

Towards a critical psychology of chronic fatigue syndrome: Biopsychosocial narratives and UK welfare reform

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ABSTRACT: Chronic fatigue syndrome, understood as per (bio) psychosocial discourse, is a political construction, serving actors and structures associated with welfare reform, to the detriment of patients.

KEY WORDS: ME, iatrogenesis, professionalism

The condition typically known as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, disabling condition characterised by post-exertional malaise, often accompanied by cognitive impairment, pain, sleep disturbance, gastro-intestinal and autonomic dysfunction (Goudsmit et al., 2009). ME/CFS is positioned as having multifactorial aetiology, including a genetic predisposition, precipitated by viral, bacterial and parasitic infection, toxins and stress, perpetuated through neuro-immune and metabolic dysfunction (Cortes Rivera et al., 2019). The dominant conceptualisation of ME/CFS in UK healthcare, generated through a biopsychosocial model with a cognitive-behavioural focus, is that of a psychosocial entity which, whilst possibly precipitated by a virus or other stressor, is perpetuated by 'maladaptive' illness beliefs, fear-avoidance behaviours, and social reinforcement (Sharpe et al., 1997; Deary et al., 2007; Harvey & Wessely, 2009). This conceptualisation has been critiqued for lacking empirical support

and theoretical coherency (Geraghty et al., 2019). This article takes a critical psychology perspective in examining how and why this biopsychosocial narrative came to dominate, focusing upon power structures created by associations between academic-clinicians, UK government and the health insurance industry in the context of UK welfare reform (Rutherford, 2007a; Stewart, 2019a, 2019b).

ME/CFS originally came to prominence through a number of epidemics believed to be viral, including an outbreak at the Royal Free Hospital in London in 1955 (Ramsay, 1988). Whilst the World Health Organization (WHO) recognised ME as a disease of the nervous system in 1969, the term ‘chronic fatigue syndrome’ (CFS) gained prominence on both sides of the Atlantic from the 1980s onwards (Holmes et al., 1988; Sharpe et al., 1991). ‘CFS’ foregrounds subjective symptoms over biological changes and the term was accompanied by case definitions subsequently criticised for not distinguishing CFS from other forms of chronic fatigue (Goudsmit et al., 2009). The reconstruction of ME as CFS was accompanied by a move to re-frame outbreaks of ME/CFS as psychosocial phenomena: in the case of the Royal Free outbreak, mass hysteria was proposed on grounds that most of the patients were women (McEvedy & Beard, 1970). The dominant biopsychosocial narrative of ME/CFS has been heavily critiqued for ignoring indications of biological pathology, psychologising the illness and discounting patient narratives, contributing to epistemic injustice and patient harm (Geraghty & Blease, 2019; Blease et al., 2017). Psychosocial interventions developed to ‘treat’ ME/CFS, cognitive behavioural therapy (CBT) and graded exercise therapy (GET), have been heavily critiqued for lack of an evidence base (Wilshire et al., 2017). In October 2021, the UK National Institute for Health and Care Excellence (NICE) dropped recommendations for GET and demoted CBT from clinically approved ‘treatment’ to supportive adjunct in their revised guidelines for the diagnosis and management of ME/CFS.¹ However, influential biopsychosocial proponents have not changed course,² and there are some indications that clinical bodies are willing to circumvent the new NICE provisions.³

A critical psychology lens

Critical psychology holds that “concepts used in psychological theories and practices are sources of power” (Teo, 2015, p.246); this naturally gives rise to a preoccupation with the role of language as a social practice that may empower and oppress, that

1 Please see NICE guideline [NG206] available at: <https://www.nice.org.uk/guidance/NG206>

2 Expert reaction to updated NICE guideline on diagnosis and management of ME/CFS at <https://www.sciencemediacentre.org/expert-reaction-to-updated-nice-guideline-on-diagnosis-and-management-of-me-cfs/>

3 Please see the Royal College of Physicians statement in response to NICE guidance on ME/CFS: <https://www.rcplondon.ac.uk/news/medical-leaders-sign-joint-statement-response-nice-guidance-mecfs>

constructs as well as reflects reality (Teo, 2015; Arfken & Yen, 2014; Fox et al., 2009). The biopsychosocial preference for 'CFS' (often further reduced to 'chronic fatigue') over 'ME' is in this regard significant; many people with ME/CFS consider 'CFS' reductive and misleading, whilst research suggests that clinicians may consider CFS a less serious diagnosis relative to ME (Nicholson et al., 2016; Jason et al., 2002). Thus, certain labels may facilitate stigma and epistemic injustice, whereas other labels legitimise suffering. Further, it will be demonstrated that biopsychosocial discourse has been applied to constitute 'deserving disability' in policing the boundaries between what is a 'serious medical condition' and what is a 'common health condition' (see: Waddell & Aylward, 2010).

