Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Philosophical Investigation

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Abstract

Situated somewhere in no man's land, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) presents scientific and social issues to those who research, treat and experience it. Living with CFS/ME is profoundly disruptive; it is exceptionally physically, emotionally and socially difficult. This thesis offers the first philosophical analysis of the condition, how it is experienced, and how it is handled.

A phenomenological perspective is present throughout this analysis. How does the world of the person with CFS/ME change? How do we understand the sense of loss in CFS/ME, and does it amount to grief, or is grief reserved for bereavement? How does CFS/ME obstruct emotion regulation? How, if at all, are these experiences distinct from depression? How much epistemic privilege, and over which domains, belongs to medical professionals, and how much of it belongs to patients? Which social and political issues can be attributed to distinctive types of injustice, and which have their roots in something else? What does this mean for how we understand the newly-emergent phenomenon of "Long Covid"?

The answers to each of these questions are taken to support the view that a significantly improved understanding of CFS/ME is dependent upon the revision of a collection of commonplace distinctions and categories which currently restrict our efforts. A nuanced investigation of CFS/ME reveals the restrictiveness of the distinctions between psychiatric and somatic illness, between functional and organic illness, and between primary and secondary psychopathology. An approach to CFS/ME which is not bound by the confines of these distinctions shows itself to be uniquely illuminating.

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This thesis is dedicated to my mother, whom I trust will read it in its entirety despite the fact that, due to a combination of her wisdom and our fierce kinship, she will learn nothing from it.

Author's declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as References.

Introduction

This is a philosophical exploration a poorly-understood phenomenon: that which is often referred to as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (hereafter CFS/ME). Here I will offer the first detailed philosophical account of the phenomenology of CFS/ME, and use this analysis to highlight important steps which ought to be taken if the condition is to be better understood. As well as philosophical phenomenology, I engage with various other areas of philosophy such as the philosophy of mind and the emotions, the philosophy of medicine, psychiatry, and social epistemology.

There is a significant existing body of work on the phenomenology of illness (van den Berg, 1966; Fuchs, 2005b; Krueger & Henriksen, 2016; Ratcliffe, 2015; Sass, 2014; Toombs, 1988; Trigg, 2016; Williams & Carel, 2018). There are also phenomenological accounts of experiences which are not necessarily pathological, but which can in some ways resemble illness in that they are profoundly emotionally and physically disruptive, such as grief (Fuchs, 2018; Ratcliffe, 2019), trauma (Wilde, 2019), childbirth and pregnancy (Staehler, 2016).

There has, however, been comparatively little study of "boundary" conditions which have no obvious home with either psychiatrists or medical doctors of so-called organic disease (for an exception, see Slatman, 2018). CFS/ME is a paradigm case of a condition which sits at this uncomfortable boundary. There is, and has long been, considerable debate within the medical community about what *kind* of illness CFS/ME is, that is, whether it is "psychiatric" or "somatic", "functional" or "organic". Related to this, there is considerable debate over whether and how to distinguish CFS/ME from a range of other existing diagnoses. Depression is the most salient object of comparison here, and arguably, the most challenging.

The arguments presented in this thesis have relevance for a number of fields and disciplines. Principally, I make significant contributions to contemporary philosophical research. Using CFS/ME as an illustrative case, this thesis contributes to ongoing work in various philosophical areas and debates, such as the nature of (psycho)pathology, identity, and grief, as well as contributing to the process of refining newer philosophical concepts such as

epistemic injustice and *transformative experience*. Beyond philosophy, the account I offer has potential to inform the ongoing refinement of concepts in medical science, and highlight areas where change is necessary. Supplementing existing ways of understanding CFS/ME with a novel philosophical perspective can help to inform classification, diagnosis, and treatment.

Why it's complicated

Typically under the category "organic disease", some illnesses (or diseases) have clearer physiological bases than others. Chromosomal diseases, viral infections, tumours and so on exist at one extreme end of a scale, and as such we tend to be more comfortable calling such things natural kinds.[1] At least on the acute level, we have a good understanding of how a viral infection affects the body. We can, for example, fairly reliably recognise the symptoms of certain viruses, identify the presence of virus in the blood, and thus attribute the identified symptoms to a given biological marker. As medical knowledge increases, we are better able to match symptomatic profiles to physiological states.[2] Generally, psychiatric illnesses have weaker such available explanations. As Nassir Ghaemi writes:

> Psychiatry is a discipline that deals with subjective syndromes: the mind, mental phenomena, thoughts and feelings. And these mental phenomena are not yet amenable to complete explanation by means of mathematics, statistics, biology of physics. […] There are few clear pathologies of the brain, biochemical abnormalities, or physiological dysfunctions that can consistently be shown to occur in psychiatric conditions. (Ghaemi, 2003, p.252).

