Examining the political underbelly of ME/CFS and Long Covid

Welfare reform, corporate profiteering, academic collusion, and the biopsychosocial model, by Joanne Hunt

How the world sees me

INTRODUCTION: MY ROUTE INTO RESEARCH

I have lived with the symptoms of ME/CFS since very early childhood but was diagnosed in my teenage years. Now in my forties, I have experienced endless tugs-of-war with healthcare practitioners over my treatment, which has comprised little more than psychosocial interventions (including graded exercise and cognitive behavioural therapies), that I believe have caused me significant harm.

Additionally, I have found the attitude of most of my healthcare providers – dismissive, apparently unconcerned and sometimes derisive – to be incredibly damaging. This has been exacerbated by delayed diagnoses, having very little social support and, as a woman from a working-class background, apparently occupying the 'hysterical, incompetent, attention-seeking' space in the collective clinical imagination.

After a short career in central government (curtailed by untreated chronic illness and unaccommodated disability), I re-trained in psychology and psychological therapies, slowly and painfully over many years, and became fascinated as to what was driving the systematic clinical and societal disability denial that I was experiencing.

I began to research the political backdrop to ME/CFS healthcare and to consider what individual and collective psychological needs might be served by mainstream representations of ME/CFS (that is, representing ME/CFS as a psychosocial entity to be 'treated' by cognitive and behavioural interventions).

The result has been a number of scholar-activist style blogposts and a few published papers – a meagre offering in the grand scheme of things, but significant for me as a now severely chronically ill and disabled person, with no funding or pay, no appropriate healthcare and very little social accommodation of basic needs.

Rather than summarise the papers individually, which I am doing elsewhere, I will outline the political underpinnings of ME/CFS healthcare and offer an interpretation of the possible purposes served by a psychosocial framing of this neglected condition.

The Hijacking of a Healthcare Model

The biopsychosocial model is typically associated with the work of George Engel, a doctor who sought a more contextualised alternative to the biomedical model by recognising and addressing psychological and social influences in health and illness.

However, disability studies scholars and activists have long since asserted that this model has been used in a highly politicised way in health and social policy in the UK and beyond.

In fact, 'the biopsychosocial model' is misleading on various grounds:

- its status as a model is widely contested,
- it can be applied in potentially fundamentally conflicting ways (i.e., 'the' biopsychosocial model confuses the issue),

NOMENCLATURE

I prefer the term ME because, as I will discuss here, I believe that CFS is a term that has been constructed for political purposes (this preference is not intended to be divisive, nor is it rooted in value judgements about the relative suffering of people who associate with one term over the other).

However, since research and practice have conflated ME with CFS, and it is currently impossible to extricate these terms with precision, I will use the term ME/CFS throughout, unless I am reiterating the term used in the source under discussion. To understand the politicisation of ME/CFS, it is necessary to understand how a particular healthcare model, the biopsychosocial model, has been manipulated for political purposes.

■ and – as most people with ME/CFS know only too well – the 'bio' is more or less ignored in clinical practice, with the focus on psychosocial factors that allegedly perpetuate the condition.

Therefore, although I use the term 'the biopsychosocial model', it is to be understood with the caveats above.

Importantly, the ambiguity surrounding the model has allowed it to be used as per the biases of whomever applies it. In the UK, the model has been exploited by a network of interests coalescing around welfare reform and disability insurance industry profiteering, within a broader context of neoliberalisation that carries implications for health and social policy far beyond the UK.

As I have discussed elsewhere, power structures, politics and psychological investments implicated in the marginalisation of people with ME/CFS, as outlined here, are likely also implicated in efforts from certain quarters to marginalise and psychologise Long Covid. This, particularly since some of the actors involved in the marginalisation of ME/CFS have now turned their attention to Long Covid.

Simply put, the biopsychosocial model has been applied as a part of a neoliberal project to re-frame chronic health conditions (particularly those surrounded by medical controversy or uncertainty) as primarily psychosocial entities, purportedly perpetuated by psychological and social factors and thus allegedly amenable to psychosocial healthcare interventions, to 'recovery' and thus a return to work.

This framing reduces eligibility for welfare provision, private disability insurance, income protection, and on-going biomedical care, decreasing state expenditure whilst boosting private sector profits in the disability insurance and rehabilitation industry.

It might thus be argued that the political hijacking of ME/CFS is all about making or saving money for those in positions of power. However, alongside financial, and professional gains, I think this re-framing of ME/CFS – and wider chronic illness and disability – is also about society's collective psychological gains in bolstering a comforting neoliberal 'just world' view where people get what they deserve, and where the 'deserving' can be clearly distinguished from the 'undeserving'. More on that later.

The Welfare State

The progressive destruction of the welfare state in the UK can be traced back to Margaret Thatcher's administration, further embedded in global structural adjustment programmes (neoliberal economic management strategies) of the 1970s onwards. However, significant events contributing to the politicisation of ME/CFS occurred during the 1990s.

