

# Are ME/CFS Patient Organizations “Militant”?

## Patient Protest in a Medical Controversy

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**Abstract** Myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) is a contested illness category. This paper investigates the common claim that patients with ME/CFS—and by extension, ME/CFS patient organizations (POs)—exhibit “militant” social and political tendencies. The paper opens with a history of the protracted scientific disagreement over ME/CFS. We observe that ME/CFS POs, medical doctors, and medical researchers exhibit clear differences in opinion over how to conceptualize this illness. However, we identify a common trope in the discourse over ME/CFS: the claim of “militant” patient activism. Scrutinizing this charge, we find no compelling evidence that the vast majority of patients with ME/CFS, or the POs representing them, have adopted any such militant political policies or behaviours. Instead, we observe key strategic similarities between

ME/CFS POs in the United Kingdom and the AIDS activist organizations of the mid-1980s in the United States which sought to engage scientists using the platform of public activism and via scientific publications. Finally, we explore the contours of disagreement between POs and the medical community by drawing on the concept of epistemic injustice. We find that widespread negative stereotyping of patients and the marginalization and exclusion of patient voices by medical authorities provides a better explanation for expressions of frustration among patients with ME/CFS.

**Keywords** Epistemic injustice · Doctor–patient communication · Healthcare ethics · ME/CFS · Patient activism

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## Introduction

Around 250,000 people in the United Kingdom and one million people in the United States suffer from the illness referred to as myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) (hereafter, ME/CFS). At the mild end of the spectrum, sufferers experience fatigue and curtail everyday activities; at the moderate to severe end sufferers are often left housebound, even bedbound for years, experiencing severe lethargy, light and noise sensitivity, cognitive deficits, cardiovascular complaints, and chronic pain (Smith et al. 2015).

ME/CFS is poorly understood because the aetiology of the condition is not yet known. The mechanisms underpinning the disease are still open to speculation,

and compared with other chronic diseases and conditions, such as cancer or multiple sclerosis, research is still in its infancy. To adopt Imre Lakatos' terminology, no progressive research programme has yet merged in ME/CFS scholarship and the direction of basic scientific research is still subject to deep debate and disagreement (Lakatos 1970). Indeed, for nearly forty years researchers, doctors, and patients appear to have been engaged in debate over the cause of the illness and the best treatment approach in the absence of clear evidence for disease pathogenesis.

ME/CFS is also widely recognized in the public sphere as a controversial illness, having received extensive coverage in the mainstream British press. In this paper, we scrutinize the nature of this debate: in particular we focus on the use of the "militant" trope to characterize patients' and patient organizations' (POs) protests. We observe that the language and tactics deployed by prominent medical professionals in this field in response to PO actions has scarcely received critical attention to date (though this is changing, see Blease, Carel, and Geraghty 2017 and Spandler and Allen 2017). We ask: *Does the advocacy of ME/CFS POs warrant the descriptor "militant"?* In a previous paper, we focused on injustices in ME/CFS related to patient–doctor communication in the medical encounter. Here, we expand on Miranda Fricker's philosophical framework of "epistemic injustice" to explain how POs have endured injustices from the medical profession (Blease, Carel, and Geraghty 2017; Kidd and Carel 2017).

## Background—A History of Controversy

The naming of this illness has generated heated discussion. The term myalgic encephalomyelitis emerged in the 1950s following a viral outbreak at the Royal Free hospital in London. A resident infectious disease doctor, Melvin Ramsay, used the acronym ME to describe what he hypothesized was a disease of the muscular and nervous systems caused by a pathogen, triggered by a post-infectious illness, causing sufferers to experience severe malaise, lethargy, and symptoms such as muscle pain or weakness (Ramsay 1957). Ramsay suggested that some sufferers would remain unwell for long periods, while a significant percentage would be unable to recover.

During the 1970s, U.K. psychiatrists re-examined Ramsay's case notes and proposed that ME—or "Royal Free disease" as it was also known—was nothing more than a case of "mass hysteria" (McEvedy and Beard

1970). During the 1980s, newspapers ran articles describing ME as "yuppie flu," an illness purportedly associated with high profile professionals experiencing burnout. In the late 1980s, psychiatrists proposed George Engel's biopsychosocial model (BPS) as appropriate model for understanding ME or CFS. The biomedical model of ME gives more credence to the underlying dysfunctional biology/physiology as precipitating factors, whereas according to the BPS model of CFS, this is an illness perpetuated or maintained by the beliefs and behaviours of the sufferer (Surawy et al. 1995; Sharpe et al. 1991). The BPS model of CFS has gained prominence via the work of a number of key medical experts in the United Kingdom, whom we refer to collectively as the "ME/CFS medical establishment" (Wessely 1996). These experts suggest that the course of the illness can be altered with psycho-behavioural interventions, principally cognitive behavioural therapy (CBT) to alter patients "unhelpful illness beliefs" (so called "perpetuating factors") and graded exercise therapy (GET) to alter "fear avoidance behaviours" (Sharpe et al. 1991; Wessely et al. 1989).