Critical social and critical health psychology perspectives are of particular relevance to this article. Whilst critical social psychology interrogates power relations underpinning the social imaginary and dominant discourse, critical health psychology acknowledges that an individual's health is thoroughly embedded in the socio-cultural and political context in which individuals reside, a context infused with power differentials (Murray, 2015; Fox et al., 2009). Accordingly, it will be argued that CFS, now conflated as ME/CFS, can be understood as constructed (through biopsychosocial discourse) by power structures arising from associations that revolve around UK welfare reform, serving the purposes of those who (re)produce this discourse to the detriment of people with ME/CFS. Along with power and oppression, critical psychology is concerned with issues of complicity and resistance, particularly within the context of taking an overt stance on social justice (Arfken & Yen, 2014; Fox et al. 2009). Whilst an exploration of strategies for resisting a particular form of biopsychosocial hegemony is beyond the scope of this article, structural complicity will be discussed, where structural complicity is understood as collective internalisation and (re)enactment of unjust social practices (here, a politicised variant of biopsychosocial discourse and practice). Finally, the underlining of unconscious processes in critical psychology (Fox et al., 2009) is acknowledged through discussion of clinician psychology and complicity in healthcare practice.

Politicization of the biopsychosocial model

The biopsychosocial model is typically associated in mainstream psychology with Engel (1977), a doctor who sought a more holistic alternative to the biomedical model. However, disability activists and scholars have argued that the variant of the biopsychosocial model dominating UK health and social policy has arisen from economic and political agendas, including an increasingly punitive social security system, supported by complicity from other mainstream structures (Rutherford, 2007a; Shakespeare et al., 2017; Stewart, 2019a, 2019b). More specifically, discourse around ME/CFS has been constructed by a powerful

complex of interests that has been referred to as the ‘academic-state-corporate nexus’,⁴ highlighting associations between certain academic-clinicians, the UK government and health insurance companies. These associations and related agendas have resulted in the misrepresentation, marginalisation and disempowerment of chronically ill and disabled people (Stewart, 2019a; Stewart, 2019b), including people with ME/CFS. Conditions that could be constructed as predominantly psychosocial in nature, and thus amenable to ‘recovery’ through psychosocial interventions, could be exempted from social security provision and disability insurance payments, reducing state expenditure on welfare and (bio)medical care whilst increasing private sector profits (Rutherford, 2007a). In fact, ME/CFS appears to have been the blueprint diagnosis on which welfare reform policy, underpinned by biopsychosocial theorising, was predicated (see: Waddell & Aylward, 2010; Waddell & Burton, 2004; White, 2005; Halligan et al., 2003).

Central to the psychosocial construction of ME/CFS is the work of the Psychosocial Research Centre at Cardiff University, for some years sponsored by health insurance giant Unum and directed by Mansel Aylward, a former official in the Department of Work and Pensions (DWP) (Stewart, 2019b; Rutherford, 2007a). Certain ME/CFS academic-clinicians communicated with Aylward on the subject of ME/CFS prior to this time, notably to discourage ME/CFS being considered a serious and permanent disability, highlighting ‘rehabilitative treatments’ (interventions developed by said academic-clinicians), and emphasizing the costs of supporting ME/CFS as a disability.⁵ Some ME/CFS academic-clinicians have also worked as consultants to an array of health insurance companies, including Unum, advising how to effect a return to work and thus preclude disability insurance claims⁶ whilst also working at all levels within the NHS⁷. The Cardiff centre produced papers (Waddell & Burton, 2004; Waddell & Aylward, 2005; Waddell & Aylward, 2010), some commissioned by the DWP, which formed the intellectual framework for UK welfare reforms and a reform of disability insurance policy (Stewart, 2019a, 2019b). The papers drew on Waddell’s work on back pain (Waddell, 1999), melded with the work of academic-clinicians in the field of CFS who were given special acknowledgment for contributions (see: Waddell & Burton, 2004). The approach to back pain and CFS was strikingly similar: Distinguish objective

4 Jonathan Rutherford writes on the link between the US disability insurance company Unum and UK welfare reform: <https://www.moStewartresearch.co.uk/wp-content/uploads/2018/05/Jonathan-Rutherford-US-dis-ins-co-Unum-UK-welfare-reform.pdf>

5 Please see Wessely, S. (1993, October 1) and White, P. (1993, November, 10) [Letters to Mansel Aylward]. *The National Archives*. <https://valerieeliotsmith.files.wordpress.com/2015/01/natarchbn141dss.pdf>