The UK government (with John Major as Prime Minister) invited a representative of UNUM (a disability insurance company) to consult on how to reduce welfare spending through policing benefits eligibility. UNUM, like many companies in the insurance industry, was losing profits because of increasing pay-outs for conditions lacking established diagnostic biomarkers, such as ME/CFS.

Both the government and the insurance industry sought a means of denying certain chronically ill and disabled patient groups financial support. Framing these groups as essentially healthy people beset by 'maladaptive' psychology reinforced by a problematic social context, as opposed to suffering from a 'serious' medical condition, was an effective way of doing that.

Securing mainstream complicity with this blatant socially unjust agenda required ideological persuasion; this was provided through a group of academics (notably, psychiatrists), many of whom had a particular interest in what they call 'CFS' and who built their careers on researching psychosocial interventions that allegedly 'treat' ME/CFS.

Together, these three collectives (academics, government and the disability insurance industry) have been referred to as an 'academic-state-corporate nexus' (to my knowledge, this term was first used by Jonathan Rutherford, who, for many years, was Professor of Cultural Studies at Middlesex University).

Academic-state-corporate narratives

At the centre of this nexus was the Centre for Psychosocial and Disability Research at Cardiff University, established in 2004, which was for several years sponsored by disability insurance giant UNUM and directed by Professor Sir Mansel Aylward, a former official in the Department of Work and Pensions (DWP).

Prior to this, burgeoning alliances are documented between Aylward and certain academics (psychiatrists) with an interest in 'CFS'. Of note is a series of exchanges in the early 1990s between Aylward and psychiatrists Professor Sir Simon Wessely and Professor Peter White (then, Drs Wessely and White). At this time, Aylward was involved in various benefits-related bodies associated with the DWP (then, the Department of Social Security or DSS), including the Benefits Agency

Medical Service and the Disability Living Allowance Advisory Board (DLAAB).

These exchanges revolved around the psychiatrists' conviction that ME should not be considered a neurological condition associated with severe and permanent disablement, and that CFS was a preferable term, designating an entity that was allegedly recoverable via psychosocial interventions (cognitive behavioural therapy and graded exercise therapy). Interestingly, this psychosocial framing is similar to the position of UNUM, which in 1995 positioned CFS as perpetuated by 'failure of coping mechanisms', additionally referring to CFS as 'neurosis with a new banner' and framing patients as taking advantage of doctors and the disability insurance industry.

Wessely also presented his views on ME/CFS to government officials during a plenary session of the DLAAB at Richmond House, London, in November 1993. He was accompanied by Professor Peter Thomas, who worked at the Royal Free Hospital after the 1955 viral outbreak of ME, and who is on record as stating that this outbreak was in fact 'mass conversion hysteria'. During the plenary, both Thomas and Wessely downplayed biological factors whilst emphasising psychosocial factors (despite lack of evidential support for the latter). Here, the beginnings of a now dominant (bio)psychosocial discourse on ME/CFS are evident.

Such associations and emergent narratives (which are far from exhaustive) are tangled and complex, and I have written about these in more detail elsewhere. Suffice to say, narratives constructed by the academic-state-corporate nexus of associations served as the intellectual justification for successive UK welfare reforms and facilitated disability insurance policy reforms, notably through DWP-commissioned monographs issuing out of the Cardiff research centre. This research drew on the work of their honorary professor, Gordon Waddell, in the field of back pain, further melding this work with literature authored by some of the above-mentioned psychiatrists. In both CFS and back pain, the approach was the same: differentiate 'subjective complaints' from 'objective disease', claim that 'illness behaviour' in the former is driven by 'maladaptive' behaviours and cognitions, and develop interventions that target this alleged maladaptive psychology, facilitating return to work.

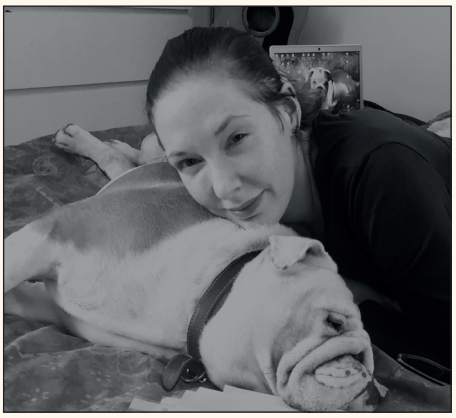
The Cardiff centre's research constructed a distinction between 'common health problems' and 'serious medical conditions', whereby common health problems were deemed less worthy of biomedical healthcare, social security support and private income protection. Predictably, CFS was positioned as a common health problem.

In this respect, Peter White's documented exhortation to the UK government (notably, to Aylward) that ME and CFS should not be separated is highly significant. By constructing a moral tale around CFS and then merging ME with CFS, decades of biological research on ME – which was recognised by the World Health Organization as a neurological condition as far back as 1969 – was eclipsed by a psychosocial story about ME/CFS. That some of the psychiatrists involved in this re-writing of history would go on to work as paid consultants to the insurance industry, government, and NHS, is also highly pertinent.