There are some exceptions here. For instance, under "neurocognitive disorders", the American Psychiatric Association's current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) details a variety of psychiatric disorders classified by their biological-level dysfunction, such as neurocognitive disorder as a result of Lewy Bodies or Prion Disease

[1] There are various different ways of understanding what a natural kind is such that some might dispute even this claim. For a general discussion of the debate about natural kinds in philosophy of science see Khalidi (2013). For a discussion of natural kinds in psychiatry and medicine see Cooper (2005); Tsou (2013).

[2] Multiple Sclerosis is a good example of a disease that medical understanding has become considerably more sophisticated of in recent years.

(APA, 2013). Most would grant, however, that Ghaemi's assessment applies to psychiatric categories such as depression and anxiety disorders; these are the kinds of psychiatric illnesses which will be relevant to my analysis.[3]

Conversely, it is of course not the case that all non-psychiatric illnesses are currently amenable to complete scientific explanation. Indeed, CFS/ME might be considered a striking example of this. That said, despite CFS/ME significantly implicating the body, there is little consensus about how CFS/ME ought to be classified. It has been proposed by some that CFS/ME should be classified as a "functional syndrome", that is, a syndrome that cannot be explained by identifiable disease (Mayou & Farmer, 2002). However, this has been met with resistance since the term is associated with psychogenesis, the role of which in CFS/ME still remains much disputed.

It is in the epistemic trouble caused by attempting to understand and manage conditions which are seen to sit at the "boundary" between the somatic and the psychiatric that commonplace medical categories and distinctions come under scrutiny. Bell et al (2020) examined the use of the functional/organic distinction in contemporary psychiatry only to discover that there is very little consensus about what exactly these terms mean. Moreover, despite clinicians disagreeing with one another about what these terms mean, and even doubting the aptness of the distinction themselves, they continue to employ it strategically.[4] The restrictiveness of the functional/organic distinction has long been recognised; in fact, 20th century neurologist Kinnier Wilson wrote that it "lingers at the bedside and in medical literature, though it is transparently false and has been abandoned long since by all contemplative minds" (Wilson, 1940). Doubtful of the helpfulness of the distinction like many before them, Bell et al write:

[3] Tsou (2016) is a candidate for somebody who might not grant such a thing. Tsou claims that depression is underwritten by a "stable, biological mechanism" of the kind "disturbances of serotonin function". See Kendler 2019 for a challenge to this way of understanding depression.

[4] Crudely, the distinction is supposed to pick out a difference between illnesses which can and cannot be explained by reference to biological change.

> The contribution of people who experience the interaction between 'functional' and 'organic' factors has rarely informed the validity of this distinction and the dilemmas arising from it, and we highlight this as a research priority. (Bell et al, 2020)

People with CFS/ME constitute one such group of people who experience the interaction between so-called functional and organic factors (Wojcik et al, 2011). Safely categorised as an organic factor, we typically have a good understanding of the *acute* effects of viral infections on the body. The long-term effects of viral infection, however, are one such class of illnesses that medical science is yet to fully understand. It has been long-recognised that a range of different viral infections can have long-term effects on the body. However, certain viruses have been compellingly implicated in the subsequent development of fatigue syndromes, though we lack a sophisticated understanding of the disease processes at play here. Possibly receiving the most scrutiny of all, Epstein-Barr Virus (EBV) has long been strongly linked to the subsequent development of fatigue syndromes, namely CFS/ME (Candy et al, 2003; Kristiansen et al, 2019; Pedersen, et al 2018; White, 2007).

Of course, however, infection with EBV is not sufficient for the subsequent development of CFS/ME; in fact, most people are infected with EBV early in their lives, and it is only comparatively few people who experience significant acute illness with infectious mononucleosis or glandular fever[5], and even fewer who experience long-term complications. It is also not the case that any *particular* viral infection is necessary for the subsequent development of CFS/ME: EBV is not implicated in all cases of CFS/ME, and some cases of CFS/ME do not appear to involve viral agents at any stage; indeed, a wide range of aetiological mechanisms appear to be implicated (Harvey & Wessely, 2009).