## From Disagreement to "Patient Militancy"

In recent years these two models of the condition—the biomedical model of ME versus the biopsychosocial model of CFS—have frequently pitted patients against both GPs (which we refer to in this article as "the medical profession") and the ME/CFS establishment. On the one hand, major national POs advocating on behalf of ME/CFS sufferers, such as the U.K. ME Association and the United States' Solve CFS Initiative, have consistently proposed that ME/CFS is a biological illness (as described by Ramsay).<sup>1</sup> On the other hand, the medical profession have predominantly adopted the BPS model of CFS. Indeed, research by Hossenbaccus and White suggests that patient groups and medical authorities differ considerably in their attitudes about

<sup>1</sup> POs are not one homogenous set of groups. In ME/CFS, there are groups representing the interests of children and families (such as the Tymes Trust), groups that represent the most severely sick (the "25% Group") and organizations focused on promoting research into the illness (ME Research UK and InvestInME). Each group focuses on different priorities. However, we observe some commonalities across these POs: as groups involved in a *health access movement* (seeking equity in healthcare) and the *embodied health movement* (challenging the science on aetiology, diagnosis, and treatment) (Brown and Zavestoski 2004).

how to conceive of ME/CFS. Using a content analysis (including newspaper articles, patient organization websites, medical websites, textbooks, and selected articles) they found that 89 per cent of patient groups considered the illness to be physical, compared with 24 per cent of medical authorities (Hossenbaccus and White 2013). There is a clear divergence of opinion between medical experts and many patient organizations concerning illness aetiology and pathogenesis.

POs frequently challenge the CFS model, particularly the notion that it is an illness of aberrant beliefs. In particular, POs argue that such a conceptualization downplays the seriousness of the disease. Patient groups have also strongly countered that an overemphasis of psychosocial aspects (at the expense of possible biological causes of the illness) leads to stigmatization of patients and serious neglect, such as scant basic biomedical research into new treatments. In contrast, proponents of the BPS model of CFS, largely drawn from psychiatry, clinical psychology, and primary care medical specialties, argue that PO opposition is often the result of confusion, lack of expertise, or anti-scientific and anti-psychiatry sentiments.

Perhaps not unexpectedly, the discourse around the nature of ME/CFS is often characterized as something of a conceptual deadlock between patients and medical authorities. The editor of *BMJ* refers to this disagreement as a “stalemate between doctors and patients” (Godlee 2011). An earlier paper in the *Journal of the Royal College of GPs* (a circular read by many community physicians) argued that the advice given by patient groups to members is “counter-productive” (Wessely et al. 1989) in this illness. Indeed, members of the ME/CFS medical establishment and the mainstream media often go further than depicting a mere stalemate by tagging the activism of ME/CFS POs and patients as “militant” (Hawkes 2011). In August 2011, the U.K. newspaper *The Observer* ran with the headline “Chronic fatigue syndrome researchers face death threats from militants” (McKie 2011); and *The Daily Telegraph* with the scoop “Protesters have it all wrong on ME” (Pemberton 2011). Interviewed in *The Times*, Kings College London Professor of Psychiatry, Sir Simon Wessely, a leading advocate of the BPS model of CFS, who now works in military medicine, said of his experiences with ME/CFS patients:

I now go to Iraq and Afghanistan, where I feel a lot safer ... They're not as bad as the animal

liberation people ... But they're just as fanatical. It's constant stalking, harassment, attempts at intimidation ... They use—abuse—the Freedom of Information Act ... I mean it's just a constant litany (Marsh, 2011).

Arguably, the metaphorical language of “militancy,” “weapons,” and “armoury” has set the scene for doctors perceiving ME/CFS POs as a malign force, one that stands in opposition to what they view as “best for patients” (see also Hawkes 2011). The use of military metaphors, and even direct comparisons with warfare, has not gone unnoticed within the patient community: one PO counters that a key aspect of patient advocacy is “Overcoming the militant meme” (ME Action 2016), which they argue is unfair and unjust. Indeed, an irony that is often overlooked is that ME/CFS is an illness that causes many sufferers to be profoundly fatigued and incapacitated: its symptomatology is profoundly at odds with the imagery of “militancy,” violence, and obstruction—thus there is an implicit suggestion that militancy in ME/CFS is less physical and more subversive, such as via the Internet.

Interestingly, the use of freedom of information (FOI) requests has frequently been portrayed by the medical establishment as an example of “militancy.” The goal of FOI is to create a right of access to information held by public authorities and to improve transparency and accountability for decisions by state actors. Indeed, the move towards greater transparency is a recently identified responsibility within science: open access and data sharing enables systematic and purposeful research, as well as the methodological interrogation and re-use of research products. This is increasingly seen as an ethical imperative in science. In ME/CFS, patients used FOI in the United Kingdom to obtain access to research data from a large clinical trial (the PACE trial). As we will shortly see, it was the very insistence by patients and POs to obtain access to research information that contributed to the decision by the National Institute for Clinical Excellence (NICE) to change ME/CFS treatment guidelines (these changes are currently pending) (NICE 2017).

