Contesting the Psychiatric Framing of ME/CFS

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Abstract

ME/CFS is a medically contested illness and its understanding, framing and treatment has been the subject of heated debate. This paper specifically examines why framing the condition as a psychiatric issue - what we refer to as 'psychiatrisation' - has been so heavily contested by patients and activists. We argue that this contestation isn't simply about stigmatising mental health conditions, as some have suggested, but relates to how people diagnosed with mental illness are treated in society, psychiatry and the law. We highlight the potentially harmful consequences of psychiatrisation which can lead to people's experiential knowledge being discredited. This stems, in part, from a psychiatric-specific form of epistemic injustice which can result in unhelpful, unwanted and forced treatments. This understanding helps explain why the psychiatrisation of ME/CFS has become the focus of such bitter debate and why psychiatry itself has become such a significant 'field of contention', for both ME/CFS patients *and* mental health service users/survivors. Notwithstanding important differences, both reject the way psychiatry denies patient explanations and understandings, and therefore share a collective struggle for justice and legitimation. Reasons why this shared struggle has not resulted in alliances between ME and mental health activists are noted.

Key words: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS); epistemic injustice; mental health activism; psychologisation; psychiatrisation; psychiatric field of contention.

Contesting the psychiatric framing of ME/CFS

ME/CFS: a struggle for recognition

CFS/ME is an umbrella term for an illness characterized by profound, debilitating fatigue including delayed post exertional fatigue and various neurological symptoms, resulting in substantial reduction in activity and function. The definition of the illness has been subject to much debate and contestation (Jason et al. 2007; 2016; Millen et al 1998). Many sufferers and activists prefer the term 'ME' (Myalgic Encephalomyelitis) to highlight the seriousness of the illness and distinguish it from 'fatigue' which may occur in many other conditions.
Critics maintain that the catch-all phrase 'chronic fatigue syndrome' is vague, all-encompassing and does not specifically delineate symptoms specific to ME (Jason 2007), Notwithstanding the continuing struggle over definition, and in the absence of a generally agreed alternative, the term ME/CFS is used here, except when referring to 'ME' activists as this is their preferred term.

CFS/ME can leave people housebound, bedbound and isolated, not just from society, but also in terms of accessing medical support (Munson 2000; Institute of Medicine 2015). 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 (Roberts et al. 2016). Sufferers elicit very little sympathy - from the public, the media or the medical

establishment:

> 'hierarchies of diseases exist among patients and healthcare professionals...and when it comes to hierarchies of illness, evidence shows that chronic fatigue syndrome (CFS) /myalgic encephalomyelitis (ME), features at the bottommost end of the medical "favoured" list (Blease et al. 2016)

ME/CFS has received remarkably little research funding. For example, the US National Institute for Health reported that ME/CFS is still near the bottom of all diseases funded (NIH 2015). In 2014 it received less research funding than hay fever and significantly less than diseases with a similar or lesser disease burden (NIH 2015). In addition, studies have shown that patients with CFS/ME routinely feel disbelieved and deeply dissatisfied with their medical care, especially when doctors ignore or challenge the legitimacy of their illness experience (Blease et al. 2016; Deale and Wessely 2001; Geraghty & Esmail 2016; Jason et al. 2002). It is clear that the response of health practitioners to the condition can have an impact on the well-being of patients and sociological research has explored the consequences of living with an illness which lacks medical legitimacy on the sense of self and identities of individual sufferers (Millen and Walker 2002; Travers and Lawler 2008; Whitehead 2006).

ME/CFS is a 'medically contested illness' (Millen et al 1998). While most medical authorities now formally recognise the condition exists, there are no specific and sensitive diagnostic tests, and there is a lack of clearly defined diagnostic criteria. Its aetiology and pathogenesis remain unknown and there are no established cures. Its lack of medical

legitimation makes it difficult for sufferers to access support, services or disability benefits. Moreover, the lack of any clear 'bio-markers' indicating an obvious medical origin for the condition has provided a rich context for the formation of psychological and psychiatric explanations. If, or when, a clear organic cause is found, it may result in treatments to alleviate debilitating symptoms and even a cure. However, in the meantime, because knowledge about the condition is so uncertain and contested, the way it is framed has particular consequences for patient care. However, little critical or scholarly attention has been paid to the process or consequences of framing of ME/CFS as a psychological or psychiatric issue.