Clinical and Societal Complicity

As previously alluded, the marginalisation of ME/CFS requires complicity of mainstream

Researching on a good day



structures. The UK press has played a role here, largely (with some exceptions) subscribing to the psychosocial framing of the condition with some implication of deficient moral character among sufferers.

Biases in academic publishing, where (for example) editors of widely respected medical journals have accepted stigmatising articles on ME/CFS for publication, and refused to retract methodologically flawed psychosocial research, have replicated this dynamic.

Moreover, the UK media has been shown to have exaggerated the levels of benefits fraud, with some research demonstrating how stigmatising media narratives are reflected in public opinion. In this regard, it is noteworthy that research shows that some healthcare practitioners draw on the media to inform their understanding of ME/CFS, presumably in the absence of adequate practitioner education.

It is perhaps then unsurprising that many people with ME/CFS report dismissive and stigmatising healthcare encounters. Clinicians draw upon multiple sources to inform clinical understanding of the condition (training, research, the media etc.) and many of these sources have been demonstrated as biased toward a psychosocial understanding of ME/CFS.

The persistence of (bio) psychosocial hegemony in the

field of ME/CFS, and the strong resistance from some medical bodies to the landmark revised 2021 NICE Clinical Guideline, suggests that individual and collective investment in psychosocial framing of ME/CFS is deep-rooted. Again, this may well be investment of a financial nature in some cases, but I also think there exists a collective clinical and societal psychological investment in preserving the historical status quo, which I outline in the remainder of this article.

Research suggests that the lack of fit (lack of 'epistemological congruence') between medical practitioners' explanatory frameworks and clinical presentations of ME/CFS threatens practitioners' assumed expertise, leading to feelings of frustration, powerlessness, hopelessness, inadequacy, and fear.

That is to say, medics prefer a biomedical model of health and illness, yet ME/CFS – currently lacking diagnostic biomarker(s), and with a wealth of biomedical research eclipsed by psychosocial narratives – renders biomedical conceptualisation challenging in clinical practice.

Negative stereotyping and poor treatment of people with ME/CFS may thus be theorised as a clinical defence against medical uncertainty, threatened loss of expert status and associated anxiety on the part of clinicians. These defences might also explain clinical victim-blaming dynamics (clinicians blaming patients for their inability to recover) as can be found in research and widely reported by patients.

In other words, clinicians may seek to avoid the discomfort of medical uncertainty, protect their expert positioning and preserve moral value in the face of negative healthcare outcomes by shifting health-related accountability onto patients. Such dynamics may be internalised from and reproduced within the broader social arena, where societal defences can be discerned in victim blaming and scapegoating of chronically ill and disabled people. In turn, societal victim blaming is likely reinforced by media rhetoric and neoliberal government narratives regarding 'undeserving disability'.

In all cases, victim blaming, systematic disbelief and associated behaviours may be understood as a clinical and societal attempt to defend against the anxiety that arises from the collision point (lack of 'epistemological congruence') between two conflicting realities or worldviews.

On one hand, a biomedical paradigm, broadly consistent with neoliberal 'just world' assumptions, dictating that the problem resides in the individual and can be managed through compliance with expert interventions. On the other, the reality of medically and societally misunderstood and neglected suffering, which threatens this dominant worldview.

The marginalisation of ME/CFS can thus be said to serve psychological needs of clinicians and social actors more broadly: bolstering a comforting 'just world' view through rationalising or denying health, healthcare and social inequity, whilst protecting epistemic authority, relative social privilege and assumed moral legitimacy in the face of injustice and uncertainty. However, behaviours aimed at satisfying these needs – observable in dismissive clinical and social encounters - also render social actors (including clinicians) complicit with systematic injustices committed against patients.

Moving Forward

Much, perhaps most, of this defensive behaviour is likely unintentional and driven by preconscious or unconscious processes such as implicit bias; it thus requires elucidation in order to address it. For this reason, I have argued for more emphasis on 'critical reflexivity' and 'structural competency' in clinical education.

These two related but distinct concepts involve an awareness of how the wider social context impacts on both patients and practitioners – psychologically and physiologically. Additionally, critical reflexivity incorporates an awareness of how intersected social positionality, personal, institutional and ideological bias may impact on clinical behaviours.

Understanding the political backdrop to ME/CFS is a crucial part of this endeavour; it would allow clinicians and patients to understand how they have been positioned as pawns in a political project that is damaging to both parties, and would encourage co-operation, even allyship, within the clinician-patient relationship instead of conflict.

It is unclear what the future holds for a biopsychosocial approach to ME/CFS and other politically contested conditions.

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What is eminently clear, in my humble opinion, is that the political variant of this model, as dominant in UK health and social policy, is profoundly harmful and needs to be exposed and – permanently – medically retired. ■

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