### Are Allegations of ME/CFS Militancy Justified?

The Oxford dictionary defines “militancy” as the “use of confrontational or violent methods in support of a political or social cause.” Do ME/CFS POs regularly

employ “confrontational” or “violent” methods in support of what they perceive to be the patient cause? While violent methods may be easily identified, confrontational methods may be more challenging to define. We interpret confrontational methods as involving intimidation or threat to medical professionals. Is there documented evidence of such occurrences? Here we must tread cautiously. In another *BMJ* article, Hawkes interviewed a number of high profile ME/CFS researchers about their experiences of personal attacks, mainly in the form of complaints and defamatory postings on social media (Hawkes 2011). In his *Times* interview, Wessely admits, “I’ve had people ringing up and say, ‘We’re gonna get you.’ I’ve had death threats. Not many but, you know, you don’t need many to find them a little bit disturbing” (Marsh 2011).

On the strength of this personal anecdote, it seems possible that a very small minority of ME/CFS activists may have resorted to personally aggressive or confrontational methods. Of critical importance is the observation that the purported actions of a few individuals (out of 250,000 U.K. sufferers) appear to have been characterized by the medical establishment as representative of many (arguably even most) patients with ME/CFS and POs. Certainly, the medical establishment does not appear to have challenged or sought to distance itself from newspaper headlines and features which have constructed negative global characterizations of ME/CFS POs and patient groups on the basis of individual incidents. Similarly, a feature article in *BMJ* resonates with a similar timbre: POs and ME charities are described as “militant” and it is claimed that conducting ME/CFS research is “dangerous” (Hawkes 2011).

Notwithstanding nor dismissing any such attacks or threats, when it comes to the accusation of “militancy” among POs, we argue that a strong case can be made that this trope has been stretched beyond credibility. Instead we observe—as sociologists Harry Collins and Trevor Pinch have previously argued—that ME/CFS POs have adopted similar methods to AIDS activist organizations and patient groups (Collins and Pinch 2008). ACT UP—the AIDS Coalition to Unleash Power—which was launched during the Reagan administration, proved highly successful as an activist PO. The explicit agenda of ACT UP (as declared in AIDS Treatment News) was: “The more important question is what treatments do in fact work and how can the evidence be collected, evaluated and applied quickly and effectively” (quoted in Collins and Pinch 2008, 170). It aimed to focus public,

scientific, and medical attention on neglect of basic scientific funding into AIDS research, ethical misconduct in the treatment of patients within existing clinical research contexts, and the stigmatization of individuals suffering from HIV and AIDS. As Collins and Pinch argue:

Unlike other activist movements, such as those in favour of animal rights, ACT UP did not see the scientific establishment as the enemy. In public they applied pressure via well-publicized protests; in private, however, they were quite prepared to engage with the scientists and argue their case. It was the scientists, indeed, to whom the activists increasingly turned their attention. (Collins and Pinch 2008, 170)

It is important to acknowledge that while ME/CFS POs have criticized the medical establishment, they have also sought the attention of scientific researchers. In short, contrary to the charge of “militancy” we argue that the modus operandi of ME/CFS POs is best understood as the strategy of organized public awareness campaigns, twinned with a policy of scientific engagement. While a few individuals may be culpable of engaging in abusive or aggressive tactics on social media (as is common across many domains) we find that there is no evidence that advocacy groups have promoted or adopted any violent or confrontational methods as political or social strategy; rather, there is clear evidence that POs and many patients have used social media platforms to express deep frustration and to advocate for new research avenues. An exploration of the very recent and public debate over high-profile clinical trials like the PACE trial helps to illustrate this interpretation of the activities of the wider ME/CFS patient community.

### The Controversy Over Evidence-Based Treatments

The hegemony of the BPS model of CFS has, in recent years, led to considerable research expenditure on testing psychological treatments. As we have noted above, the favoured model of the medical establishment is that the course of ME/CFS can be altered with psycho-behavioural interventions—principally cognitive behavioural therapy (CBT) and graded exercise therapy (GET). The largest randomized controlled trial (RCT) is the PACE trial (part-funded by the U.K. Department for Work and Pensions, the NHS, and the Medical Research Council) funded at a cost of almost £5 million. Results

from the trial published in *The Lancet* in 2011 cited that 60 to 61 per cent of those taking CBT or GET improved and 22 per cent recovered (White et al., 2011). Findings from this trial have been fiercely contested. POs and individual patients sought to get access to data from the trial. The lead authors and Queen Mary University of London (QMUL) (the host institution) resisted releasing trial data. This episode undoubtedly enhanced feelings of mistrust between POs and the medical profession.