Therefore, this paper attempts to understand why the psychiatric framing of ME/CFS has been so heavily contested by ME patients and activists. We argue that resistance to the psychiatrisation of ME primarily concerns what might be called epistemic injustices which are inherent in legally enforced psychiatric systems. In other words, once an individual receives a mental health diagnosis they potentially lose legitimacy, status and rights. As such, it is perhaps not surprising that this is actively resisted by ME/CFS activists and patients. In this context patient resistance can be understood as contesting the process of psychiatrisation itself and the attendant loss of power, knowledge claims and rights which are implicit in psychiatric framing.

Thus, there are potential shared interests between ME/CFS activists/patients and psychiatric survivors/mental health activists. This is because both respond to a shared context where they find themselves subject to similar processes of de-legitimation and disempowerment. Indeed, they could be described as sharing a common resistance habitus formed in the specific context of the field of psychiatric contention (Crossley 2004; 2006). Whilst both psychiatry and ME activists are heterogenous and opinions differ within these categories, we describe them as broad tendencies which illustrate the key issues at stake in these debates.

The Psychiatrisation of ME/CFS

Psychiatrisation refers to the process whereby a person's difficulty is framed as a psychiatric problem and thus treated within psychiatry and wider related 'psy' disciplines (such as psychology, mental health social work and psychiatric nursing). Whilst there are important differences between the psychiatrisation and psychologisation of health conditions, the terms are used interchangeably in this context because, in relation to ME/CFS, psychatrisation has primarily involved psychologisation. That is, the psychiatric view of ME/CFS has tended to focus on patients' faulty thoughts and beliefs, rather than faulty biology or biochemistry.

Since the 1980's treatment of ME/CFS came under the auspices of psychiatry and mental health services and most research has been undertaken within a psychiatric paradigm, conducted by psychiatrists and psychologists (David et al. 1988; Jason et al. 1998; Torres-Harding et al. 2005; NAM 2015). During this time, there was an underlying belief amongst some psychiatrists, the general public, and even social science scholars that ME/CFS is 'psychological' and might even be related to 'mass hysteria' (Petrie and Wessely 2002; Showalter 1997; Geraghty & Esmail 2016). This assumption has been criticised due to the predominance of women ME/CFS sufferers and the chequered history of the psychiatric and medical profession's mistreatment of women (Richman and Jason 2001; Wright 2016).

A dominant psychiatric approach to ME/CFS emerged that accepted that whilst the illness may be 'triggered' by an illness, such as a viral infection, it is prolonged over time by unhelpful and inaccurate thoughts, feelings and behaviours or 'abnormal illness beliefs' leading to self-perpetuating vicious circles of fatigue, behaviour, beliefs and disability (Geraghty & Esmail

2016; Mountstephen and Sharpe 1997; Page and Wessely 2003). Medical practitioners often assume that CFS/ME is primarily a psychological or psychiatric problem and that symptoms can be alleviated by modifying patients 'perception' of their illness using methods such as Cognitive Behavioural Therapy and 'Graded Exercise' (Jason et al. 2001; Steven et al. 2000; Geraghty & Esmail 2016). Despite a heavily contested evidence base (ME Association 2015; Tuller 2015), these have been endorsed in health policy guidelines (e.g. NICE 2007). In addition, a level of certainty about the psychological basis to ME/CFS is often inserted into these debates which doesn't appear to be justified by the existing evidence. For example, in an editorial about CFS/ME, ironically advising doctors to 'listen to the story of their patients', the author states:

> *'Certainly*, changing one's dysfunction illness beliefs, attributions and behaviours into more adaptive ones, and progressively building up one's physical condition, are *necessary* steps towards acquiring self-efficacy' (Houdenhove 2002:497 our emphasis).

This quote highlights an implicitly held belief that ME patients have negative behaviours and beliefs which either cause or reinforce their symptoms. Arguably, such framing expressly militates against 'listening' to patients as they are, by definition, unreliable. This positions patients in a 'double bind' as to be heard they need to campaign vociferously, yet the very 'stridency' of their campaigning can be seen as evidence of their mental instability. As a result, an explicit schism has developed between patient advocacy groups and medical authorities over how ME/CFS should be framed (Blease et al 2016; Hossenbaccus and White 2013; Jason 2012).

