Mapping the government of disability in myalgic encephalomyelitis / chronic fatigue syndrome: A critical feminist account

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Introduction

This paper examines the 'government of disability' in the context of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), where 'government' refers to the ways in which power operates to regulate behaviour and shape 'subjectivities' (how people understand themselves and the world). It explores how an individualistic application of biopsychosocial model causes widespread harm in the ME/CFS arena and beyond: overlooking socio-political context, framing (and blaming) disabled people as perpetuating their own exclusion through 'deviant' behaviours and mindsets, and positioning them as allegedly 'undeserving' of disability-related support. Whilst the paper focuses upon the UK, international implications of biopsychosocial dominance are noted.

Analytical approach

The paper integrates thinking from critical disability studies into a 'Foucauldian genealogy' (historical analysis of present-day issues), tracing the rise of biopsychosocial discourse and practices. It foregrounds Tremain's concept of the 'government of disability', where disability is understood 'biopolitically': shaped by power relations that govern groups deemed threatening to dominant (here, neoliberal-capitalist-ableist) norms. Emphasising the radical potential of subjugated (marginalised yet resistant) knowledges - especially those of disabled activist-scholars - the paper additionally embraces feminist standpoint. It argues that grounding analysis in marginalised contributions yields a less partial account of ME/CFS governance than dominant (biomedical or psychological) frameworks allow.

Main arguments

Most academic accounts of the biopsychosocial model - as applied to ME/CFS and other stigmatised conditions - privilege dominant scientific (biomedical or psychological) epistemologies or knowledge frameworks. These frameworks typically overlook the biopolitical, socio-economic, and cultural context that enables biopsychosocial practices. However, this context is well-illuminated by subjugated knowledges, particularly research produced by disabled activists and scholars.

Drawing on these knowledges, the paper offers an analysis of the government of ME/CFS against a backdrop 'common health problems': conditions portrayed as 'subjective' (non-disabling, self-perpetuated) and amenable to cure/recovery through changing behaviour and mindset. This governance operates through interrelated expressions of 'biopower' (ways of monitoring and controlling people's behaviours and thinking), including: (i) policies and administrative tools regulating access to welfare and healthcare; (ii) alliances between the state, psychiatry, and corporate sector; (iii) exploitative socio-economic policies; (iv) oppressive cultural narratives.

(i) Biopsychosocial discourse and practices are supported through 'disciplinary technologies': administrative tools regulating behaviour according to neoliberal-capitalist-ableist norms. These include benefits assessments, work-focused interviews, training, recovery-oriented therapies, and increasingly punitive, welfare reforms. Such modes of biopower are increasingly outsourced to the private sector, turning disability/impairment into a source of profit.

(ii) These technologies are facilitated by a 'psy-corporate-state complex': alliances between psychiatry, corporate interests (notably disability insurance and rehabilitation industries), and the state. This complex influences policies, institutions, and related truth-claims from which dominant clinical and social understandings of ME/CFS emerge. By shaping subjectivity (how disabled and non-disabled people understand themselves and the world), this apparatus governs life in powerful ways.

(iii) Socio-economic policies reinforce biopolitical control by reframing ME/CFS-related disability/impairment as self-imposed and therefore 'undeserving' of support. This aligns with neoliberal-capitalist priorities, positioning those unable to work as economic burdens and tethering people to the labour market regardless of capacity. Clinical uncertainty and social disbelief are exploited to control labour supply and suppress wage growth. The harms of these policies are unevenly distributed, structured by capitalism's entanglement with other exploitative systems. The government of disability and its biopsychosocial logic therefore map onto intersectional exclusions: impacting differentially along lines of race, gender, class, and other axes of inequity.

(iv) Cultural narratives contribute to biopolitical governance. Biopsychosocial discourse has historically drawn upon invalidating narratives (e.g., hysteria and neurasthenia) to suggest that people with ME/CFS are undeserving of care. These narratives are shaped by stereotypes linked to gender, disability, class, race, and sexuality. Meanwhile, recovery-oriented therapies reflect privileged values such as productivity, rationality, and independence. Such cultural representations, combined with unequal socio-economic impacts, help explain widely overlooked research findings that ME/CFS disproportionately affects not only women but also racially and economically marginalised groups.

Overall, the paper demonstrates how dominant representations of ME/CFS reflect and reinforce a neoliberal-capitalist drive to prioritise market and private interests over compassionate citizenship and human rights. It also shows how the government of ME/CFS expands across time and space. For example, long Covid is now subject to parallel governance, whilst invalidating discourse around common health problems - a category that includes 'mental health' diagnoses - persists in UK policy.

Main implications

Greater respect for marginalised knowledges - including recognition that marginalised groups can offer unique insights and contribute to novel modes of resisting injustice - is urgently required in research spaces. This is clearly evidenced in relation to ME/CFS and other politically exploited conditions, where dominant research epistemologies have obscured much of the wider context that illuminate the persistence of systemic harms and the mechanisms through which they are reproduced.

Respect for subjugated knowledges is not only a moral imperative but a foundation for producing less partial and more nuanced understandings of any given injustice. In turn, less partial understandings - the 'bigger picture' - lead to greater possibilities for resistance and systemic change. This should be approached in a spirit of complementarity and collaboration across knowledge frameworks and viewpoints, as opposed to competition and hierarchy.

In this spirit of collaboration, disabled experts-by-experience, researchers, policymakers and healthcare practitioners should attend to reimagining and building a post-biopsychosocial policy landscape, where compassionate citizenship, human rights, equity and inclusion are valued over market, private and professional interests. This work should centre multiply-marginalised people's knowledges, recognising how the government of disability impacts unevenly along the lines of race, gender, sexuality, class and other axes of power/disempowerment.

Finding out more

I am currently a research affiliate at Uppsala University, Sweden, although I live in the UK. My research is grounded in, and inseparable from, my lived experience as a disabled person navigating oppressive political, social and healthcare systems. It is rooted in a UK context whilst engaging with transnational struggles for justice, solidarity, and the reimagining of disability.

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My publications can be found here:
https://www.researchgate.net/profile/Joanne-Hunt