6 Please see Functional symptoms and syndromes: Recent developments. In: Unum Provident: Trends in Health and Disability at https://issuu.com/maxhead/docs/unum_cmo_report_2002/18

7 Please see the website: <http://www.investinme.org/Article400%20Magical%20Medicine.shtml>

disease from subjective complaints, recognise that ‘illness behaviour’ in the latter case is perpetuated by maladaptive cognitions and behaviours, and develop interventions that promote positive mindset and increased activity, facilitating return to work (Waddell, 1999; Waddell & Aylward, 2010). Both back pain and CFS were considered subjective complaints, or ‘common health problems’, to be distinguished from ‘serious medical conditions’ and positioned as less worthy of state support (Waddell & Aylward, 2010; Waddell & Burton, 2004). In fact, welfare receipt was framed as a rational decision for which disabled people must take responsibility (Waddell & Aylward, 2010), and a factor that might perpetuate disability (Waddell & Aylward, 2010), for example through a lens of secondary gains (Halligan et al., 2003).⁸ Here, the power of language and narrative construction in constituting certain disabled people as not really disabled, possibly ‘gaining’ from illness and thus unworthy of state support is evident.

Collectively oppressive strategies typically require complicity or collusion. In fact, psychology as a discipline has been charged with complicity with oppressive social practices and power structures (Arfken & Yen, 2014). Whilst the (bio)psychosocial construction of CFS and, through extension, ME/CFS has been facilitated by the complicity (or collusion) of actors with the academic-state-corporate nexus, structural complicity can be found from within the UK press, which has historically largely misrepresented ME/CFS as a psychosocial entity with an implication of deficient moral character of patients.⁹ From this perspective, it is noteworthy that some clinicians source information about ME/CFS from the media (Chew-Graham et al., 2008); this highlights how dominant discourse, even in healthcare settings, may have as much to do with power as it has to do with ‘truth’. Further, biases in academic publishing have done little to present an accurate and non-stigmatizing understanding of the condition (Godlee, 2011; Hawkes, 2011).¹⁰ Structural (perhaps more specifically institutional) complicity may also be discerned in the publishing trajectory of the revised NICE ME/CFS guidelines, whereby NICE appeared to bend to pressure from clinical lobbying to ‘pause’ publication at the eleventh hour (RCGP, 2021).¹¹ Finally, structural complicity can be understood as arising

8 Please also see: <https://meagenda.wordpress.com/2009/05/18/the-elephant-in-the-room-series-two-more-on-mups/>

9 Please see the following Newspaper stories: <https://www.theguardian.com/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis> and <https://www.thetimes.co.uk/article/always-fatigued-yet-they-never-tire-of-claiming-their-malady-really-is-a-virus-d7s7qlvbk>

10 Please also see *Trial By Error: Open Letter to The Lancet*, version 3.0. Virology Blog: About viruses and viral disease at: <https://www.virology.ws/2018/08/13/trial-by-error-open-letter-to-the-lancet-version-3-0/>

11 Please also see NICE press release: <https://www.nice.org.uk/news/article/nice-pauses-publication-of-updated-guideline-on-diagnosis-and-management-of-me-cfs> and the website: <https://www.investinme.org/IIMER-Statement-20210817-1.shtml>

from the collective of largely well-meaning clinicians who are unaware of the political underpinnings of the biopsychosocial construction of ME/CFS and whose training does not prepare them for poorly delineated diagnoses.

Complicity in healthcare practice

The (bio)psychosocial construction of ME/CFS, and the disempowerment and marginalisation of people with this condition, occurs at a micro level as well as a macro level. In this regard, examination of the clinician-patient relationship is important. Whilst health psychology literature has examined power relations in ME/CFS clinical encounters from the perspective of patients and clinicians (Johansen & Risor, 2017), biopsychosocial discourse ignores the role of social power (or disempowerment) in contributing to health and illness, an important focus of critical health psychology. Yet, harms sustained by people with ME/CFS associated with biopsychosocial discourse and practice have been theorised through a lens of epistemic injustice, where negative stereotyping, undue psychologisation and dismissal of patient narrative is widely reported in healthcare settings (Blease et al., 2017). Whilst the arguments made in respect of epistemic injustice will not be repeated here, it is noteworthy that epistemic injustice can be understood as arising from misuse of social power, the latter concept defined as “a practically socially situated capacity to control others’ actions” (Fricker, 2007, p. 13). Clearly, clinicians enjoy epistemic advantages and a degree of social power over patients that may be misused. Whilst undue psychologisation of patients is pervasive in biopsychosocial theorising, there is little to no mention of the psychology of clinicians in biopsychosocial literature. Examination of such psychology is important in understanding complicity.