The contested framing of ME/CFS

On the one hand, ME activists argue that a narrow focus on the psychological elements of the

illness has blocked bio-medical research and treatment (Jason 2012). For example, in the UK the Department of Health controversially invested five million pounds into researching the benefits of psychological therapies ('the PACE trial') whereas an institute recently established at the University of East Anglia as a centre of excellence for biomedical research into ME/CFS had to be crowdsource funded by patients[1]. This highlights the difficulties medical researchers experience in securing grants for CFS/ME research (Kitei 2014). Some commentators have noted that less research funding is spent on conditions where patients are seen as responsible for, or contributing to, their illness, as can be seen in the underfunding of research into lung disease and liver cancer (Johnson 2015; Dimmock et al 2016)). When an illness is framed as psychological, it is people's reactions, emotions and behaviour, rather than any underlying illness, that becomes the focus of scrutiny, and it is a short step from this to the assumption that people are 'responsible' for their illness and recovery.

In addition, critics argue that assuming ME/CFS is a psychological problem has resulted in poorly designed research studies which may have included people without the condition and excluded those severely affected by the condition from the studies (Jason et al. 1997; Jason 2012; ME Association 2015; Tuller 2015). ME activists argue that this situation has:

> "diminished the legitimacy and belief in the severity of the illness among physicians and allowed the psychiatrists to appropriate the condition to their own realm of influence...and put pressure on governments to apply psychiatric labels in order to reduce work claims for illness compensations" (Millen 2001: 8).

On the other hand, the psychiatric profession has portrayed ME activists as blocking progress

[1] See report at :http://www.meassociation.org.uk/2017/01/29820/

by campaigning against *any* psychological or psychiatric research investment and treatments (Smith and Wessely 2014). Some psychiatrists and medical practitioners have criticised ME activists for their 'strident' denial of any psychological component to their illness as 'frankly offensive' by 'stigmatising mental health patients and vilifying psychiatry' (ibid: 218).

Yet both sides of this divisive debate have found it difficult to evidence their case. Whilst 'psychology' is seen as an important factor in people's recovery from many different types of illnesses, the psychiatrisation of ME/CFS means that psychology is often seen as the underlying *determining* factor of the illness, not just an additional element in recovery (Jason 2012). This assumption has been hard to prove, or indeed disprove. Similarly, whilst ME/CFS activists can point to some physiological abnormalities in patients (Institute of Medicine 2015), to date they have been unable to generalise from these findings. Whilst more research and better diagnostic tests may well establish a physiological basis for the condition, the evidence is presently weak. Moreover, a clear cut division between 'mental' and 'physical' is hard to sustain in practice. It is important to note that the discipline of psychiatry has considerably more power and influence than patients' organisations and individual sufferers, so these debates are not conducted on a level playing field. In the meantime, people who experience contested illnesses, like ME/CFS, face a particular struggle for legitimation or, what has been referred to as, epistemic justice.

ME/CFS and Epistemic Injustice

A number of scholars have applied Miranda Fricker's (2007) concept of 'epistemic injustice' to illness experience (Kidd and Carel 2016; Wardrope 2015), including ME/CFS (Blease et al. 2016) and also 'mental illness' (Liegghio 2013; Crichton 2016). Epistemic injustice refers to

the systematic discrediting of oppressed people's knowledge claims about their own experience. It involves both testimonial and hermeneutical injustices. Applying this notion to ME/CFS, Blease et al 2016) have argued that testimonial injustice occurs where sufferers' views about their illness are ignored, dismissed or downgraded and hermeneutic injustice occurs where people with ME/CFS are excluded from participation in shared meaning-making, or from having an input into the medical understanding of their condition.

For example, the practice of pacing, which was favoured by many ME/CFS patients, has been actively discredited by the medical establishment and contested by a controversial 'evidence base' (ME Association 2015; Goudsmit et al. 2012). In a context where there is little medical help available to sufferers, the dismissal of an approach which many patients claim helps them manage their condition has been much criticised by patient groups. This example illustrates the way that the credibility of patients own knowledge is disbelieved or 'unfairly deflated' (Blease et al 2016:5). Individuals who suffer epistemic injustice are ultimately dehumanised, and this has significant negative consequences for patient care (Carel and Kidd 2014). It is notable that people with CFS/ME report not being believed as one of the most distressing aspects of their illness experience (Asbring and Närvänen 2002).

