

## PAPER

## Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome

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## ABSTRACT

Chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME) remains a controversial illness category. This paper surveys the state of knowledge and attitudes about this illness and proposes that epistemic concerns about the testimonial credibility of patients can be articulated using Miranda Fricker's concept of epistemic injustice. While there is consensus within mainstream medical guidelines that there is no known cause of CFS/ME, there is continued debate about how best to conceive of CFS/ME, including disagreement about how to interpret clinical studies of treatments. Against this background, robust qualitative and quantitative research from a range of countries has found that many doctors (and medical students) display uncertainty about whether CFS/ME is real, which may result in delays in diagnosis and treatment for patients. Strikingly, qualitative research evinces that patients with CFS/ME often experience suspicion by healthcare professionals, and many patients vocally oppose the effectiveness, and the conceptualisation, of their illness as psychologically treatable. We address the intersection of these issues and healthcare ethics, and claim that this state of affairs can be explained as a case of epistemic injustice (2007). We find evidence that healthcare consultations are for a where patients with CFS/ME may be particularly vulnerable to epistemic injustice. We argue that the (often unintentional) marginalisation of many patients is a professional failure that may lead to further ethical and practical consequences both for progressive research into CFS/ME, and for ethical care and delivery of current treatments among individuals suffering from this debilitating illness.

## INTRODUCTION

Chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME),<sup>1</sup> also known as ME, is a contested illness domain: even how we label the disorder is disputed by clinicians, diagnosticians and patient groups.<sup>1</sup> During the 1980s and 1990s, the media coined the term 'yuppie flu', characterising sufferers as 'stressed out professionals' unable to cope with the fast pace of life. However, CFS/ME is more thoroughly understood to be a disabling, debilitating condition of prolonged unexplained fatigue lasting 6 months or longer, together with other symptoms, such as postexertional malaise, cognitive problems and pain;<sup>2</sup> many persons with

CFS/ME become homebound and bedbound. Many patients are vulnerable to anxiety and depression,<sup>ii 3 4</sup> indeed, there is evidence that CFS/ME impinges on quality of life to a greater extent than other chronic illnesses including cancer.<sup>5</sup> Evidence also shows that CFS/ME does not respect socioeconomic status (undermining the 'yuppie flu' epithet) with evidence that the condition is more common among females than males.<sup>6</sup> Current estimates indicate that around 2.5 million people suffer from CFS/ME in the USA, with around 250 000 sufferers in the UK.<sup>7</sup>

Today, CFS/ME is a condition that mainstream medical science has yet to explain in terms of aetiology or pathophysiology. While there is consensus that CFS/ME is a chronic illness, controversy exists over how to conceive of the illness and how to interpret the evidence base for treatments. Studies report that many sufferers report negative encounters with doctors with significant numbers of patients feeling dissatisfied, disbelieved and distressed.<sup>8</sup>

We suggest that the complaint that healthcare professionals fail to take seriously these patient reports amounts to an epistemic concern that can be brought to light most effectively using Miranda Fricker's concept of *epistemic injustice*. Fricker<sup>9</sup> has argued that epistemology is deeply entwined with ethics. For Fricker, the sharing and production of knowledge is a valued good: as such, inequalities in legitimate access to such knowledge and to participation in knowledge formation constitute an ethical wrong leading to primary and secondary harms. Fricker classifies these wrongs and harms as 'epistemic injustice'. Developing its application, Havi Carel and Ian Kidd have recently argued that Fricker's framework provides a fruitful perspective for analysing the distinctive epistemic injustice that may arise within the healthcare arena, and in particular in healthcare consultations, medical education and policymaking.<sup>10 11</sup> This paper applies this theoretical framework to the case of CFS/ME and examines the ethical repercussions of the deep differences between lay and healthcare professional perspectives on this illness.

In this paper, we suggest that there is empirical evidence to substantiate the claim that patients with CFS/ME are indeed being negatively stereotyped in ways that unfairly deflate their credibility and that

<sup>i</sup>In this paper, we acknowledge that there is no uncontroversial name for the illness but in the interests of consistency, we refer to the illness as chronic fatigue syndrome or 'CFS/ME'.

<sup>ii</sup>A recent study in *The Lancet Psychiatry* reported that the suicide rate among individuals with CFS/ME in the UK is six times greater than in the general population.<sup>4</sup>



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they also suffer disadvantage due to lack of shared hermeneutical resources through which to frame and interpret their experiences. Importantly, such epistemic injustice, when playing itself out in the healthcare arena, has significant consequences for patient care, as we argue in 'Epistemic injustice leads to patient harm' section. We claim that an analysis of empirical studies of patient and healthcare professional attitudes is required in order to reveal epistemic injustice. This epistemic injustice, we argue, is also bound with other forms of injustice in the healthcare arena, and hence uncovering it has broader significance to our understanding of healthcare, patienthood and the relationships, epistemic and otherwise, between patient and healthcare professionals. The injustices we identify and discuss in the paper are epistemically and ethically bad, but they are also clinically bad in ways that are important to consider.

The structure of the paper is as follows. We begin with an overview of the state of knowledge of CFS/ME in medicine, encompassing international mainstream medical consensus about the explanatory gap with respect to the causes of CFS/ME, as well as prominent clinical disagreements about the value of treatments. Following this, we outline Fricker's account of epistemic injustice which describes how social practices entangle epistemic and ethical dimensions. In this section, we define Fricker's key concepts of *testimonial injustice* and *hermeneutical injustice* which—as Fricker has argued—may infringe on medical professionalism and lead to patient harm.<sup>9</sup> More specifically, we suggest that the aetiological and nosological uncertainty of CFS/ME arguably affects healthcare professionals' tacit judgements of the testimonies of those reporting CFS/ME symptoms. Our claim is that in this case an uncertainty about the condition translates into uncertainty about its sufferers. This, we argue, is where the epistemic injustice arises in the case of CFS/ME.

