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The biopolitics of CFS/ME

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ABSTRACT

This paper argues that Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) constitutes a biopolitical problem, a scientific object which needs to be studied, classified and regulated. Assemblages of authorities, knowledges and techniques make CFS/ME subjects and shape their everyday conduct in an attempt to increase their supposed autonomy, wellbeing and health. CFS and CFS/ME identities are however made not only through government, scientific, and medical interventions but also by the patients themselves, a biosocial community who collaborates with scientists, educates itself about the intricacies of biomedicine, and contests psychiatric truth claims. CFS/ME is an illness trapped between medicine and psychology, an illness that is open to debate and therefore difficult to manage and standardise. The paper delineates different interventions by medicine, science, the state and the patients themselves and concludes that CFS/ME remains elusive, only partially standardised, in an on-going battle between all the different actors that want to define it for their own situated interests.

1. Introduction

This paper examines Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), a contested and controversial medical category. In CFS/ME there is still no epistemic closure in the controversy surrounding its aetiology, diagnosis, prognosis, treatment, and prevention. Drawing on Foucault's notion of biopolitics (Foucault, 1979, 2007; Lemke, 2011), the paper argues that CFS/ME can be viewed as a biopolitical problem. CFS/ME subjects are caught up in between the various discourses that constitute it in the process of knowing it, and in between social authorities that would like to regulate it. I argue that diagnosis becomes a field of contestation not only in the clinic (e.g. Åsbring & Närvänen, 2004; Horton-Salway, 2004; Cooper, 1997; Swoboda, 2008), but on a larger scale too because especially under the prevailing neoliberal conditions welfare and insurance[1] systems are concerned with the 'excessive' claims being made by parts of the population. Medicine treats non-organic illnesses as psychogenic or 'medically unexplained' (Jutel, 2010; Lipowski, 1984; Sykes, 2010; cf.; Greco, 2012), or as 'malingering' (Kanaan & Wessely, 2010). Contrary to claims of 'objectification' of patients, it is well-known that patients often actively participate in shaping biomedicine (e.g. Callon & Rabeharisoa, 2008; Epstein, 1997; Hacking, 1995; Rabeharisoa, 2006; Rabinow, 1999; Zavestoski et al., 2004). As other health activists have done, CFS/ME organisations collaborate with and employ scientists who are sympathetic to their cause, and try to make their illness more visible and persuade state institutions to increase research funds and welfare benefits by various tactics such as documentaries,[2] campaigns, and petitions. I focus in this paper not on the experiential side of the patients diagnosed with CFS/ME (e.g. Aroll & Senior, 2008; Bülow, 2004; Edwards, Thompson, & Blair, 2007; Travers, 2004; Whitehead, 2006), but on showing that CFS/ME is made not only through government, scientific, and medical interventions but also by the patients themselves who collaborate with scientists, educates themselves about the intricacies of biomedicine, and contest psychiatric truth claims.[3] To do so I utilize Rabinow (1996; see also Dumit, 2000; Gibbon & Novas, 2008; Rabinow, 2008) notion of 'biosociality' and Novas' work on what he calls the 'political economy of hope'. The paper thus claims that the CFS/ME community can be viewed as a 'biosocial community', that is a new collective identity gathered through various means around central shared vulnerabilities, beliefs and aims. Finally, the paper adopts a science and technology approach (explained below) with regards to the notion of scientific 'objectivity' which allows us to avoid taking illnesses as 'mere' ideological constructs or as pre-given.

Abundant meticulous studies of scientific objects in the science and technology studies (STS) literature have convincingly shown that scientific objectivity is neither transhistorical nor a matter of

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[1] See Coetzer, Lockyer, Schorn, and Boshoff (2001, p. 170). It should be also noted that in the UK, disabled and ill people over the last years have been facing cuts in their benefits and attacks as being 'lazy' or as making fraudulent claims.

[2] A new documentary about CFS/ME recently came out called 'Unrest'. See https://www.unrest.film/(accessed 19 December 2017).