In addition, ME/CFS support groups have been criticized by the psychiatric establishment for: supporting 'false illness beliefs', 'stimulating chronicity'; being over-represented by chronic sufferers; denying patients effective treatments; not wanting people to recover; and even creating a 'mass psychogenic illness' by transmitting unsubstantiated health worries via the internet (Petrie and Wessely 2002). Yet many sufferers find specialist ME/CFS support groups and services offer invaluable information and support, especially when they have little support from mainstream services (Broughton et al. 2017); Millen et al. 1998; Geraghty & Esmail

2016). Indeed one consistent finding is that patient's value having their illness experience accepted and validated (Broughton et al. 2017). Yet frequently, ME/CFS patients own experiential knowledge is de-valued, even when this knowledge has developed from the collective wisdom of sufferers.

Blease et al. (2016) argue that the epistemic injustice faced by people with ME/CFS arises from uncertainty about the condition, which translates into uncertainty about its sufferers. In other words, without a diagnostic test to provide 'hard evidence' of illness, the experiences of patients can be more easily discredited and professionals engage in psychological 'gap-filling' in order to theorise about the nature of the condition. Yet they argue that with such an uncertain knowledge base 'medical doctors are not entitled to stake a claim of incontestable epistemic privilege' and patients alternative views are 'plausible...given the state of current research' (Blease et al. 2016). Indeed, where clear gaps exist in medical knowledge, as in the case of ME/CFS, they claim that the patient perspective should have even greater standing (Blease et al. 2016b).

However, the epistemic injustice faced by people with ME/CFS is about more than a lack of knowledge about the condition. It is exacerbated by the framing of ME/CFS as a psychiatric problem. This is more than just an 'additive' process where people with ME/CFS face multiple forms of epistemic disadvantage - illness (Carel and Kidd 2014); medically unexplained symptoms (Blease et al. (2016a); and 'mental illness' (Crichton et al. 2017). It may be that psychiatric-specific injustice operates as the 'trump card' in the pack. Appreciating this helps understand patient's opposition to psychiatrisation.

Psychiatric-specific injustices

In Mental Health Law, and in common lay understandings, mental (in)capacity and mental disorder are usually conflated. This often relates to the notion of 'unsound mind'. In other words, when people are deemed mentally ill, they are *already deemed to lack epistemic capacity*. This is often related to, and intertwined with, notions of irrationality and untrustworthiness (Szmukler 2006). This issue is so important to our argument that it requires further elaboration.

For example, when someone is diagnosed as 'psychotic' they are, in effect, told that they see things that aren't there, believe things that aren't true, or hear things that others can't. In other words, they are seen as experiencing 'delusions'. Similarly, if someone is diagnosed as 'clinically depressed' their depression is viewed as an unreasonable reaction to their social circumstances, unlike grief which may be seen as a *reasonable* response to a significant loss. Transferring this logic to CFS/ME, psychiatrisation means that sufferers are effectively told that they are not 'really' suffering from a physical illness, are 'deluded' and believe things that aren't true. This is understandably distressing to many ME/CFS patients, even if the medical professional is well intentioned. This may be why ME activists often claim that psychiatry frames them as 'hysterical and malingering', even though is rarely stated explicitly by the psychiatric profession. In turn, a vociferous response on the part of ME activists is framed as 'strident and adversarial' by the medical establishment (Huibers and Wessely 2006; Raine et al. 2004). Blease et al (2016a) argue this 'style of expression' may be shaped by ME activists struggle for epistemic justice (Blease et al. 2016a):

'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' (Kidd and Carel 2016, in Blease et al 2016: 4).