It is also important to emphasise from the outset that testimonial and hermeneutical practices (which can be characterised roughly as giving information to others and making sense of one's experiences) are foundational social-epistemic practices, both within medical practice and beyond it. Thus, a concern about epistemic injustice is not merely a narrow medical or bio-ethical concern, but a broad and pervasive problem that has particular ethical consequences, in terms of suffering, health inequality and medical treatment, when it plays itself out in the healthcare arena (for a full discussion of epistemic injustice in healthcare, see Carel and Kidd and Kidd and Carel).<sup>10 11</sup>

Next, we present qualitative and quantitative studies of patients' and doctors' attitudes towards CFS/ME (including respective experiences of CFS/ME and understanding of the condition). We find that a range of evidence appears to corroborate the possibility of recurrent testimonial and hermeneutical injustice among patients with CFS/ME in some healthcare encounters. The paper concludes with discussion of the ethical implications of epistemic injustice for patients with CFS/ME, including recommendations for how healthcare professionals and patients might reduce the risk of epistemic injustice. We end by suggesting that if epistemic justice is a professional virtue of healthcare professionals, and required for the exercise of other medical-professional duties and virtues, then epistemic justice ought to be the focus of further reflection for professional ethical practice in healthcare and in particular in CFS/ME.

### CFS/ME: THE UNEXPLAINED, CONTESTED ILLNESS

The aetiology and pathogenesis of CFS/ME remain unknown and there are no laboratory or diagnostic tests to identify sufferers and no known cures for CFS/ME.<sup>12</sup> While medical

authorities recognise that CFS/ME exists, the lack of a specific and sensitive diagnostic test and clearly defined diagnostic criteria has hampered research on pathogenesis, treatment and conceptualisation of CFS/ME as a distinct entity.<sup>13</sup>

### Explanatory models of CFS/ME

Two broad approaches to the aetiology of CFS/ME dominate current research: a biopsychosocial model (hereafter 'BPS') and biomedical theories of the illness.<sup>14</sup> A number of prominent psychiatrists in the UK propose that CFS/ME is a multifaceted illness, which results from an interaction between biology, psychology and social conditions. Theoretically, at least, on this BPS model, it is hypothesised that CFS/ME is the result of an (as yet unknown) biological vulnerability and/or trigger, but the illness may be perpetuated by abnormal illness beliefs with somatisation of bodily sensations among patients.<sup>15</sup> Proponents of this model contend that cognitive behavioural therapy (CBT) is therapeutically important in helping patients to alter 'unhelpful illness beliefs' and that graded exercise therapy (GET) may help to alter 'fear avoidance behaviours', thereby progressively engaging patients in physical activities.<sup>15</sup>

Biomedical models of the illness include a wide range of theories including hypotheses that CFS/ME is a cellular level dysfunction, immune system disorder, muscular system disorder, an inflammatory condition and/or a neurological dysfunction.<sup>16 17</sup>

### Ambiguities over psychological treatments

To date, there is consensus among clinical researchers that no research programme has resulted in a cure for CFS/ME. However, unlike biomedical theories, the BPS model has led to treatment recommendations that have been endorsed in the UK by the National Institute for Health and Care Excellence (NICE) and the National Health Service.<sup>18 19</sup> Indeed, in the UK, in the last 10 years health and government bodies have invested considerable sums into testing the effectiveness of CBT and GET treatments for CFS/ME. In 2011, the largest clinical trial in the UK on CFS/ME known as the 'PACE trial'<sup>iii</sup> (part-funded by the Department for Work and Pensions, the NHS and the Medical Research Council) attracted almost £5 million of funding, but the published results have been controversial. The PACE trial compared CBT, GET and pacing (pacing refers to 'doing things within physical limits and not exerting oneself if one feels unwell') with standard medical care and reported a 20%+ recovery rate with CBT-GET.<sup>20</sup>

This trial has faced a number of serious criticisms.<sup>21</sup> Commentators have argued that 'recovery' did not mean return to full functional status and critics have pointed out that the positive results were not mirrored in so-called objective measures of functional ability (eg, walking tests).<sup>22–24</sup> Recently, a Cochrane Review of psychotherapies, including CBT for functional syndromes concluded that there was only weak to moderate improvement outcomes for patients with CFS/ME.<sup>25</sup> In September 2016, concerns with the PACE trial culminated in a court tribunal which ruled that investigators must release trial data. The data released now show that the previously published, purported benefits of CBT and GET have a much lower efficacy than previously thought. In addition to these concerns, the limited (and so far, controversial) outcomes of the trial have not yet been successfully replicated.<sup>22</sup> Finally, some very recent

<sup>iii</sup>PACE stands for Pacing, graded Activity and Cognitive behaviour therapy: a randomised Evaluation.

reviews conclude that CBT and GET may be harmful, exacerbating symptoms of CFS/ME.<sup>iv 23 24</sup>

In the UK, the NICE and NHS guidelines reflect the unknown causes of CFS/ME, and the ambiguities about treatment options.<sup>18 19</sup> For example, among other advice, NICE asserts that, 'your healthcare professional should recognise that your condition is real and how the symptoms are affecting you; give you information about CFS/ME, the treatments and care described in this information'.<sup>18</sup> Among a list of advice on treatments—including CBT and GET—it notes that, 'If you are offered CBT, it does not mean that your healthcare professionals think your symptoms are *in your head*'.<sup>18</sup> Similarly, the NHS Choices website (providing information about illnesses and treatments) asserts that there is no known cause for CFS/ME, and that various theories have been proposed (including viral infections, problems with the immune system and psychological causes).<sup>19</sup> The NHS further advises that 'an individual programme of treatment should be offered to you', and again lists CBT and GET as possible treatments.<sup>19</sup> It asserts, for example, that CBT may help patients to 'manage CFS/ME by changing the way (*you*) think and behave', emphasising that 'the use of CBT does not mean that CFS/ME is considered to be a psychological condition'.<sup>19</sup> This advice seems to advocate psychological treatment as well as acknowledging the somatic nature of CFS/ME.