Insight into clinician psychology is provided by a synthesis of 13 qualitative studies exploring GPs’ perception and management of ‘medically unexplained symptoms’ including ME/CFS (Johansen & Risor, 2017). Epistemological incongruity, the lack of fit between clinicians’ (biomedical) training models and the presentation of patients in clinical encounters, was found to threaten the assumed authority of clinicians. Studies included in the synthesis highlighted clinicians’ perceived threat to professional identity, discomfort with the perception that the balance of power favoured patients, and acknowledgement of inability to solve patients’ problems, alongside associated feelings of frustration, fear, inadequacy and helplessness (Johansen & Risor, 2017). Further, research capturing clinicians’ negative stereotyping of people with ME/CFS (Raine et al., 2004) suggests that this stereotyping is related to the perceived challenge posed by ME/CFS to the epistemic privilege of clinicians. Negative stereotyping and stigmatization of people with ME/CFS by clinicians may thus be theorized as a defense against medical uncertainty and feared loss of expert status and associated social power. That is, whilst mainstream health psychology literature highlights themes of uncertainty and a search for a moral legitimacy among people with ME/CFS (Whitehead, 2006), such themes might apply just as much to clinicians. Whilst an individualistic exploration of clinician

psychology is insightful, it is important to situate such psychology within the broader structural context.

Broader structural complicity

Critical psychology holds that individuals' micro interactions are never fully separable from their broader (macro) context (Murray, 2015). Accordingly, the (mis)use of power evidenced in clinical encounters can be understood as reflecting and reinforcing structural misuses of power. These parallel dynamics can be understood through the lens of victim blaming. Various studies demonstrate that people with ME/CFS feel blamed by clinicians (Anderson et al., 2012), whilst discourse analysis demonstrates how medical doctors may draw upon psychosocial theorising in ME/CFS to preserve their 'expert' status and avoid the discomfort of medical uncertainty by shifting health-related accountability onto patients (Horton-Salway, 2002). A parallel process can be discerned on a macro level in the way that academic-state-corporate narratives around ME/CFS draw upon individualistic psychology in the context of healthcare policy and welfare reform; the blame is shifted onto chronically ill people, whilst actors within the nexus seek moral legitimacy through claims of following best available 'evidence' (Waddell & Aylward, 2010; White, 2005). A similar dynamic can be observed in mainstream health psychology's tendency towards victim blaming through over-emphasising individual factors in health and illness, whilst ignoring socio-structural context (Murray, 2015). In particular, the clinical framing of ME/CFS as lacking in work ethic and stoicism (Raine, et al., 2004) runs parallel to the neo-liberal rhetoric observed in government narratives around undeserving disability (Rutherford, 2007a).

The above-mentioned dynamics can also be conceptualised through the lens of scapegoating (Rothschild et al., 2012). That is, clinicians strive to maintain perceived moral value by minimising difficult feelings over negative healthcare outcomes whilst maximising perceived control of the clinical encounter through seeking epistemological congruence between their training models and patient narrative. In a parallel process, society strives to maintain perceived moral value by minimising responsibility for social injustices (here, health and healthcare inequities), whilst preserving perceived personal control over their environment by seeking epistemological congruence between a 'just world' view and the discomfiting reality of societally neglected chronic illness and disability. In both cases, the preferred world view (a biomedical worldview and a 'just world' view respectively) is ordered, predictable and safe. In both cases, people with ME/CFS are othered, blamed and stigmatized. It might therefore be argued that 'chronic fatigue syndrome', as constructed through biopsychosocial theorising, represents a medical and societal defence against chaos and uncertainty, an attempt to preserve a position of relative privilege and to maintain perceived moral legitimacy in the face of socio-structural injustices. Whilst scapegoating shifts the spotlight of scrutiny and accountability away from the system and onto the individual, critical psychology shifts

the spotlight back onto the system.

Looking forward

This article has demonstrated how a critical psychology approach to 'chronic fatigue syndrome' and ME/CFS reveals key tenets of critical theory: how psychological concepts can oppress as well as empower, how power and knowledge are bound up in discourse, how such discourse constructs as well as reflects the social imaginary and how complicity reinforces unjust practices. Points raised here are of increasing importance given the emergence of long Covid, whereby certain sub-groups lack objective biomarkers and may thus be more susceptible to undue psychologisation and politicisation. In fact, actors involved in the politicisation and psychologisation of ME/CFS are also involved in the clinical positioning of long Covid (Willis & Chalder, 2021).¹² The possibility of a tidal wave of post-viral disability has been noted, raising questions of how society will accommodate this in the long-term, and it has been suggested that the clinical and societal positioning of long Covid may be influenced by political and economic agendas.¹³ Mainstream acceptance of a critical approach to 'contested' (politicised, stigmatised) conditions is long overdue.

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