So, even if the presence of a virus is identifiable in the blood of a person with CFS/ME, very little to nothing might be known about the aetiology of the subsequent syndrome since it is not clear what, if any, role the viral agent has played in triggering the final causal pathway which gives rise to the symptoms. That is, even an identifiable history of certain viral infections does not necessarily give an indication of a physiological marker for the resultant

[5] These are equivalent terms and, in both cases, refer to the infection caused by EBV.

syndrome. Despite this, periods of scientific interest in grand hypotheses for the cause behind CFS/ME have been and gone, most notably the xenotropic murine leukaemia virus-related virus (XMRV) hypothesis (van Kuppeveld & van der Meer, 2011; Panelli, 2017). Despite disappointing cycles of research into various causal mechanisms behind CFS/ME, there is promise in some interesting new data, such as hyperosmotic stressor responsiveness (Esfandyarpour et al, 2019; see also Wirth & Scheibenbogen, 2021).[6] Ultimately, though, there is no well-established and reliable biomarker or identifiable physiological process which can be taken to identify or diagnose CFS/ME.

An unfortunate consequence of the difficulties in identifying informative biomarkers for CFS/ME is that there is considerable controversy about whether CFS/ME is legitimate as a diagnostic label of its own, either (i) as opposed to an existing psychiatric diagnostic label or (ii) *at all*. In acknowledging this, it comes to light how, despite "organic" factors being implicated in many cases, CFS/ME is also considered a "functional" illness.

Further supporting dispositions towards understanding CFS/ME as "functional" is the high incidence of psychiatric illness in CFS/ME. There is a significant body of research which suggests that depression and anxiety can be a significant pre-morbid risk factor as well as a causal factor in the development of CFS/ME (Borsini, et al 2014; Harvey et al 2009; Harvey & Wessely, 2009). Moreover, there can be considerable shared symptomatology between some cases of CFS/ME and psychiatric illness such as depression. This association has a long history: indeed, there is evidence to suggest that there is an important relationship between

[6] Some of the empirical research I draw upon will take its experimental group to be patients with "CF" or "CFS", some "CFS/ME", some "ME/CFS" and some "ME". I will use the terms as they are given in their context. Sometimes medical and social motivation for employing the term "CFS" over "ME" or vice versa are explicit, and other times not. For an excellent summary see Wojcik et al (2011). Sometimes the choice reflects the rejection of a previously used term that has become saturated with stigma and thus exceeded its social shelf-life. As well as this, sometimes the preference for a given term over another is an incidental product of the different degree of uptake that the component labels have across the globe. All of this considered, and in line with contemporary medical research, in what follows I will use the term "CFS/ME" unless context requires otherwise. For more on this, see Wessely on CFS/ME (1991), and Hacking (1991) for a related general discussion of the naming of "retardation": "The populations singled out overlap markedly. Each label was thought of as a classification or subclassification that improved on previous ones. Each classification has been associated with a regimen of treatment, schooling, exclusion, or inclusion. […] Each reflects the medical and social attitude of a particular epoch. They could have been otherwise." (p.111).

some cases of CFS/ME and historic cases of neurasthenia, a loosely-defined psychopathological disorder first labelled as such in the 19th century which was characterised by persistent fatigue, anxiety and depression (Harvey et al, 2009).

Neurasthenia, and later CFS/ME, have throughout history been associated with people with higher socio-economic profiles. For example, in the early twentieth century, drug company Rexall sold a "nerve tonic for over-wrought business men" purported to treat "Americanitis", a nickname for neurasthenia thought to have been coined by William James (Jung, 2019). More recently, and with the sentiment the same, the 1980s saw CFS disparagingly referred to as "yuppie flu". These purported correlations have since been discredited; what is instead more likely is that a range of biases are responsible for this impression (Jason et al, 1999; Wessely, Hotopf & Sharpe, 1998). As well as class, race is also implicated in this history:

> The dramatic under-representation of ethnic minorities in our CFS clinic is more likely to represent a combination of diagnostic and referral bias by clinicians and selection bias from health-seeking behaviour rather than any lack of vulnerability to CFS. Just as the myth of the 'happy savage' contributed to under-reporting of depression in the African populations until the 1950s. (Luthra & Wessely, 2004).[7]

These considerations make clear that there is a long history of social factors being at play in the diagnosis of such conditions in primary care. It would be a mistake to talk of this in the past tense, though: the problems are ongoing, and are exacerbated by related difficulties beyond the context of primary care. A significant challenge for the advancement of the understanding of CFS/ME is refining the tools to better understand the relationship between CFS/ME and psychiatric diagnoses like depression. Amongst the many things which makes this task difficult, is that depression faces just as many epistemic, metaphysical and scientific questions as CFS/ME. I will look in detail at a variety of these issues throughout the thesis, and will look more closely at some contemporary perspectives on depression in Chapter One.