However, as new developments show, the research aimed at challenging the methodology behind CBT and GET trials is a pertinent example of “outsiders” forcing a new agenda and direction within ME/CFS scholarship using the platform of science. Beyond this single trial, the evidence base for CBT and GET has been the subject of vibrant and ongoing scientific criticism and debate (Geraghty 2016). Some of this debate has undoubtedly been driven by individual patient advocates who have “turned expert.” These “citizen scientists” have made a genuine contribution to scientific knowledge by nudging the direction of debate: as self-educated individuals they have produced reliable (peer-reviewed) scientific contributions, and they have highlighted the need for greater research attention from the scientific community (Irwin 2002). Their contributions have thereby gained the attention of other scientific experts; while further research is also promoted and funded by POs, such as the ME Association in the United Kingdom.<sup>2</sup>

In particular, the methodologies underpinning CBT and GET research have been extensively criticized by citizen scientists and (increasingly) by scientific researchers within the forum of leading scientific journals (Núñez et al. 2011; Twisk and Geraghty 2015; Geraghty 2016; Kindlon 2017).<sup>3</sup> For example, the citizen-scientists Tom Kindlon, a patient with ME/CFS (who has published over sixteen articles and letters in peer-reviewed

journals, including *The Lancet*), and others have been successful in commandeering the attention of other scientific researchers and notably the reluctant attention of some members of the ME/CFS medical establishment (e.g., Kindlon 2015, 2017; Wilshire et al. 2017). In addition, other established and formally credentialed scientists including many who are funded by POs (such as the ME Association) have increasingly challenged dominant medical discourse on ME/CFS, including the scientific integrity of CBT and GET clinical trials (Geraghty 2016; Geraghty and Blease 2018; Geraghty 2017).<sup>4</sup> In this way, patients and scientists have replicated (intentionally or otherwise) the model of AIDs activists as described by Collins and Pinch: “by learning the language of science the activists were able to translate their experience into a potent criticism of the standard methodology of clinical trials” (2008, 176).

Demonstrating the effectiveness of their strategy despite considerable negative press coverage during the last twenty years, the efforts of POs have culminated in a “surveillance report” published by NICE in the United Kingdom (NICE 2017). This report is the product of a consultation among stakeholders including POs and surveys recently published research into ME/CFS. The conclusion of this report is that NICE guidelines—which advise on clinical standards for treating patients in the United Kingdom—will now be revised and updated.

The controversy following publication of the PACE trial and other trials, such as GETSET (Clark et al. 2017) clearly signifies the increasingly—if forced—*scientific* dialogue between POs and citizen scientists on the one hand and the ME/CFS medical establishment on the other. However, the characterization of ME/CFS POs and individual patients as “militant” has retained currency across the media and medical establishment (at least until recently) and it remains to be seen whether this will change in the near or long-term future. For example, in 2017 clinical psychologists have also claimed that opposition to the PACE trials was “... led mainly from patient groups attacking the study’s findings” (Petrie and Weinman 2017, 1198). Similarly, in the FOI Tribunal case brought by patient Alem Matthees, who sought access to data from the PACE

<sup>2</sup> POs (in particular) have asserted that important data from the trial was withheld from patients and that the trial protocol had been altered mid-trial, whereby the trial authors changed an important measurement tool they used to assess improvement and recovery (the SF-36 physical function scale) (Geraghty 2017). Notably POs have consistently made representations to the U.K.’s National Institute for Clinical Care Excellence (NICE) that the evidence for the use of CBT and GET is at odds with patient surveys (Kirke 2017) and that RCTs generally recruit sufferers with milder symptoms, given sufferers who are house or bedbound are too unwell to take part in clinical trials.

<sup>3</sup> Among the methodological criticisms of the PACE trial is the claim that it relies on a small number interventions which have been tested against inadequate controls—most commonly, standard medical care (GP care in the community) (Núñez et al., 2011; Twisk and Geraghty 2015; Geraghty 2016).

<sup>4</sup> It is also worth pointing out, that clinical psychologists and medical ethicists have recently challenged the standards of informed consent provided to patients undergoing psychotherapy—including cognitive behavioural therapy—for conditions or symptoms not limited to ME/CFS (Blease, Lilienfeld, and Kelley, 2016; Blease, Kelly, and Trachsel 2018; Gaab et al. 2016).

trial, QMUL, which represented the trial authors, claimed that the request for data was “vexatious” and part of an ongoing campaign by “militant activists” wishing to discredit the trial (tribunal records quoted by Kennedy et al. 2016). The tribunal judges asked one lead PACE author, Professor Trudie Chalder, about what harassment she had suffered. She admitted in evidence that she had suffered very little, other than being heckled at a conference. In considering all of the evidence, the tribunal ruled that accusations of harassment and militant actions by POs were wildly exaggerated by the trial authors and their expert witnesses. This is perhaps the most striking and unequivocal example of prominent medical experts being publicly reprimanded for levelling charges of militancy against ME/CFS POs and individual patients (Kennedy et al. 2016).<sup>5</sup>

### Explaining the Endurance of the Militancy Epithet

So, looking back, what explains the endurance of the charge of militancy against the wider ME/CFS patient community and POs? This question invites another: given that patients and POs have expressed criticism as well as anger and frustration at the medical profession, why might their responses have been subject to misinterpretation or even misrepresentation by hyperbolic phrases such as “militancy”? Correlatively, what explains the tendency of POs and patients to express frustration and criticism at all?