In other words, patient's increasingly desperate efforts to have their experiences acknowledged is interpreted as further evidence of their underlying psychopathology. Put another way, the strategies marginalised groups adopt to seek epistemic justice or recognition are taken as 'evidence of the group's *lack of rationality'* (Blease et al 2016a: *5* my emphasis*)*. This is a specific form of injustice arising from psychiatrisation. Martin J Walker, who has written about other illnesses such as Gulf War Syndrome, which he also claims have been inappropriately psychiatrised, describes this process:

> You get ill, you are accused of being mentally ill, denied effective treatment, then when you campaign for 'real science', you are accused of terrorising those who do not believe in your illness...after all, if your message is that people who say they are suffering from ME or CFS are mentally ill, then accusing them of irrational attacks adds strength to your case (Walker 2003: 225)

If people who are designated as mentally ill are seen as de-facto 'irrational' then we can clearly see the double bind in which ME/CFS patients are trapped. T h e y can be seen as victims of the classic psychiatric tautology: you are mentally ill and therefore everything you do can be interpreted as evidence of that illness. The more patients resist that framing, the more resistance can be seen as 'evidence' of their mental illness. This has been a classic criticism of psychiatry, from social labelling theory onwards (Scheff 1966). Perhaps it is not surprising that ME/CFS patients have become 'angry and bitter' (Fitzpatrick 2002). It is often

argued that ME activist's contestation of psychiatrisation arises from their prejudice about people with mental health conditions and this reinforces the stigma about mental illness (Fitzpatrick 2002; Smith and Wessely 2014; Huibers and Wessely 2006; Page and Wessely 2003). However, perhaps a better explanation for the strength of feeling among patients and advocacy groups is that it expresses a 'distinctive sense of, perhaps unarticulated but nonetheless robust, epistemic injustice (Blease et al 2016a: 6).

It is well recognised that a diagnosis of mental illness is pathologizing and stigmatising (Callard et al 2011). However, this stigma has deeper origins than just poor public attitudes. The next section examines the specific legal implications of a mental health diagnosis.

Discrimination in mental health law

The existence of separate Mental Health Law can be seen as a legally enforced form of epistemic injustice. This is because patient's choices about their care and treatment can legally be over-ruled. For example, in the UK, the Mental Health Act takes precedence over (or 'trumps') the Mental Capacity Act and the Human Rights Act, both of which explicitly exclude people deemed 'mentally ill' from the rights afforded other human beings (Szmukler 2004; Dawson and Szmukler 2006; Spandler and Calton 2009). Some have argued that this places people diagnosed with mental illness as the 'exception' to assumed universalist human rights legislation.

For example, whilst current legislation allows people with physical illnesses to be legally treated against their will, this can happen *only if* they are assessed as lacking capacity to make specific decisions regarding their treatment. However, if a person is deemed 'mentally ill'

and subject to Mental Health Law, they can be treated against their will *even if they retain treatment related capacity*. This remains the case even though studies suggest that up to half of people who are in acute psychiatric distress retain some treatment specific decision-making capacity (Owen et al. 2011). The decision-making capacity of patients with CFS/ME is likely to be much higher than this since the condition does not involve mind-altered states, like psychosis, which are more likely to affect a person's decision-making capacity. Thus, despite evidence of potential capacity, legislation effectively *assumes* a person lacks capacity to make treatment-related decisions if they are subject to mental health law. Therefore, critics have argued that separate Mental Health legislation is inherently discriminatory because it treats people with mental illness as essentially different from the rest of humanity and frames them as inherently irrational, no matter what level of capacity they may actually possess at a given time (Szmuzler 2004). Therefore, psychiatric framing can have serious consequences as it can result in coercive treatment or compulsory detention. This has resulted in the UN Convention on the Rights of People with Disabilities stating that forced detention and treatment *on the basis of psychosocial disability* (i.e. mental illness) is a human rights violation (Minkowitz 2015).

Indeed there have been examples of severely ill CFS/ME patients, including children and young people, being detained and treated in psychiatric hospital against their will, and against the wishes of their parents (Jason 2012). In these cases, it appears that patients refused psychiatric treatment, not because they rejected any medical assistance, but because of previous negative experiences of psychiatrisation which they felt worsened their condition. Some critics also point to instances where parents have been pathologised for supporting their children in objecting to their psychiatisation and being diagnosed with 'Munchausen's Syndrome by Proxy' or 'Pervasive Refusal Syndrome' (Walker 2003: 171). Although there

may be instances where parents convince their children that they are ill, especially where other forms of abuse and neglect occur in the family, Walker argues that to 'use this diagnosis in the case of a disputed physical illness could be classed as a denial of human rights' (Walker 2003: 171):

> 'There can be a developing cycle of adverse responses to patients who refuse to accept that their illness has a psychiatric origin. Psychiatrists, some physicians and a number of judges have agreed over the last decade that in cases where children supported by their parents claim that they have ME or CFS, the parents are guilty of forcing upon the child *irrational illness perceptions*. A number of cases have occurred, with children being taken into care for enforced psychiatric-based therapy' (Walker 2003: 170-1 emphasis in the original).