### Explanations for patient dissatisfaction

The previous two sections gave a brief overview of the current clinical state-of-the-art knowledge of CFS/ME. We now provide an account of how aetiological and nosological uncertainties about the condition negatively affect judgements of patients with CFS/ME, ultimately providing the basis for epistemic injustice. As we show, despite the relative evenhandedness of the UK guidelines in their conceptualisation of CFS/ME, some research has emphasised an explicit schism between patient advocacy groups and medical authorities over how to conceive CFS/ME.<sup>8 26 27</sup> For example, in a recent literature review, Hossenbaccus and White argued that patient groups and medical authorities in the UK differ considerably in their attitudes towards CFS/ME.<sup>27</sup> Using a content analysis of newspaper articles, patient organisation websites and medical websites, textbooks and selected articles regarding ME (CFS/ME) found that, '89 per cent of patient groups considered the illness to be physical [...] compared with 24% of medical authorities'.<sup>27</sup> Like other researchers, they contend that this discrepancy in views leads to disagreement in medical encounters, and in turn, this disagreement causes patient dissatisfaction.<sup>8 27–29</sup>

We identify three problems with the methodology in this study. First, the content analysis of 'medical authorities' in the survey by Hossenbaccus and White is overinclusive.<sup>27</sup> Their study goes beyond the NICE and NHS guidelines to include text books, and selected 'recommended reading lists' (articles). However, the literature classified under the rubric 'medical authorities' is arguably vulnerable to selection bias since the recommended reading lists were obtained from the hospitals in which the authors taught (St. Bart's and the London Medical

School) and it is at least conceivable that the lists may have been weighted more heavily in favour of BPS models of CFS/ME.

Second, perhaps more substantially, it is unclear what this literature review shows about disagreement: as we have seen, the symptomatology of CFS/ME often includes both physical and cognitive dysfunctions (including, eg, impaired memory) and there is consensus in the NICE and NHS guidelines in the UK that the causes of CFS/ME remain a mystery, and that there is no agreed explanatory model for the illness.<sup>18 19</sup> Thus, it is unclear whether the literature review reflects differences in beliefs with respect to physical versus mental *symptoms*, differences in *explanations* for the causes of the illness or differences with respect to the *treatment level* (including, perhaps, its effectiveness). While there may indeed be substantial differences between patient groups and doctors, the review methodology is too coarse-grained to form the basis for firm conclusions.

Third, while it may be the case that some (perhaps even many) patients and doctors in fact disagree over explicit conceptualisations of CFS/ME, we contend that the causes of patient dissatisfaction are likely to be subtler and more complex than a straightforward intellectual or taxonomical dispute.<sup>v</sup> Instead, we explore the claim that patient dissatisfaction may arise from: (i) the implicit and explicit negative stereotyping of patients leading to the downgrading of patient reports on their condition (what Fricker calls 'testimonial injustice') and (ii) conceptual impoverishment about CFS/ME within healthcare, giving rise to a lack of a framework within which to account for CFS/ME (which Fricker terms 'hermeneutical injustice').<sup>9</sup> In the remainder of the paper, we develop these two claims. Before we do that, it is necessary to examine Fricker's account of epistemic injustice in more detail.

### EPISTEMIC INJUSTICE

The notion of epistemic injustice points to a specific kind of injustice done to someone in their capacity as a knower, that is, unfair treatment that takes place in the context of distinctively epistemic practices and activities.<sup>9</sup> Fricker suggests two foundational kinds of discriminative epistemic injustice, testimonial and hermeneutical, which are discussed below. Before we turn to these, it is important to note that subsequent work by Fricker and others has identified many subforms within the two kinds of epistemic injustice, testimonial and hermeneutical. We do not discuss these in detail here.

#### Testimonial injustice

Fricker proposes that testimonial injustice occurs when a speaker is unfairly accorded a lower level of credibility as a result of prejudice—centrally, prejudice concerning their membership of a negatively stereotyped group. In such circumstances, a listener (implicitly and/or explicitly) interprets the speaker to have a diminished capacity *qua* testifier and bearer of knowledge (eg, they may view the speaker as untrustworthy or unreliable due to prejudice). The result is that the speaker's contribution to the shared epistemic enterprise is unjustly excluded, dismissed or relegated to a lower status as a result of negative stereotyping associated with some of the speaker's characteristics (eg, race, accent, age, gender, disability). It is important to

<sup>iv</sup>A 2015 patient survey of 1428 patients conducted by the ME Association found that CBT had minimal impact on illness symptoms with 88% individuals reporting that GET had no positive impact or an adverse impact on symptoms. ME Association (May 2015) 'ME/CFS/ME Illness Management Survey Results: No decisions about me without me', Patient Survey (Accessed 18 May 2016).