[7] The "happy savage" is quoted from Bhugra (1996).

Qualitative data

As well as quantitative data investigating biological-level causes and pathophysiology, there is a strong body of existing qualitative work into experiences of CFS/ME, but its scope is limited. This research has predominantly investigated and screened for comorbid depression or low mood, as well as investigating the role of illness beliefs, the patient perspective on cause and what treatment strategies are perceived as helpful (see Bould et al, 2011; Bould et al, 2013; Loades et al, 2019; Loades et al, 2020; Loades, 2021a; Loades, 2021b; Pedersen, 2019; Taylor et al, 2017).

Throughout this thesis, I will draw upon data obtained in a self-conducted online qualitative questionnaire study, the Experiences of Fatigue Questionnaire (hereafter, EFQ).[8] The EFQ had a final sample size of 31 free-text responses. In conducting this questionnaire, I set out to obtain a different kind of qualitative data to that which has so far been sought from people with CFS/ME. Participants were asked a series of twelve open-ended questions which were inspired by extant work in philosophical phenomenology and first-person reports of illness in philosophy and literature.[9] The questions put to participants were structured around a range of aspects of experience such as bodily feeling, emotion, temporal experience, identity, and world experience. Throughout, I will draw on selected responses in order to illustrate philosophical points and make lesser-recognised aspects of CFS/ME experience salient, rather than in order to motivate or offer evidence for philosophical hypotheses.

Participants were eligible to participate if they identified as having CF/CFS/ME. The receipt of a formal diagnosis was not mandatory for eligibility given how "low and slow" diagnosis for these conditions is; this allowed the sample to exclude fewer "hidden cases". There are

[8] See Appendices for full list of questions and notes on methodology.

[9] Phenomenological qualitative data has been sought from people with psychiatric disorders like depression and schizophrenia. What I have done here most closely resembles Ratcliffe's Depression Questionnaire (DQ), another online qualitative questionnaire inspired by philosophical phenomenology (for methodology and selected in data from the DQ, see Ratcliffe, 2015). With a different goal and method, but with similar phenomenological grounding, see the Examination of Anomalous Self Experience (EASE) diagnostic checklist devised by Parnas and colleagues (Parnas et al, 2005).

thought to be a significant number of hidden, undiagnosed cases of CFS/ME: an Institute of Medicine report estimated that 2.5 million Americans live with CFS/ME, and that roughly 90% of those people have not been diagnosed (Institute of Medicine of the National Academies, 2015). It has also been estimated that *at least* 0.2% to 0.4% of the UK population are affected, meaning that up to 1 in 250 people in the UK could be living with the condition (The Optimum Health Clinic, 2017). Though it is unclear what the exact rates of diagnosis are in the UK, UK patient organisations and papers which focus on UK-based patients consistently document difficulties obtaining diagnosis (Geraghty & Blease, 2018).[10] Similar dynamics are identifiable elsewhere across the globe (de Boer, 2021).

Throughout, I will refer to the "illness" or "condition" of CFS/ME, rather than the "disease". Following Carel (2016), I take "illness" to capture the qualitative, experiential aspects of certain changes to one's body as well as how those changes affect how one is categorised and treated within society. "Disease", on the other hand, requires only some physiological dysfunction.[11] This distinction is also a useful one for the topic of current concern. Identification of disease, restricted to the narrow biological sense, has of course historically been difficult for CFS/ME. There is, therefore, room to debate whether or not CFS/ME represents any particular disease or cluster of diseases. This has consequences for patients: where biomedical tests for physiological dysfunction come back "normal", patients can be told that there is "nothing wrong" with them. This is clearly false, though what is meant by

[10] It is worth noting that some might reject the term "patient" in this context, just like in other health/disability contexts. I use it in this thesis when discussing encounters with healthcare professionals, but otherwise attempt to avoid the term in favour of "people with CFS/ME". The same might be said for the terms which imply suffering. For the same reason, I have tried to limit use of such terms except in contexts where it seems appropriate, such as where a respondent is explicitly describing a painful, difficult or upsetting experience.