In answering these questions, we draw on the work of Miranda Fricker (2007), and Havi Carel and Ian Kidd (2014). ME/CFS, we argue, is an illness that strongly illustrates the phenomenon of *epistemic injustice* (Blease, Carel, and Geraghty 2017; Kidd and Carel 2017). Fricker has argued that epistemology is deeply

<sup>5</sup> It should also be pointed out that while U.K. health authorities are in the midst of altering their recommendation that CBT and GET are appropriate treatments for the condition, in the United States the Agency for Healthcare Research and Quality (AHRQ) has recently downgraded its recommendations for CBT and GET following reviews of the evidence base by the U.S. National Institute of Health (Smith, Haney, McDonagh, et al. 2015; Green et al. 2015). Thus the picture differs between countries. In addition, a wealth of emerging biological evidence has recently been published that has begun to cast serious doubt over the accuracy of the BPS psychiatry-derived model of CFS. The U.S. Institute of Health conducted an extensive review in 2015 and stated ME/CFS is a biological illness (IOM 2015) and there is promising evidence of the relationship between brain inflammation and immune abnormalities as implicated in ME/CFS (Nakatomi, Mizuno, Ishii, et al. 2014; Hornig, Montoya, Klimas, et al. 2015).

entwined with ethics: that the sharing and production of knowledge is a valued good and that inequalities in the production or access to knowledge (including medical knowledge) constitute an ethical wrong that can lead to patient harm. Fricker defines these ethical wrongs and harms as “epistemic injustice.” Epistemic injustice describes a particular kind of injustice against an individual (including a patient) in their capacity as a knower. In a previous paper we have argued that ME/CFS healthcare consultations, medical education, and policy-making are fora that exhibit epistemic injustices for patients with ME/CFS (Blease, Carel, and Geraghty 2017). It is important to focus on the concept of epistemic injustice in more detail to explore why accusations of PO militancy exhibit such staying power—beyond reasonable justification.

### Testimonial Injustice

Fricker proposes that testimonial injustice occurs when a speaker is accorded a lower level of credibility as a result of unfair negative stereotyping. Such negative stereotyping may occur either unconsciously or consciously on the part of the hearer. For example, the speaker’s testimony and therefore their contribution to knowledge may be demoted on the basis of the speaker’s age, gender, accent, illness, or disability. Fricker asserts, “[A] speaker suffers testimonial injustice just if prejudice on the hearer’s part causes him to give the speaker less credibility than he would otherwise have given” (Fricker 2007, 4). Empirical findings appear to provide robust support for the claim that testimonial injustice occurs among patients with ME/CFS (Blease, Carel, and Geraghty 2017). A number of cross-cultural studies demonstrate that patients with ME/CFS commonly experience stigmatization including from doctors (Najman, Klein, and Munro 1982; Åsbring and Närvänen 2002; Ward et al. 2008; Van Hoof 2009).<sup>6</sup>

Other qualitative research conducted among the medical community supports patients’ claims that negative stereotyping is widespread. Studies of doctors’ attitudes report mixed comments including heavily stereotyped

<sup>6</sup> For example, a study conducted in Sweden found that many patients experienced levels of stigmatization that were just as burdensome as the illness: “[t]hat one is not believed [...] it is so hard that it is almost the worst thing” (Åsbring and Närvänen 2002). The majority of patients interviewed in this study reported feeling under suspicion by doctors or reported feeling that their moral character was interrogated (Blease et al. 2017).

attitudes—“I thought it was people sort of passively giving up” (Chew-Graham et al. 2010, 5)—and that patients with ME/CFS are “heartsinky” and a “burden” (Raine et al. 2004, 1355). One study conducted at the University of Manchester reveals that such negative perceptions of patients are prevalent among medical students: “I’ve spoken to doctors in hospital [...] they just say it’s bullshit [...] that it’s a made up thing”; “People are lazy”; “Like everyone gets knackered no-one really cares” (Stenhoff et al. 2015, 202–203).

In these ways, the accusation of militancy might reasonably be construed as indicative of a wider, well-documented problem of negative stereotyping and testimonial deflation levelled at patients and POs by significant numbers of primary care doctors and some members of the ME/CFS medical establishment (and promulgated by mainstream media) (Blease, Carel, and Geraghty 2017; Kidd and Carel 2017).

### Hermeneutical Injustice

Whereas testimonial injustice refers to wrongs arising in one-on-one interactions, Fricker defines “hermeneutical injustice” as a structure or collective shortfall in our shared conceptual tools and resources. Hermeneutic injustice occurs when “both speaker and hearer are labouring under the same inadequate tools” (Fricker 2007, 7), and emerges when conceptual resources are absent or impoverished or when such resources are ignored, marginalized, or disrespected by members of other social groups. In this way, hermeneutical injustice can incur an asymmetric impact on groups of people: it may negatively affect one group while bestowing advantages on another group.