<sup>v</sup>Indeed, we argue that should any such intellectual disagreement in fact be a direct source of patient dissatisfaction, this also necessitates further investigation since it suggests that medical communication and disclosure within the consultation may be failing, and potentially leading to patient harm.



note that testimonial injustice can occur both to those who are or who are not perceived as being members of such groups. Fricker claims that the individual suffers an epistemic insult or injustice, and that since the discrediting occurs in a social arena, the individual is also thereby dehumanised—degraded as a contributor of knowledge. She argues, “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”.<sup>9</sup>

A growing body of work has suggested that individuals suffering from ill health are more vulnerable to testimonial injustice, and this vulnerability exists across the different stages and epistemic practices of medical work.<sup>10 11 30–32</sup> There is a risk of testimonial injustice when, for example, the inadvertent negative stereotyping of an illness or disability (on the part of a healthcare professional) constrains the patient’s epistemic contribution to consultations, and wider conversations, about their condition.

It is important to emphasise that we do not object to the *justified* level of epistemic privilege that individuals (such as healthcare professionals) have owed to their training. Rather, we propose that patients (and other marginalised groups and individuals) have a different kind of epistemic privilege that also deserves to be recognised and respected. As Carel has argued, conceptions of the lived experience of chronic illness are under-represented in healthcare theory and practice in ways that can unfairly obscure certain forms of epistemic privilege that patients might possess.<sup>33</sup> Respect for multiple domains of knowledge ensures a collaborative working relationship in healthcare encounters. Moreover, there is also scope for transgression of these boundaries: patients can be experts in their own condition (eg, researching clinical trials of treatments, the causes of their illness and so on); and doctors may have deep personal insights into illness experiences.<sup>34 35</sup> Injustice arises with respect to epistemic privilege when one group fails to recognise the unique expertise of another group, or when an individual fails to fully appreciate the epistemic contributions of another individual.

In summation, in the medical context, *unwarranted epistemic privilege* can be accorded to either group (healthcare professionals and patients); however, it is patients who have most to lose from the effects of such epistemic skewing. We do not claim that all ill persons are *de facto* epistemically reliable, but that negative stereotypes attached to illness give rise to certain biases about ill people, which make them more vulnerable to epistemic injustice.<sup>11</sup> Certain illnesses may impair the cognitive judgements and insights of patients (eg, dementia, psychoses or certain brain injuries). It is certainly true that patients may dispute medical facts on ill-judged grounds; yet, even in such cases the patient may be vulnerable to epistemic injustice. This is because judgements about credibility are elicited and sustained by prejudicial stereotypes. The systematic undermining of patient testimony ‘can lead to a vicious circle of increasing frustration, leading to more extreme styles of expression, which in turn lead to further epistemic disenfranchisement’.<sup>11</sup>

### Hermeneutical injustice

Whereas testimonial injustice is perpetrated by individuals, Fricker defines hermeneutical injustice as a collective shortfall in our shared conceptual resources: in this way, she defines hermeneutical injustice as a structural problem.<sup>9</sup> Hermeneutic practice (making sense of our own and others’ social experiences) are fundamental to our social life and requires access to relevant resources (eg, concepts, ideas, narratives). Hermeneutical

injustice takes place when those resources are absent or impoverished or when one cannot fairly access them: it can be characterised as a failure by the members of one or more social groups to employ or to develop the shared hermeneutical resources necessary for mutual understanding of some set of distinctive social experiences. Fricker contends that hermeneutic injustice takes place when ‘both speaker and hearer are labouring under the same inadequate tools’.<sup>9</sup> For Fricker, such hermeneutical shortcomings may impinge asymmetrically on particular groups of people negatively affecting one group yet often conferring an advantage on another group. Hermeneutical injustice occurs when hermeneutic resources are absent or impoverished, but it can also arise when such resources not respected and/or ignored by members of other social groups.<sup>vi</sup>

Fricker uses the example of sexual harassment in an era when the labelling (the very conceptualisation of such occurrences as abuse) was either uncommon or simply did not occur: the upshot was that victims struggled to interpret, comprehend and articulate their experiences.<sup>9</sup> She contends that this kind of conceptual impoverishment is more likely to affect members of marginalised or oppressed groups, and amounts to a ‘cognitive disadvantage’.<sup>9</sup> The collective conceptual gap occurs because marginalised individuals have unequal access to the arena of shared, social interpretation. In the case of sexual harassment, there may even be a sense in which conceptual inarticulacy on the part of the victim suits the purposes of the perpetrator.

In the healthcare context, hermeneutical practices play a significant role. They enable sense-making reflective activity on the part of patients, helping to turn a bewildering and frightening set of symptoms into an understandable illness, often with an aetiological explanation and a treatment protocol. Other practices support other kinds of medical activity, such as supporting patients in self-management of chronic illness, understanding issues around non-compliance and physician mistrust and of course the epistemic labour involved in providing a diagnosis. Thus, the hermeneutical resources relevant to healthcare and illness are having concepts of health, illness and disease, positioning illness narratives within a social context and enabling an interpretation of negative bodily experiences, such as pain. Hermeneutical injustice can lead to lack of resources in researching and treating patients with particular illnesses or disabilities; it can also result in inferior interpersonal care of patients; in other cases, the marginalised group may recognise their disadvantage, and discern their systematic exclusion from formal medical discourse and medical and policy decision making. A salient and tragic case is that of AIDS research in the 1980s, which was delayed and obstructed by the Republican government’s refusal to recognise the medical urgency and legitimacy of AIDS sufferers’ complaints.<sup>36</sup>

Kidd and Carel describe two kinds of strategies that may underpin hermeneutical injustice. It should be pointed out that these strategies refer to social and epistemic practices and are thereby neutral with respect to whether such practices arise from conscious intention or unconscious bias. ‘Strategies of exclusion’ “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”.<sup>11</sup> p. 12 Such exclusion can range ‘from physical exclusion to subtler forms of epistemic exclusion, such as the procedural insistence on the employment

<sup>vi</sup>We thank an anonymous reviewer for providing clarification on this point.

of strenuous legal, medical, or academic terminologies and conventions, so as to exclude those who are not members of those groups from participating in deliberative processes'.<sup>11</sup> p. 12 In such cases, as Kidd and Carel point out, the ill persons may be able to describe their experiences of illness (typically in non-expert terms), but 'such experiences are: (a) largely considered inappropriate for public discussion and (b) play little or no role in clinical decision-making'.<sup>11</sup> p. 13.