Some severely ill ME/CFS patients who have been hospitalised report being cajoled or forced into exercise, which may exacerbate their condition, or left without food (Gilderdale 2011; Jason 2012; Lost Voices 2008). In framing the illness as 'psychological', medical staff may have assumed that patients were simply refusing to exercise or eat, or at least presumed that there was no legitimate medical reason for them not to. It is worth noting that in at least two cases where patients were sectioned, and subsequently died, post mortem analyses showed some spinal cord/dorsal root abnormalities which appeared consistent with a physical basis to their condition (Hooper 2006; Gilderdale 2011). These examples illustrate the ways in which ME/CFS patients experience epistemic injustice through existing legal frameworks, an experience shared with mental health patients.

Shared interests between ME/CFS and mental health activists

What potentially unites ME/CFS and mental health patients is their frequently negative experience of psychiatric 'framing' which seems to deny them agency and rights. Both groups can be seen as forced to occupy a field that is dominated by understandings and interpretations in which their voices are marginalised and discounted. Like ME/CFS patients, many mental health service users contest the psychiatric framing of their difficulties as such framing has invalidated their perspectives, pathologised their experiences and led to potentially harmful and unwanted interventions. For example, psychiatric patients also commonly report negative experiences of services, especially hospitalisation, forced treatment and detention, and this is one of the main reasons many refer to themselves as 'survivors' of the mental health system.

Whilst ME/CFS and mental health activists might propose different solutions, they both problematise the tendency of psychiatry to misunderstand and pathologise their response to underlying suffering - whether that suffering is seen as caused by social factors such as trauma, oppression, racism on the one hand, or physiological, chemical or neurological factors on the other. Thus while ME activists contest what they see as *psychological* reductionism, mental health activists contest a *biological* reductionism. In addition, both are critical of the rise of 'quick fix' interventions promoted for both client groups, such as Cognitive Behaviourial Therapies which, they argue, do not address the underlying causes of suffering, whether that is seen as biological or social.

In the context of their negative experience of services, both ME/CFS and mental health service users have developed alternative non-psychiatric forms of knowledge and self-help strategies.

For example, 'pacing' is often recommended and supported by ME/CFS support groups, and increasingly by specialist support services. Similarly, strategies of self-harm minimisation developed by self-harm self-help groups and organisations which were initially rejected as 'encouraging' self-harm, have increasingly become accepted as good practice within services. In addition, voice hearers challenged the dominant psychiatric framing of voices as meaningless symptoms of an underlying psychiatric illness ('auditory hallucinations') and it is now more accepted that voices may be a meaningful part of people's life histories (Romme et al. 2009). These examples support the suggestion that, especially in a context of 'contested illnesses', where medical evidence is lacking or uncertain, there is good reason to give patient's views and experiences considerably more weight (Blease et al 2016b). In addition, where knowledge is so uncertain and contested, and there are no recognised 'cures', both ME/CFS and mental health self-help groups often promote a *plurality* of alternative approaches, in the hope that individuals might find something they find helpful to them.

Another similarity is the way that diagnostic practices have been contested. For example, the CFS diagnosis is criticised as stigmatising, vague and all encompassing, which is not dissimilar to critiques of other psychiatric diagnoses or 'syndromes'. More importantly, both diagnoses have been criticised as a way of concealing underlying causes and preventing alternative understandings of suffering, whether that be organic abnormalities in what is diagnosed as 'CFS', or underlying histories of abuse in what is diagnosed as 'schizophrenia' or 'borderline personality disorder' (Spandler 2014). Therefore, both ME/CFS and mental health patients have argued that the psychiatrisation of their experience has prevented further investigation into alternative meanings and origins and have argued for a broader investigation into their condition.