[11] Though illness is usually coupled with disease, it is possible to be ill without being diseased, and to be diseased without being ill. For instance, somebody with mild Von Willebrand disease, a blood disorder in which the blood does not clot properly, may go undiagnosed their entire lives, and have symptoms so mild that they never seek medical help. This person would be, by virtue of having Von Willebrand disease, be "diseased". However, where the person experiences no significant dysfunction, receives no medical attention and continues to live an active, undisrupted life, they would not, at least for Carel, be ill. For alternative notions of disease see well-known discussions by Boorse (1975, 1997). Also see challenges to Boorse's account in Cooper (2002).

this, is that current resources and methods of testing cannot identify any markers of dysfunction indicating disease. Accordingly, pulling a narrow notion of disease apart from the broader notion of illness leaves no room to describe people with CFS/ME as having "nothing wrong with them".

Summary of argument

The overarching aim of this thesis is to show that a more nuanced approach to distinguishing between a variety of forms of experience is necessary if we are to significantly advance our understanding of CFS/ME. The chapters of this thesis will constitute thematic steps in making this clear. A principal aim of this thesis is to provide the first detailed philosophical account of the lived experience of CFS/ME, thus drawing attention to a variety of limitations of current approaches which operate within the confines of restrictive distinctions such as between psychiatric/somatic/functional/organic illness and primary/secondary psychiatric dysfunction.

People with CFS/ME can find it difficult to describe their experience, both in social and medical contexts. In Chapter One, I point to some of the distinctive challenges this poses for patients. Some of the existing concepts and categories that we employ to attempt to understand CFS/ME are limited in a number of ways. I show how when we think about the bodily experiences involved in CFS/ME from a phenomenological perspective, it becomes clear that these experiences involve much more than the body. Rather, an experience of CFS/ME can involve radical upheaval to various dimensions of self and world.

One consequence of this radical upheaval can be a deep sense of loss. This has not gone wholly unnoticed, but existing discussions of loss in CFS/ME have been cursory and uncritical. What exactly is lost? And are these experienced losses part of an experience of grief, or are they just grief-like? In Chapter 2 I argue for the position that people with CFS/ME can and do grieve over the losses associated with the illness. To make this claim, I illuminate some under-appreciated structural features of typical grief — that is, grief over a bereavement — which are shared with grief in CFS/ME. I then use this analysis to highlight some clinical challenges that arise should this claim receive uptake in clinical practice. Extant

literature on CFS/ME makes clear that rates of comorbid depression in are atypically high. If one accepts that people with CFS/ME can grieve over losses associated with the condition, *and* that grief can be easily mistaken for depression in this context, this might suggest that rates of comorbid depression are inflated. I will show, however, that the challenge of distinguishing between healthy and pathological grief arises in its place, and is just as tricky to solve. I will conclude by suggesting that successfully diagnosing and treating grief in CFS/ME is sometimes desirable, and that clinically recognising it and distinguishing it from other predicaments is essential.

Both grief and depression are recognised as processes which can profoundly disrupt emotion regulation. In Chapter Three, I offer a nuanced account of the various ways in which CFS/ME can involve its own distinct challenges to emotion regulation. I will draw on philosophical material on emotion regulation and affective scaffolding in order to illuminate the various different ways that challenges to emotion regulation can play out. Some clinical literature takes it to be the case that emotional challenges faced by patients are secondary to the bodily dysfunction, and are principally down to extraneous factors such as lack of empathy from others. While I agree that this is an important aspect of experience for many, I show that it is not sufficient to explain all of the challenges to emotion regulation faced by people with CFS/ME. For some people with CFS/ME, being denied access to various regulation strategies is incredibly tightly bound to the bodily dysfunction. From this, I will show that the distinction between primary and secondary dysfunction is unhelpfully restrictive since it cannot accommodate the complex web of causation and constitution that appears to be at play here. I will also consider how this analysis relates to existing notions of resilience and loneliness.