Marginalised groups may also be subject to 'strategies of expression' in which their particular forms of expression are taken as evidence of the group's lack of rationality and lack of understanding of the modes of expression that are recognised as appropriate by the dominant group. Here, a form of expression that a marginalised group 'uses in its efforts to make the case for the recognition of its hermeneutical resources can serve to undermine those very efforts. And this can lead to a vicious circle of increasing frustration, leading to more extreme styles of expression, which in turn lead to further epistemic disenfranchisement'.<sup>11</sup> p. 13.

The mobilisation of these two strategies results in an epistemic insult towards the speaker, who is not perceived as 'fully rational'<sup>9</sup> and imposes a double injury on the patient: the patient is marginalised for her testimony when that testimony involves a degree of inarticulacy. Patients are also excluded from engagement in the activities that would help enhance knowledge of their illness, and which could improve articulacy of the illness experience. In this way, hermeneutical injustice (exclusion from the structural processes of knowledge formation) may also intensify testimonial injustice and vice versa.

## USING EPISTEMIC INJUSTICE TO UNDERSTAND THE EXPERIENCES OF SUFFERERS OF CFS/ME

Analysis of the scope of epistemic injustice among patients with CFS/ME is intrinsically fraught with difficulties. For example, some patients may not be aware they have been the victims of negative stereotyping and testimonial injustice (perhaps they expect the medical profession to assume a paternalistic tone, or are embarrassed to admit this in surveys). Alternatively, some patients may not realise they have been victims of hermeneutical injustice simply because they have failed to receive a diagnosis of CFS/ME. Perhaps we can generalise and suggest that a speaker will not be able to recognise fully that they have been a victim of epistemic injustice until they have the concept in hand. Nonetheless, from the 1980s to the present day, there have been a number of qualitative and quantitative studies that provide foundational research about healthcare professionals' and patients' attitudes towards CFS/ME. In this section, we examine how empirical findings support the epistemic injustice framework we propose, and suggest that these findings show that CFS/ME is negatively stereotyped in ways that introduce unjust credibility deficits. We also suggest that this framework can shed light on the high levels of dissatisfaction reported by patients with CFS/ME.

It is worth reiterating that built into diagnostic descriptions by NICE and the NHS (to date) is an acknowledgement that the causes of CFS/ME are not yet understood, and treatments (where offered) may help to manage CFS/ME, but there are no known cures for the illness. *Formally at least*, it would appear that conceptual resources for identifying and understanding CFS/ME are in place in mainstream healthcare (even in spite of ongoing controversies into the evidence base for CBT and GET); although where conceptual resources are absent or ambiguous, this may point to a possible source of hermeneutical injustice. We also seek to identify other sources of hermeneutical

injustice and of testimonial injustice, as each has distinct sources and forms and it is important not to conflate them.

## Evidence from the medical community

Despite official medical guidelines, a range of studies appear to suggest that general practitioners (GPs) struggle to recognise the legitimacy of CFS/ME. Surveys of GPs in the UK reveal a significant degree of scepticism about CFS/ME. In one survey, only half the respondents believed that CFS/ME was a real illness.<sup>37</sup> This degree of scepticism towards the existence of the condition could lead to testimonial injustice because patient reports would not be seen to have a genuine medical cause. It could also lead to hermeneutical injustice because patient complaints may not be interpreted as cohering into a set of recognised symptoms, nor given meaning as clustering around CFS/ME.

In another survey (conducted in the same year, 2005), nearly 25% of doctors did not accept CFS/ME as a clinical entity, and of those who did nearly 50% were not confident about diagnosing patients.<sup>38</sup> A UK study reports that diagnosis occurred after an average of six appointments.<sup>39</sup> These data also support the possibility of twin injustices, testimonial and hermeneutical, because the symptoms were not interpreted as part of a recognised condition, and a delay in diagnosis may point to reluctance to take the complaints seriously or to anchor them in CFS/ME. It is also possible that lack of confidence in diagnosing translates also into a lowered credibility assigned to patient reports, which can be another cause of testimonial injustice.

Surveys in other countries have revealed comparable findings: a recent Australian study found that nearly a third of GPs did not accept CFS/ME as a distinct syndrome;<sup>40</sup> a recent survey in Belgium reported that patients suffering from CFS/ME waited an average of 5 years to receive a diagnosis.<sup>41</sup> This research indicates that, even when faced with patients with CFS/ME, many doctors reject the illness category of CFS/ME, or require considerable time to reach a CFS/ME diagnosis, again supporting our suggestion that patient testimonies are not readily interpreted as arising from a recognised medical condition and are not acted on decisively. It is important to note that the period prior to diagnosis may be fraught with suffering and symptom experience, which are exacerbated by the anxiety resulting from the uncertainty about the condition and the lack of diagnosis. Such a lengthy period may also negatively affect patients' relationship with healthcare professionals, as it may erode the trust they have in their knowledge and ability to help.