In addition, when either group have contested the imposition of psychiatric framing, their challenges have been often been discredited and pathologised. As a consequence, both have criticised the expanding reach of psychiatry to include the psychiatrisation of dissent and pathologising resistance to psychiatrisation itself (Burstow et al. 2014). In other words, both are potential victims of a psychiatric tautology where psychiatrisation can be seen as operating as a totalising system. In addition, dissident medical professionals who contest dominant psychiatric practice have also been pathologised and marginalised. For example, medical doctors who support the biomedical basis of ME/CFS have been disciplined by regulating medical bodies, in a similar way to critical psychiatrists who have opposed the biologisation and medicalisation of mental distress (Double 200; Brindley 2011).

This *psychiatric* field of contention may generate particular cultures of resistance. As a result, ME and mental health activists may share a common resistance habitus (Crossley 2004) formed in the specific psychiatric context. Following Bourdieu, habitus refers to a shared set of cultural dispositions that are formed in the context of particular fields such as medicine, psychiatry and the law (Crossley 2006). Fields facilitate, shape and constrain action and different fields require different skills, dispositions and resources from their participants, which in this context could include both medical professionals and patients. The idea of habitus may be specifically useful here because it takes us out of the mental/physical impasse and focuses on the social context in which cultures of medical professionalism *and* patient resistance are formed. This context is the de-legitimation inherent in psychiatric framing, and the double bind of pathologisation. So the habitus of psy professionals and the resistance habitus of ME/CFS patients is shaped by the relations of pathologisation that characterize the mental health field. It would be interesting to explore whether ME activists have inherited the radical disposition of other patient activists. For example, the ways that mental health

users/survivors have deconstructed and challenged the discourse and practices of psychiatry.

However, despite their shared interesting in contesting psychaitrisation, intriguingly few actual alliances have developed between those who see themselves as survivors of the mental health system and ME/CFS sufferers; or between mental health practitioners who are critical of psychiatry and dissident medical doctors who contest the psychiatrisation of ME/CFS. In addition, little has been written about common connections between ME/CFS and the mental health user/survivor movement. Whilst a few commentators have suggested that criticisms mounted by those traditionally associated with the anti-psychiatry movement, such as Thomas Szasz, R.D. Laing and Thomas Scheff, could be applied to CFS/ME (e.g. Walker 2003), these are rare examples. We have already alluded to a number of possible reasons for this lack of active cross fertilisation, which are worth stating explicitly.

First, in their concern to ensure ME/CFS is considered a physical condition, activists have consciously distanced themselves from associations with mental health and this may make alliances difficult to forge. Second, the core demands from ME/CFS groups seem to contradict those of mental health activists and may pose a particular challenge for alliances. For example, whilst mental health activists usually argue for less investment into bio-medical research and interventions and more investment in psycho-social approaches, ME activists tend to argue for *more* bio-medical and *less* psycho-social research and interventions. Third, CFS/ME is unanimously viewed as a negative experience by patients. There has been no assertion of 'pride' or any reclamation of a positive ME/CFS identity, unlike in mental health where we have seen the formation of organisations like Mad Pride. In contrast, ME sufferers view their condition as a chronic illness, which deserves to be medically recognised, not a political identity.

Having said that, both groups see themselves as an oppressed and silenced minority and both are generally comfortable making alliances with the wider disabled people's movement (Spandler et al. 2015). In addition, whilst Mad Pride was inspired by Gay Pride, ME activists often see themselves as inspired by HIV/AIDS activism which had to struggle against prevailing prejudices to ensure adequate funding into research, treatment and support. Ultimately, whilst they display differences in emphasis, there share important similarities in contesting the processes and consequences of psychiatrisation.

Conclusion

Notwithstanding important differences in the way they understand their respective conditions, both ME and mental health activists struggle for a fuller acknowledgement of their suffering and a greater awareness of the negative consequences of psychiatric framing on their lives. Whilst ME activists demand medical legitimation of their illness, and mental health activists appear to argue *against* medical legitimation, both demand that their experience, knowledge and perspectives are taken more seriously. In other words, they both demand *epistemic* legitimation, recognition and justice. This is why the notion of epistemic injustice is key to understanding the ongoing oppression and discrimination of both people with CFS/ME *and* 'mental illness'. It is also why some commentators have argued for a truth and reconciliation process in psychiatry to provide restorative justice (Wallcraft & Shulkes 2012; Sheperd 2015; Spandler 2016; Spandler and McKeown 2017). This kind of process could begin to acknowledge, and apologise for, the harm caused to people with CFS/ME *and* to people diagnosed with 'mental illness'.

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