Another acknowledged type of upheaval that people with CFS/ME experience is an experienced threat to sense of self and identity. In Chapter Four, I will detail and distinguish between a variety of ways in which CFS/ME can affect one's world and identity. This account contributes to the project of refining the philosophical concept of transformative experience. Accordingly, I will suggest that there is an important family of transformative experiences which take an under-recognised structure. Transformative experiences need

not involve transforming from person A to person B, but instead can involve something much messier. I offer CFS/ME as a salient example of an experience which can take a variety of complex structures. Often, CFS/ME does not involve a clear transition from one identity to another, but rather, involves a much bumpier, more ambiguous and more protracted journey. In all cases, one's original identity is to some extent changed, but it is not always clear what replaces it.

Any experience of illness is socially and politically situated. In the final two chapters, I move away from an explicitly phenomenological study in favour of looking in greater detail at these dynamics and show how philosophical analysis can shed some light on these issues. In Chapter Five, I will explore the issue of how the testimony of people with CFS/ME is handled. I will do so by engaging with recent influential work on epistemic injustice, and in particular, I will critically assess claims made in a recent paper which focuses on epistemic injustice in the context of CFS/ME. I will show that there are tensions between taking steps to protect against committing epistemic injustice in healthcare, and taking steps to understand the complexity of one's predicament and treat it accordingly. Subsequently, I warn against work on epistemic injustice in healthcare settings obfuscating legitimate and potentially fruitful inquiry for complex conditions like CFS/ME. In some cases where practitioners are met with accusations of epistemic injustice, I suggest that the stigmatisation of psychiatric illness is under the surface.

The claim that the stigmatisation of psychiatric illness can be implicit in some claims of epistemic injustice in CFS/ME is importantly related to issues around the handling of the newly-emergent phenomenon "Long Covid". In Chapter Six, I engage with the fact that the debate around Long Covid has so far shown resistance to accept parallels between Long Covid and a set of existing conditions which have historically been subject to stigma, namely CFS/ME and psychiatric illness. This resistance risks endorsing the stigma associated with such existing conditions, and as such, these dynamics of stigma ought to be dismantled in order to facilitate the development of effective clinical resources for all such implicated conditions. As well as negatively impacting proceedings at the structural level, I will discuss how the aforementioned problems also risk affecting patients of both CFS/ME and Long

Covid at the personal level, by motivating the reconfiguration and restriction of patient illness narratives.

All of this supports the conclusion that in order to better understand CFS/ME, various commonplace distinctions and categories need to be revised or abandoned. One cannot appeal to a straightforward distinction between psychiatric and somatic illness, and existing ways of understanding experiences such as depression and grief warrant revision if they are to be fruitfully applied here. CFS/ME cannot be classified exclusively as an illness of the mind nor of the body, nor can it be reliably and neatly distinguished from or collapsed into depression: a rich philosophical perspective on CFS/ME shows that things are much messier. Recognising this messiness is important for making progress in a variety of contexts. I make an important contribution to ongoing philosophical and scientific research which can also be used to inform social and political action to support people with CFS/ME and related conditions.

Chapter One: The Fatigued Body

1. Introduction

As is suggested by the term "syndrome" in "CFS/ME", CFS/ME is diagnosed by reference to a cluster of symptoms rather than an underlying physiological marker or disease process. Since the diagnostic process is significantly dependent upon engagement with first-person patient reports of symptoms and phenomenology, identifying the condition is largely phenomenologically-driven. Can CFS/ME be easily identified by asking people about their experience? The simple answer, I suggest, is "no". Reasons for this are many, and in what follows, I will introduce some of them.

First, people with CFS/ME can find it difficult to recognise and accurately describe their experience. For instance, how does the relevant state of fatigue differ from other experiences of fatigue or tiredness, and how can that difference be expressed in language? Patient testimony supports the intuition that there are some such differences: some patients are careful to distinguish their experience of fatigue in CFS/ME from past experiences of fatigue, and describe frustration at the assumption of others that their fatigue is qualitatively alike the fatigue that the non-clinical population are familiar with.

Second, exacerbating this, existing practices and diagnostic criteria can (i) fail to distinguish between subtly different experiences and (ii) fail to recognise similarities in experiences that are significantly differently classified. I show that, compared with other approaches, philosophical phenomenology can help us to better get at the lived experience of people with CFS/ME.