In the healthcare forum hermeneutical injustice can arise when marginalized patients have unequal access to information about their illness or are unfairly excluded from contributing to the production of accurate knowledge about their condition. This collective conceptual shortfall can also lead to inadequate funding in key domains of healthcare research and impinge on the treatment and care of patients with certain illnesses or disabilities. Kidd and Carel propose that “strategies of exclusion” undergird (and can also buttress) hermeneutical injustice (Kidd and Carel 2017). Such strategies, they argue, “take the form of excluding a currently hermeneutically marginalized group from the practices and places where social meanings are made and legitimated, such as professional committees or legislative bodies” (Kidd and Carel 2017, 184). Exclusions may

arise as a result of negative stereotyping of a group of individuals.

As Blease, Carel, and Geraghty (2017) have argued, there is strong evidence that hermeneutical injustice occurs in the context of ME/CFS. Surveys reveal significant suspicion about the status of ME/CFS among doctors with many outright rejecting the legitimacy of the illness (Steven et al. 2000). In one survey, only half of GPs believed ME/CFS was a “real” condition (Thomas and Smith 2005). Cross-cultural studies demonstrate that lack of knowledge translates into delayed diagnoses. In the United Kingdom, diagnosis of ME/CFS is reported to occur after an average of six medical appointments (Raine et al. 2004); a recent study in Belgium found that diagnoses were made after an average of five years (Van Hoof 2009).<sup>7</sup>

The systematic use of epithets to describe a group of individuals, exaggerated allegations, and strategies that foreclose dialogue and debate are strongly indicative of negative stereotyping and of the cycle of exclusion that typifies testimonial and hermeneutical injustice. The discourse surrounding ME/CFS—in particular the accusation of militancy—we argue may be better understood as an illustration of epistemic deflation and exclusion on the part of one social group (some doctors and some members of the ME/CFS medical establishment) towards other groups (patients and POs) (Blease, Carel, and Geraghty 2017). We also observe that the anger and frustration of many patients with ME/CFS who experience heavy stigmatization and who become aware of their marginalization from mainstream medicine is typified by an unarticulated but robust sense that they have become victims of this form of injustice.

### Conclusions

The lens of epistemic injustice helps to elucidate the character of patient and doctor experiences; and as this paper has argued it also helps to explain the tone of ongoing debate between the medical establishment and many patients and POs. We argue that as a result of testimonial and hermeneutical injustice, patients, citizen

<sup>7</sup> An additional consequence of perceived ambiguities over the legitimacy of ME/CFS among medical professionals is the widespread failure to provide information to patients. One study found only 14.8 per cent of U.K. surgeries provided literature on the illness (and in the majority of cases this information was provided by POs) (Thomas and Smith 2005).

scientists, and POs may feel systematically belittled, ignored, or excluded from trustful conversation. Equally, as we have seen, primary care physicians who are ignorant about ME/CFS and medical researchers who are deeply invested in a particular scientific model of the illness (what we have dubbed the “ME/CFS medical establishment”) may diminish the valuable contributions of POs, patient advocates, and citizen scientists as “meddling,” “irrational,” or “fringe science.” Indeed, while Raine et al. reported that some GPs considered patients to be “adversarial” this was because “both doctor and patient seemed to violate their expected roles” (Raine et al. 2004). We argue that the “violation” of expected roles clearly falls far short of warranting the derogation of their behaviour as “patient militancy.” Indeed, as Blease, Carel, and Geraghty argue:

[D]eferring to “expected roles” can on its own be epistemically unjust—for example, if the roles in question are “authoritative doctor” and “submissive patient” ... If patients are being too assertive, they are failing to adopt an acceptable style of expression, so what they are offering will be excluded, thus perpetuating gaps in shared hermeneutical resources. (2017, 555)

We have argued that POs are merely “guilty” (to adopt the hegemonic narrative) of strongly dissenting from the dominant primary care model of ME/CFS and of challenging dissatisfactory levels of patient care (Blease, Carel, and Geraghty 2017; Geraghty and Blease 2018). The common label “militant” with its connotations of aggression, combativeness, and belligerence profoundly mischaracterizes the “strategies of expression” (Kidd and Carel 2017) and objectives of POs and of the majority of patients with ME/CFS—both in their dialogue with the wider medical and scientific community and in their interactions with primary care physicians. Such negative mischaracterizations serve to foreclose and dangerously prohibit important three-way conversations between patients, medical researchers, and primary care physicians. While there are now fresh moves to revise NICE guidelines on CFS/ME in the United Kingdom, these advances are likely to have been hindered by the scale of epistemic injustices experienced by patients with ME/CFS (NICE 2017). Of the valuable participants in the ongoing discourse about ME/CFS, it is patients who are not only the most vulnerable but have the most to lose.