[3] The ideas presented in this paper are influenced by Dumit (2003; 2006) work on CFS/ME patients' struggle for recognition and legitimacy.

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representation but of intervention (e.g. Arabatzis, 2011; Daston, 1992; Fleck, 1979; Latour & Woolgar, 1979; Mol, 2002). From this perspective, objectivity is a matter of protocols, procedures, categories and definitions (Timmermans & Epstein, 2010), something achieved when some actors can 'speak' with greater volume and authority than others (Callon & Latour, 1981) and facts are just temporary results of long complex social processes. It is important to note, nevertheless, that much more than individual laboratories and professional journals are at stake in technoscientific controversies As Jasanoff (2011, p. 5) puts it, the production of facts and artifacts takes place through 'law, money, political influence, enforcement capability, regulatory authority, [and] media access'. Thus, diseases should not be regarded as 'natural kinds' but as technoscientific arrangements enacted in particular, historically situated practices, performed in day-to-day socio-material practices (Mol, 2002). Lastly, relevant to my argument here is Cambrosio et al. (2006; see also Moreira, May, & Bond, 2009; cf. Latimer et al., 2006, p. 606) concept of 'regulatory objectivity'. Regulatory objectivity refers to a new form of objectivity in the domain of biomedicine that is based on the systematic recourse to collective production of evidence. This form of objectivity and its evidence are produced by inter-laboratory studies, multi-centre clinical trials and research consortia that develop devices such as clinical and laboratory guidelines and protocols.

The paper is structured as follows. After briefly describing the uncertainty that surrounds the illness, I look on the messy domain that is the nosology and diagnosis of CFS/ME. I describe how the CFS/ME community is in search of biomarkers that it believes will destigmitise and legitimise its illness but also improve its treatment. I then move on to look at the currently available treatments for the condition and, then, discuss the 'discovery' of a new virus which was originally believed to be the causative agent for CFS/ME. I conclude by looking at the current state of research in CFS/ME. Although I mostly focus on the construction and regulation of CFS/ME in the UK context where my research was carried out, I look also at the US context because there the prevalence of and research on CFS/ME is significant.

2. CFS/ME: A complex and performative scientific object

CFS/ME is a complex and performative scientific object and condition. It is heterogeneously classified, diagnosed, treated, researched, and lived. CFS/ME has a long and complex trajectory (e.g. Ankeny & MacKenzie, 2016, p. 229–232; Ortega & Zorzanelli, 2010).[4] The history of CFS/ME is characterised by periods where biological research on CFS/ME becomes strong and other periods where psychological explanations seem to dominate. Over the years, beginning in 1957 with the outbreak of a paralytic illness in UK which led to the 'discovery' of 'Benign Myalgic Encephalomyelitis', many different terms have been such suggested for this condition; among them, post-viral fatigue syndrome (PVFS), chronic fatigue immune deficiency syndrome (CFIDS), and chronic fatigue & immune dysregulation syndrome (CFIDS), and more recently, in 2015, Systematic Exertion Intolerance Disease (SEID). In CFS/ME there are several case definitions (20 according to Brurberg, Fønhus, Flottorp, & Malterud, 2014) and diagnostic protocols, some complementary, some contradictory, exist defining it as a category of disease. Since 1994, the term 'CFS' has been accepted as the most common term for unexplained, severe chronic fatigue, and the Centre for Disease Control and Prevention (CDC) case definition has been the most widely used case definition internationally. Still, other, broader case definitions have been suggested, as the British or the Australian case definition that favours fewer symptoms. Not everyone agrees that Myalgic Encephalomyelitis (ME) and CFS are the same condition and many, especially in the UK, only view ME as a 'scientific' disease. As Twisk (2017) claims, CFS and ME are two distinct, partially overlapping clinical entities. ME is, according to Twisk, a neuromuscular disease, while CFS's symptoms are measured by subjective measures. Moreover, as he puts it (Twisk, 2017, p. 2), '[p]atients can meet the diagnosis of ME, while not meeting the case criteria for CFS, while other patients can fulfill the diagnosis of CFS, without experiencing any of the distinctive ME symptoms'. It is therefore perhaps of little wonder that ME is often the preferred term of people diagnosed with CFS. On the other hand, doctors seem to prefer the term CFS because in most cases the main symptom is chronic fatigue.[5] Moreover, the compound 'CFS/ME' or 'ME/CFS' is sometimes preferred instead of CFS as it is believed that it implies a more serious illness than CFS which focuses simply on fatigue.