Qualitative research confirms these conceptual and hermeneutical deficits: a range of surveys conclude that negative stereotyping of patients with CFS/ME persists among doctors.<sup>8 28 40 42 43</sup> For example, a study by Raine *et al*<sup>39</sup> concluded that there are mixed attitudes about CFS/ME among GPs; some doctors claimed that they would 'do anything for these patients' while others described patients with CFS/ME pejoratively as 'heartsinky' and a 'burden'. This indicates a negative stereotyping of such patients, and may lead to testimonies from patients being so described and/or met with doubt. A recent study of GPs by Chew-Graham *et al*<sup>29</sup> documented comments such as: "I thought it was people sort of passively giving into symptoms and just sort of saying 'right that's it' and giving up". This study also revealed that many doctors believe a diagnosis of CFS/ME is inherently problematic: 'Once you start labeling a patient if you're not careful you might have a self-fulfilling prophecy'.<sup>29</sup> Cross-cultural research also shows that doctors who accept CFS/ME as a real clinical syndrome or disease are 2.5 times more likely to enjoy working with patients with CFS/ME.<sup>29 32 44</sup>

In the UK, the most common treatment provided by GPs surveyed was antidepressant therapy (84%): whether this indicated a tendency to psychologise symptoms and the treatment of CFS/ME, or whether the majority of patients presenting with CFS/ME exhibited comorbidity with depression is underdetermined.<sup>39</sup> However, Raine *et al*<sup>39</sup> found that in cases where doctors ascribed to a BPS model of CFS/ME, some doctors were, “not motivated to shift responsibility for management to other professionals; patients were able to manage themselves with ‘their own cack-handed CBT’”. Such reports indicate a level of negative stereotyping among GPs who otherwise appeared to have awareness of the illness. We suggest that such negative stereotyping can lead to testimonial injustice and also to ‘strategies of expression’ that label such patients as ‘moaners’ or depressed.

This is supported by the study by Chew-Graham *et al*,<sup>29</sup> who found that GPs queried the value of referral as unnecessary and even harmful. Of particular note, the GPs surveyed in this study were part of the FINE trial (Fatigue Intervention by Nurses Evaluation trial) on CFS/ME and therefore (presumably) had prior knowledge of CFS/ME that may have exceeded that of other doctors.<sup>29</sup> This again indicates a degree of disbelief about the reality of the condition, which may give rise to both testimonial and hermeneutic injustice.

The failure to conceive of CFS/ME as a legitimate illness classification was also reported in the only study among students conducted in the UK at the University of Manchester School of Medicine (2015).<sup>26</sup> Stenhoff *et al*<sup>26</sup> reported that students have ‘limited knowledge but many opinions’ with many students’ knowledge restricted to CFS/ME as mere ‘tiredness’. This study also found that negative attitudes were explicitly expressed by trainee doctors illustrating how testimonial injustice may be a real risk in this group, and may engender hermeneutical gaps: “[...] ‘you think god they are just knackered [...] like everyone gets knackered no-one really cares’”.<sup>26</sup> Indeed, all the students surveyed in this study reported that they had received no training in CFS/ME—that it was ‘brushed under the rug’.<sup>26</sup> Some students expressed the sentiment that if it had been included it would have been ‘a wasted week’; while others felt the condition was too rare, complex or unclear to warrant inclusion in the medical curriculum.<sup>26</sup> vii Some students offered psychiatric explanations for CFS/ME, psychologising the causes of CFS/ME, perhaps instinctually filling in a gap in learning.<sup>26</sup> In these responses, we can see echoes of the negative stereotyping identified among physicians, demonstrating the pervasiveness of such stereotyping and hence its putative pervasive effect on their judgements and decisions. This study echoed the finding among doctors that personal knowledge of someone with CFS/ME is a positive determinant in enhancing medics’ attitudes towards patients and the legitimacy of the illness: in this respect, personal encounters with patients appear to partly fill the apparent lacunae in medical education.

The conclusion we draw, based on interviews and studies among doctors and medical students, is that patients with CFS/ME are especially vulnerable to both testimonial and hermeneutical injustice. Insofar as these studies are to be relied on, there is conceptual ambiguity among doctors about diagnosing and treating CFS/ME and as we suggest, this may give rise to

reduced patient credibility, slower and more tentative reactions of medical staff, refusal to refer to specialist clinics and delayed diagnosis. It may also lead to hermeneutic injustice as patient interpretations of their symptoms may be rejected due to disbelief in the reality of the condition. CFS/ME may be a particularly difficult condition to diagnose; however, evidence of delays in diagnosis among patients also indicates a hermeneutical gap in the state of medical education, training and practice.

### Evidence from patients

The evidence for this hermeneutical gap, including the cross-cultural findings that significant percentages of doctors continue to ignore or deny the legitimacy of CFS/ME as an illness, is supported by studies of patient experience. For example, a survey in Belgium found that most of the randomly sampled patients surveyed (84%) reported that their GP needed more education on CFS/ME, with around 50% of patients changing doctors to seek better treatment.<sup>41</sup> This is a natural response to one’s sense that their testimony is devalued and disbelieved: the patient thereby seeks someone else to tell their problems to and obtain help from. If strategies for exclusion were not in place, there would be a better exchange between patients and GPs with further opportunities for GPs to understand the condition and the concepts and ideas through which sufferers interpret it.

A number of cross-cultural studies provide robust evidence of testimonial injustice: patients with CFS/ME still experience heavy stigmatisation, including by healthcare professionals. For example, the study conducted in Sweden by Asbring and Närvänen<sup>44</sup> found that many patients experienced their moral character being questioned, and that this was perceived to be more burdensome than the illness itself: “[...] that one is not believed [...] it is so hard that it is almost the worst thing”. In addition, the perception of malingering and even the feeling of ‘police interrogation’ during consultations, including the need to defend the experience of illness, were common; only a minority of patients did not report implicit or explicit expressions of suspicion by healthcare professionals.<sup>44</sup> In light of this, perhaps a better explanation for the strength of feeling among advocacy groups is that a significant number of patients feel the need to express their epistemic concerns and have a distinctive sense of, perhaps unarticulated but nonetheless robust, epistemic injustice. As Carel and Kidd have argued, online blogs and patient fora provide individuals with the platform to ‘attest to persistent experiences of feeling ignored, marginalized, or epistemically excluded by health professionals’ (pp. 529–530).

