell and Aylward's Biopsychosocial (BPS) Model of Disability." *Critical Social Policy* 37 (1): 22–41.
- Sharpe, M. 2021. "Post-Covid-19 Syndrome (Long-Covid)." https://www.swissre.com/dam/jcr:788aa287-7026-430a-8c14-f656421b6e71/swiss-re-institute-event-secondary-covid19-impacts-presentation-michael-sharpe.pdf.
- Sherry, M. 2016. "A Sociology of Impairment." Disability & Society 31 (6): 729-44.
- Shildrick, M. 2020. "Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity." In Routledge Handbook of Disability Studies, edited by N. Watson and S. Vehmas, 32–44. Abingdon, Routledge.
- Shrewsbury, D. 2014. "Disability and Participation in the Professions: Examples from Higher and Medical Education." *Disability & Society* 30 (1): 87–100.
- Sloan, T. 2009. "Doing Theory." In Critical Psychology: An Introduction, edited by D. Fox and Prilleltensky S. Austin I, 2nd ed, 318–33. London: SAGE Publications.
- Soldatic, K. 2020. "Social Suffering in the Neoliberal Age: Surplusisty and the Partially Disabled Subject." In Routledge Handbook of Disability Studies, edited by N. Watson and S. Vehmas, 237–49. Abingdon, Routledge.

- Stanley, I., P. Salmon, and S. Peters. 2002. "Doctors and Social Epidemics: The Problem of Persistent Unexplained Physical Symptoms, Including Chronic Fatigue." The British Journal of General Practice 52 (478): 355–56.
- Stewart, M. 2016. Cash Not Care: The Planned Demolition of the UK Welfare State. London: New Generation Publishing.
- Tait, R. C., and J. T. Chibnall. 2014. "Racial/Ethnic Disparities in the Assessment and Treatment of Pain: Psychosocial Perspectives." *The American Psychologist* 69 (2): 131–41
- Taylor, A. K., T. Kingstone, T. A. Briggs, C. A. O'Donnell, H. Atherton, D. N. Blane, and C. A. Chew-Graham. 2021. "'Reluctant Pioneer': A Qualitative Study of Doctors' Experiences as Patients with Long COVID." Health Expectations 24 (3): 833–42.
- Thomas, C. 1999. Female Forms: Experiencing and Understanding Disability. Maidenhead: Open University Press.
- Thomas, C. 2007. Sociologies of Disability and Illness. London: Springer Nature. https://doi.org/
- Thomas, G. M. 2022. "A Legacy of Silence: The Intersections of Medical Sociology and Disability Studies." *Medical Humanities* 48 (1): 123–32. https://doi.org/
- Tremain, S. 2001. "On the Government of Disability." Social Theory and Practice 27 (4): 617–36. https://doi.org/
- Trueland, J. 2020. "Doctors with Long Covid". BMA." https://www.bma.org.uk/news-and-opinion/doctors-with-long-covid.
- Tucker, M., and P. Kenyon. 2021. "Long Covid Pay Decision for Key Workers Could Take a Year". BBC News." https://www.bbc.co.uk/news/uk-57146120.
- Turan, J. M., M. A. Elafros, C. H. Logie, S. Banik, B. Turan, K. B. Crockett, B. Pescosolido, S. M. Murray, et al. 2019. "Challenges and Opportunities in Examining and Addressing Intersectional Stigma and Health." BMC Medicine 17 (1): 7.
- Turk, E., A. Durrance-Bagale, E. Han, S. Bell, S. Rajan, M. M. M. Lota, C. Ochu, et al. 2021. "International Experiences with Co-Production and People Centredness Offer Lessons for Covid-19 Responses." BMJ (Clinical Research Ed) 372: m4752.
- Union of the Physically Impaired against Segregation (UPIAS). 1976. Fundamental Principles of Disability. London: UPIAS.
- Veal, C. T. 2021. "We Burn Out, We Break, We Die: Medical Schools Must Change Their Culture to Preserve Medical Student Mental Health." Academic Medicine 96 (5): 629–31. https://doi.org/
- Venturelli, S., S. V. Benatti, M. Casati, F. Binda, G. Zuglian, G. Imeri, C. Conti, et al. 2021. "Surviving COVID-19 in Bergamo Province: A Post-Acute Outpatient Re-Evaluation." Epidemiology and Infection 149: e32.
- Verveen, A., F. Müller, A. Lloyd, R. Moss-Morris, T. Omland, B. Penninx, R. P. H. Raijmakers, et al. 2022. "A Research Agenda for Post-COVID-19 Fatigue." Journal of Psychosomatic Research 154: S0022-3999(22)00011-3.
- Yong, S. J., S. Liu, S. J. Yong, and S. Liu. 2021. "Proposed Subtypes of Post-COVID-19 Syndrome (or Long-COVID) and Their Respective Potential Therapies." Reviews in Medical Virology.
- Ziauddeen, N., D. Gurdasani, M. E. O'Hara, C. Hastie, P. Roderick, G. Yao, and N. A. Alwan. 2022. "Characteristics and Impact of Long Covid: Findings from an Online Survey." Plos One 17 (3): e0264331.