As with all illnesses, CFS/ME is permeated by socio-cultural beliefs and values and economic rationalities. The 'nature' of CFS/ME is passionately debated by psychiatrists and other medical scientists, researchers, patients' organisations, and social scientists. CFS/ME is discursively framed as an economic problem, an educational problem (van Hoof, De Becker, & De Meirleir, 2006, p. 46), possibly an infectious disease that needs to be securitised,[6] and, finally, a moral problem as the persisting inactivity of these bodies is troubling. In the western, Anglo-American world, idleness and inactivity are considered a moral failure (Hay, 2010; see also; Rabinbach, 1992). CFS/ME bodies are unruly. They are bodies that have failed to be productive or to keep up with the frenetic work rhythms many of them previously had (e.g. Clarke & James, 2003; Ware, 1992). The majority of people diagnosed with CFS/ME are unable to work and function according to the dominant social norms while in line with the general tendency of the 'responsibilitisation' of individuals (Rose, 1999), people diagnosed with CFS/ME are discursively positioned as 'autonomous', 'self-determined' and 'active'.

Antony Pinching, Professor of Immunology and principal medical advisor for Action for ME (AfME), a UK CFS/ME advocacy group, believes that some of the reasons CFS/ME has not attracted much attention – despite the fact that epidemiology has increasingly showed CFS/ME to have a relatively high prevalence in the US[7] – include the lack of aetiology, the marginalisation of patients, its small market size, but also patients' 'unproductive' activism (Pinching, 2003). Shorter (1986) argues that the nature of 'medically unexplained syndromes' has changed, shifting from apparently neurological symptoms such as paralyses, tremors and fits, to more ill-defined and subjective symptoms such as fatigue and pain, while Showalter (1997) takes CFS/ME to be a contemporary form of hysteria like alien abduction.[8] On the other hand, Richman, Jason, Taylor, and Jahn (2000) claim that, in contrast to multiple sclerosis which also disproportionately affects women, biomedicine's failure to provide a viral aetiology for CFS/ME led to largely psychosocial explanations that encompass a flight to a 'sick role' in order to escape burdensome social roles. In CFS/ME, it is said that women are twice as likely as men to have suffer from it (Yancey & Thomas, 2012, p. 741).

Regarding ethnicity and socio-economic status, community-based studies in the US, for example, there appears to be a higher prevalence of CFS/ME in people of lower socio-economic groups, and in African-Americans and Latino populations (see Luthra & Wessely, 2004). However, Luthra and Wessely (2004) note that these populations are not frequently referred for diagnosis and that these studies perpetuate the myth inherited from neurasthenia which takes CFS/ME to be an illness of the 'developed' countries. In the UK, as in other countries, CFS/ME seems to affect all social classes equally (while at least in the

[4] Scholars often treat the history of 'CFS/ME' as if this object has ontological stability. I make no such assumptions.

[5] 'Chronic fatigue' is sometimes referred to as a separate clinical entity.

[6] On 1st November 2010 people diagnosed with CFS/ME were banned from giving blood in the UK.

[7] Estimates on CFS/ME's prevalence seem to vary (e.g. Johnston, Brenu, Staines, & Marshall-Gradisnik, 2013; Nacul et al., 2011). Holgate et al. (2011, p. 543), for instance, argue that in the UK it affects around 1% of the adult population.

[8] Cf. Dumit (1997).