With regard to furnishing patients with information on CFS/ME, a study by Thomas and Smith found that only 14.8% of the UK surgeries provided literature on CFS/ME (supplied, for the most part, by the ME Association).<sup>37</sup> An extensive Swedish study revealed a tendency among doctors to psychologise patient symptoms, and while many patients in the study did not object to discussing psychological causes (perhaps also adhering to a BPS model of CFS/ME), the occurrence of implicit psychologising when the healthcare professional did not explicitly disclose their preferred explanation for CFS/ME, was considered by patients to be condescending and undermining.<sup>38</sup> This finding supports Fricker’s contention that negatively stereotyped patients may thereby find themselves ‘excluded from trustful conversation’.<sup>9</sup> It is also an instance of exclusion, whereby the interpretation of the condition and its causes excluded the patients’ preferred explanation.

Raine *et al*<sup>39</sup> reported that some GPs considered patients with CFS/ME to be ‘adversarial’; these doctors reportedly considered patients who rejected their views on the causation of CFS/ME

vii Others claimed these attitudes were transmitted by medical educators and doctors (“I have spoken to doctors in hospital [...] they just say it’s bullshit [...] that it’s a made up thing” [...]); ‘GPs will kind of make [...] comments about how it’s just [...] people are lazy’).

to challenge their medical authority, and may have led them to employ strategies of exclusion. The authors concluded that 'both doctor and patient seemed to violate their expected roles', and that doctors' stereotyping of patients with CFS/ME 'meant that the condition ceased to be seen as a discrete disorder and became the defining feature of that patient'.<sup>39</sup> However, deferring to 'expected roles' can on its own be epistemically unjust—for example, if the roles in question are 'authoritative doctor' and 'submissive patient'. Also, complaints about adversarial modes of engagement might be seen as 'strategies of expression' (patients being perceived as 'irrational'). 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.

The findings of this study contrast with the study by Hossenbaccus and White (pp. 7–8), who argue that extensive patient dissatisfaction arises from a clash over how to conceive CFS/ME among patients and doctors.<sup>27</sup> The implication of the study by Hossenbaccus and White is that some patients with CFS/ME simply *are* disagreeable and adversarial due to their dissent from medical opinion; such patients may be construed as displaying a level of epistemic autonomy unacceptable to physicians, in the request for a particular interpretation of their illness. Such a struggle over hermeneutical resources and the right to declare a cause for the condition is an instance of strategies of exclusion, in which, again, patients' interpretations play no role in the diagnostic and clinical process.

However, in light of the foregoing evidence of negative stereotyping, and the lack of consensus within medicine about how to explain CFS/ME, we argue that medical doctors who espouse a BPS model are not thereby entitled to stake a claim of incontestable epistemic privilege. Their favoured interpretation excludes alternative interpretations in ways which may amount to hermeneutical injustice towards the patients contesting this interpretation. Such exclusion strategies, where they occur, are indicative of both testimonial and hermeneutical injustice: the patient may feel belittled or even maligned for voicing a different (and, given the state of research, plausible) viewpoint, and his or her testimony may be minimised, interpreted as a symptom of, say, depression, or entirely disregarded. We suggest that gaps in relevant shared resources are being subjected to strategies of exclusion, whereby physicians are refusing to heed calls on them to enrich their conceptual resources or to engage in debate about the enrichment of these resources. The psychologising of patients' complaints evidenced above is an example of such exclusion; offerings of testimonies and interpretations about somatic suffering is reduced to psychological complaint, thus obviating the need to directly engage with the somatic symptoms.<sup>10</sup>

Evidence of patients' experiences with psychotherapists corroborates these findings. A British study of client-centred therapy is particularly illuminating because it documents the anonymised views of patients in non-directive therapy, a version of therapy in which patients direct the sessions according to their own perceived problems and experiences, setting the agenda for dialogue. The study reported that the issue which was identified and discussed most in conversations between patients with CFS/ME and therapists was 'the difficulties in relating to others due to misunderstandings of, and attitudes about ME (CFS/ME)'.<sup>45</sup> In addition, clients reported 'anger due to the way in which relatives had reacted'.<sup>45</sup> This anger and frustration may fuel the style of expression such patients adopt and eventually lead to 'strategies of expression'-based hermeneutic and testimonial injustices as patient attempts at communication become more fraught and angry, thus making their expression less accessible to others.

## Summary

In this paper, we have argued that patients with CFS/ME are negatively stereotyped and unfairly prevented from making sense of their experiences. This then deflates their credibility and undermines their hermeneutic and communicative efforts. We suggested that this effect can be articulated using the concept of epistemic injustice, and provided such an analysis, highlighting the ways in which evidence and patient and physician testimonies can reveal the operation of both hermeneutic and testimonial injustices.

Even the most modest conclusion based on these findings supports the claim that negative stereotyping of patients suffering from CFS/ME still persists in many healthcare encounters and more broadly in society. We therefore suggest that, as the above discussion shows, these negative stereotypes make patients with CFS/ME more vulnerable to both testimonial and hermeneutical injustice, in the ways described above. We emphasise that research shows that the experiences of patients, and the attitudes of healthcare professionals, is mixed; nonetheless, we conclude that testimonial injustice—the deflation of testimony of patients with CFS/ME on the ground of unjustified negative stereotyping—appears to be a continued problem within mainstream healthcare across a range of settings and countries. Furthermore, it would seem that the testimonial injustice is sustained and also accompanied by hermeneutical injustice because the dominant group (healthcare professionals) may routinely fail to provide adequate training about CFS/ME, leading to prejudiced deflations of patient credibility, and/or an unfair lack of shared concepts with which to make mutual sense of the experience of the patient.