## References

- #ME Action 2016. Progress in ME/CFS patient advocacy: Overcoming the militant meme & why we must keep evolving. #ME Action, February 24. <http://www.meaction.net/2016/02/24/progress-in-mecfs-patient-advocacy-overcoming-the-militant-meme-why-we-must-keep-evolving/>. Accessed October 20, 2017.
- Åsbring, P., and A.L. Närvänen. 2002. Women’s experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research* 12(2): 148–160.
- Blease, C., H. Carel, and K. Geraghty. 2017. Epistemic injustice in healthcare encounters: Evidence from chronic fatigue syndrome. *Journal of Medical Ethics* 43: 549–557.
- Blease, C., J.M. Kelley, and M. Trachsel. 2018. Informed consent in psychotherapy: Implications of evidence-based practice. *Journal of Contemporary Psychotherapy* 48(2): 69–78.
- Blease, C., S.O. Lilienfeld, and J.M. Kelley. 2016. Evidence-based practice and psychological treatments: the imperatives of informed consent. *Frontiers in psychology*, 7, 1170.
- Brown, P., and S. Zavestovski. 2004. Social movements in health: An introduction. *Sociology of Health & Illness* 26(6): 679–694.
- Carel, H., and I.J. Kidd. 2014. Epistemic injustice in healthcare: A philosophical analysis. *Medicine, Health Care and Philosophy* 17(4): 529–540.
- Chew-Graham, C., C. Dowrick, A. Wearden, et al. 2010. Making the diagnosis of chronic fatigue syndrome/myalgic encephalitis in primary care: A qualitative study. *BMC Family Practice* 11(2): 16.
- Clark, L.V., F. Pesola, J.M. Thomas, et al. 2017. Guided graded exercise self-help plus specialist medical care versus specialist medical care alone for chronic fatigue syndrome (GETSET): A pragmatic randomised controlled trial. *The Lancet* 390(10092): 363–373.
- Collins, H., and T. Pinch. 2008. *Dr. Golem: How to think about medicine*. University of Chicago Press.
- Fricke, M. 2007. *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press.
- Gaab, J., C. Blease, C. Locher, and H. Gerger. 2016). Go open: A plea for transparency in psychotherapy. *Psychology of Consciousness: Theory, Research, and Practice* 3(2): 175.
- Geraghty, K.J. 2016. PACE-Gate: When clinical trial evidence meets open data access. *Journal of Health Psychology* 22(9): 1106–1112.
- . 2017. Further commentary on the PACE trial: Biased methods and unreliable outcomes. *Journal of Health Psychology* 22(9): 1209–1216.
- Geraghty, K.J., and C. Blease. 2018. Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent. *Journal of Health Psychology* 23(1): 127–138.
- Godlee, F. 2011. Ending the stalemate over CFS/ME. *BMJ* 342: d3956
- Green, C.R., P. Cowan, R. Elk, et al. 2015. National Institutes of Health pathways to prevention workshop: Advancing the research on myalgic encephalomyelitis / chronic fatigue syndrome. *Annals of Internal Medicine* 162(12): 860–865.
- Hawkes, N. 2011. Dangers of research into chronic fatigue syndrome. *BMJ* 342: d3780.