## EPISTEMIC INJUSTICE LEADS TO PATIENT HARM

Consultations whereby patient testimony is discredited, or otherwise marginalised or ignored, or where patients' contributions to meaningful dialogue are excluded, risk undermining diagnostic accuracy and provision of adequate treatment. In the worst case, this can lead to isolation, confusion and patient withdrawal from the healthcare system. Patients who feel that they are disbelieved, mistrusted and treated with suspicion may choose to withdraw contact with healthcare professionals altogether. A study conducted in Belgium by Van Hoof revealed that there is a lack of ongoing professional development and disbelief among doctors that CFS/ME is real, and that this, in turn leads to inferior communication and management of the condition among patients.<sup>41</sup> Furthermore, medical 'ambivalence about treatment options' has been directly attributed to the breakdown in the relationship between doctor and patient.<sup>41</sup> Research reveals that the earlier the diagnosis of CFS/ME, the better the prognosis;<sup>41 46 47</sup> the failure to diagnose CFS/ME is cited as a direct cause of lack of empathy in primary care.<sup>41</sup>

The continued psychologising of patients' problems is a complex issue in CFS/ME. Given that no psychological-level or biological-level causal factors have been identified, research into psychological therapies remains controversial. Indeed, there is evidence that some patients with CFS/ME are excluded from full disclosure about the rationale for psychological treatments suggesting that patients with CFS/ME may be perceived as, in some sense, epistemically immature, or incapacitated when it comes to autonomous decision-making.<sup>39</sup> one UK study of patient experiences with psychotherapy reported that most patients were unaware which form of therapy they had undergone (only one in three were clear that they had received CBT).<sup>36</sup> While it is at least conceivable that lack of disclosure is



a common experience among all psychotherapy patients, in the case of clearly defined mental health issues the *rationale* for therapy must at least be understandable to clients.<sup>48–50</sup> Yet studies reveal that patients with CFS/ME report mixed feelings about psychotherapy: while some patients find sessions helpful in countering engulfing depressive feelings about their illness, others have reported sessions as ‘very patronising and negative’ with the perception that they were being ‘blamed’ for their ongoing illness.<sup>36</sup>

It is therefore not surprising that one British survey estimates that as many as two-thirds of patients with CFS/ME are dissatisfied with the quality of care they have experienced.<sup>8</sup> This conclusion is consistent with a number of studies that found that negative stereotyping acts as a barrier to successful support for the patient,<sup>51–52</sup> leading to a ‘vicious spiral of alienation between doctor and patient’.<sup>39</sup>

When patients perceive negative attitudes from healthcare professionals, this risks their trust and confidence in services. Patients surveyed in qualitative studies reported adopting social distancing and concealing strategies to avoid stigmatisation by others<sup>38</sup>—to preserve what Goffman referred to as ‘the presentation of self in everyday life’.<sup>53</sup> Some patients even reported withdrawal from healthcare professionals (in particular doctors) in order to avoid ‘feeling as though they were called into question or violated in another way’; while significant numbers of patients changed doctors in order to avoid being labelled a problem patient.<sup>38</sup>

## CONCLUSIONS AND RECOMMENDATIONS

There are deep differences between patients and healthcare professionals in conceptualising CFS/ME. In extreme cases, the differences amount to an epistemic gulf between healthcare professionals who do not believe in the existence of CFS/ME, and patients who experience distressing and debilitating symptoms. Our first recommendation is that even if patients are committed to the idea that their illness has a physical basis, and healthcare professionals think otherwise, the professionals ought to find ways to work with this conceptualisation to ensure that patients feel listened to, rather than use the consultation as a forum for ‘correcting’ or disputing fundamental aetiological factors of CFS/ME.<sup>36</sup>

Second, medical education clearly has a role to play in improving healthcare professionals’ knowledge and attitudes about CFS/ME. A recent study of medical students in the UK found that, like qualified GPs, the students appeared to struggle with a classification that had no known cause: without a known biomedical framework, students articulated the view that the illness was not real. We thus suggest that CFS/ME and other conditions that are currently medically unexplained ought to be addressed clearly in medical teaching and training. It is estimated that around 20% of GP visits are triggered by medically unexplained symptoms (MUS).<sup>54</sup> Such a significant proportion merits both attention and specialist training to ensure that patients presenting with MUS have their needs met and that healthcare professionals refer appropriately and involve other agencies as needed, rather than committing epistemic injustice by dismissing the complaints. Such training would also combat the sense of helplessness that such consultations may give rise to in both patients and healthcare professionals.<sup>viii</sup>

We strongly believe that recognition of epistemic injustice, and having philosophical tools with which to articulate it, are a first step towards the future abolition and prevention of such injustice recurring. We therefore suggest that further reflection is sought on the issue of how patients with CFS/ME are communicated with, and treated.

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professionals in their attempt to discern and express the experience of CFS/ME. The toolkit was developed in order to support patients in their goal of reflecting on and expressing their illness experience.<sup>34</sup> The toolkit (and similar reflective practices) may improve communication between patients with CFS/ME and healthcare professionals because patients may be better able to articulate their experiences and thereby be more effective contributors to their care. Similarly, healthcare professionals may gain a more nuanced grasp of CFS/ME experience, as well as honing their epistemic sensibilities and skills, such as listening to and understanding multiple perspectives.

<sup>viii</sup>One recommendation is to consider using Carel’s phenomenological toolkit, which can support mixed groups of patients and healthcare



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