- Hornig, M., J.G. Montoya, N.G. Klimas, et al. 2015. Distinct plasma immune signatures in ME/CFS are present early in the course of illness. *Science Advances* 1(1): e1400121.
- Hossenbaccus, Z. and P.D. White. 2013. Views on the nature of chronic fatigue syndrome: Content analysis. *JRSM Short Reports* 4(1): 1–6.
- IOM. 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. *National Academies Press*. Institute of Medicine.
- Irwin, A. (2002). *Citizen science: A study of people, expertise and sustainable development*. Routledge.
- Kennedy, B., D. Stephenson, and N. Watson. 2016. First-Tier Tribunal, Information Rights. Appeal Number: EA/2015/0269. 20: 12–18. [http://informationrights.decisions.tribunals.gov.uk/DBFiles/Decision/11854/Queen% 20Mary % 20University% 20of% 20London% 20EA-2015-0269](http://informationrights.decisions.tribunals.gov.uk/DBFiles/Decision/11854/Queen%20Mary%20University%20of%20London%20EA-2015-0269). Accessed October 20, 2017.
- Kidd, I.J., and H. Carel. 2017. Epistemic injustice and illness. *Journal of Applied Philosophy* 34(2): 172–190.
- Kindlon, T. 2015. Elements of rehabilitative strategies associated with negative outcomes in CFS/ME: The need for further investigations. *Disability and Rehabilitation* 37(5): 466–467.
- Kindlon, T. 2017. Do graded activity therapies cause harm in chronic fatigue syndrome? *Journal of Health Psychology* 22(9): 1146–1154.
- Kirke, K.D. 2017. PACE investigators' response is misleading regarding patient survey results. *Journal of Health Psychology* 22(9): 1168–1176.
- Lakatos, I. 1970. Falsification and the methodology of scientific research programmes. In *Criticism and the growth of knowledge*, edited by I. Lakatos and S. Musgrave, 91–195. Cambridge: Cambridge University Press.
- Marsh, S. 2011. Doctor's hate mail is sent by the people he tried to cure. *The Times*, August 6.
- McEvedy, C.P., and A.W. Beard. 1970. Royal Free epidemic of 1955: A reconsideration. *British Medical Journal* 1(5687): 7–11.
- McKie, R. 2011. Chronic fatigue syndrome researchers face death threats. *The Observer*, August 20. <https://www.theguardian.com/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis>. Accessed 21 June 2018.
- Najman, J.M., D. Klein, and C. Munro. 1982. Patient characteristics negatively stereotyped by doctors. *Social Science & Medicine* 16: 1781–1782.
- Nakatomi, Y., K. Mizuno, A. Ishii, et al. 2014. Neuroinflammation in patients with chronic fatigue syndrome/myalgic encephalomyelitis: An 11C-(R)-PK11195 PET study. *Journal of Nuclear Medicine* 55(6): 945–950.
- NICE. 2018. NICE announces next steps in updating its guidelines on ME/CFS. February 18. <https://www.nice.org.uk/news/article/nice-announces-next-steps-in-updating-its-guideline-on-me-cfs>. Accessed 21 June 2018.
- Núñez, M., J. Fernández-Solà, E. Nuñez, J. M. Fernández-Huerta, T. Godás-Sieso, and E. Gomez-Gil. 2011. Health-related quality of life in patients with chronic fatigue syndrome: Group cognitive behavioural therapy and graded exercise versus usual treatment. A randomised controlled trial with 1 year of follow-up. *Clinical Rheumatology* 30(3): 381–389.
- Pemberton, M. 2011. *Protestors have got it all wrong about ME*. *The Times*, August 29.
- Petrie, K.J., and J. Weinman. 2017. The PACE trial: It's time to broaden perceptions and move on. *Journal of Health Psychology* 22(9): 1198–1200.
- Raine, S., S. Carter, T. Sensky, et al. 2004. General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: Qualitative study. *British Medical Journal* 328: 1354.
- Ramsay, A.M. 1957. Encephalomyelitis in north west London. *The Lancet* 270(7007): 1196–1200.
- Sharpe, M.C., L.C. Archard, J.E. Banatvala, et al. 1991. A report —chronic fatigue syndrome: Guidelines for research. *Journal of the Royal Society of Medicine* 84(2): 118–121.
- Smith, M.E.B., E. Haney, M. McDonagh, et al. 2015. Treatment of myalgic encephalomyelitis/chronic fatigue syndrome: A systematic review for a National Institutes of Health Pathways to Prevention workshop. *Annals of Internal Medicine* 162(12): 841–850.
- Spandler, H., and M. Allen. 2017. Contesting the psychiatric framing of ME/CFS. *Social Theory & Health* 16(2): 127–141.
- Stenhoff, A.L., S. Sadreddini, S. Peters, et al. 2015. Understanding medical students' views on chronic fatigue syndrome: A qualitative study. *Journal of Health Psychology* 20(2): 198–209.
- Steven, I.D., B. McGrath, F. Quereshi, et al. 2000. General practitioners' beliefs, attitudes, and reported actions towards chronic fatigue syndrome. *Australian Family Physician* 29: 80–85.
- Surawy, C., A. Hackmann, K. Hawton, et al. 1995. Chronic fatigue syndrome: A cognitive approach. *Behaviour Research and Therapy* 33(5): 535–544.
- Thomas, M.A., and A.P. Smith. 2005. Primary healthcare provision and chronic fatigue syndrome: A survey of patients' and general practitioners' beliefs. *BMC Family Practice* 6(1): 49.
- Twisk, F., and K.J. Geraghty. 2015. Deviant cellular and physiological responses to exercise in myalgic encephalomyelitis and chronic fatigue syndrome. *JJ Physiology* 1(2): 1–6.
- Van Hoof, E. 2009. The doctor–patient relationship in chronic fatigue syndrome: Survey of patient perspectives. *Quality in Primary Care* 17(4): 263–270.
- Ward, T., K. Hogan, V. Stuart, et al. 2008. The experiences of counselling for persons with ME. *Counselling and Psychotherapy Research* 8(2): 73–79.
- Wessely, S. 1996. Chronic fatigue syndrome. Summary of a report of a joint committee of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. *Journal of the Royal College of Physicians of London* 30(6): 497–504.
- Wessely, S., A. David, S. Butler, et al. 1989. Management of chronic (post-viral) fatigue syndrome. *The Journal of the Royal College of General Practitioners* 39(318): 26–29.
- White, P.D., K.A. Goldsmith, A.L. Johnson, et al. 2011. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): A randomised trial. *The Lancet* 377(9768): 823–836.
- Wilshire, C., T. Kindlon, A. Matthees, and S. McGrath. 2017. Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial. *Fatigue: Biomedicine, Health & Behavior* 5(1): 43–56.