So, what is the typical diagnostic process for CFS/ME? The *National Institute for Health and Care Excellence* guidelines for CFS/ME are most commonly used in practice. These guidelines have been highly influential, albeit not without controversy.[12] The current guidelines,

[12] The controversy here relates to NICE guidance on the treatment of patients rather than diagnostic guidelines. A revised version of the NICE guidelines was due to be released in Summer 2021, but was withdrawn at short notice given concerns from medical professionals about the harm of publishing guidance which offers patients no viable treatment options. This follows the revised version having removed recommendation of Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT), the existing

originally published in 2007, state that diagnosis of CFS/ME should be considered if there is disabling fatigue "that is new or started suddenly, lasts a long time or keeps coming back and cannot be explained by other causes." Satisfying this, diagnosis of CFS/ME should also be considered if the fatigue restricts activity, or if it gets worse after activity or gentle exercise (this and the intensification of other symptoms such as myalgia is now referred to as "post-exertional malaise"). Other symptoms that may contribute towards a diagnosis include:

- Sleep problems (insomnia, hypersomnia or otherwise disturbed sleep)
- Pain in muscles or joints
- Headaches
- Sore throat
- Problems thinking, remembering, concentrating or planning
- Flu-like symptoms
- Feeling dizzy or sick
- Having heart palpitations

(NICE, 2007)

The symptoms listed here are remarkably general: one might think of a range of illnesses which could meet these criteria. In other words, there is very little if anything that is distinctive about these criteria. Moreover, CFS/ME is acknowledged to involve significant heterogeneity in presentation, with various other features not listed here being strongly implicated in at least *some, but not all,* hypothesised sub-groups, such as: gastro-intestinal distress; mood disorder; orthostatic intolerance; panic disorder and chest pain (Williams, Chalder, Sharpe & White, 2017; Huber, Sunnquist & Jason, 2018).

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treatment recommendations which were the subject of controversy on the grounds that they are at best ineffective, and at worst harmful (see Geraghty & Blease, 2016; see Sharpe, Goldsmith & Chalder, 2019 for a response).

This highlights that there is no clear sense of the case definition for CFS/ME, and the diagnostic criteria reflect this. Given this, diagnosis is not straightforward. It is sometimes the case in practice that medical professionals will investigate the possibility of a range of alternative diagnoses before being happy to diagnose CFS/ME. That is, CFS/ME can be diagnosed by exclusion. As well as this, as I outlined in the Introduction, an additional significant and long-standing challenge for the advancement of the understanding of CFS/ME is refining the tools to distinguish it from existing psychiatric predicaments, particularly depression. This can also influence the diagnostic process. Like CFS/ME, depression is also diagnosed based on symptom presentation. Plausibly then, where the symptomatology is similar, diagnostic errors can be made; and more than this, as I will show, in some cases there may be no fact of the matter as to which diagnosis is most appropriate.

So, what are the diagnostic criteria for depression? The two most influential diagnostic criteria in Western medicine are the DSM, now in the fifth edition, and the World Health Organisation's International Classification of Diseases, now in its eleventh edition (WHO, 2018). The diagnostic criteria for Major Depressive Disorder as listed in the DSM-5 is as follows:

- A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). (Note: In children and adolescents, can be irritable mood.)

2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (Note: In children, consider failure to make expected weight gain.)

4. Insomnia or hypersomnia nearly every day.

5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

- B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

(APA, 2013, pp.160-161)

As can be easily seen, the diagnostic criteria for CFS/ME and depression are significantly different, only sharing the symptoms of problems with sleep, thinking/psychomotor skills, and interestingly, fatigue. One principal difference between the criteria here is that in each case, the necessary criteria reflect the classification of the disorder as psychiatric or somatic: for CFS/ME it is disabling fatigue that is necessary, whereas for depression it is affectively-loaded, requiring either "depressed mood" or loss of interest or pleasure. As my phenomenological analysis will show, the assumption that the respective symptomatology for each condition will reflect this fundamental difference in illness type, psychiatric or somatic, does not reflect the reality of the experiences in many cases. But before digging deeper into the issue with depression and how the two conditions can be distinguished, I want to look more closely at the necessary condition for a diagnosis of CFS/ME: disabling fatigue.

2. The limits of language

We have just seen that, perhaps unsurprisingly, a necessary condition for a diagnosis of CFS/ME is the presence of disabling fatigue. This might seem straight-forward enough. On closer inspection, however, there are potentially important ambiguities here. Namely, what is the relevant notion of fatigue here?

Something that people who have CFS/ME have long-described frustration with is the response that they get when they first tell somebody that they suffer from CFS/ME, that is, responses that go something along the lines of "I must have that; I'm always tired". There are multiple candidate explanations for why this kind of remark is unhelpful. Aside from displaying a lack of tact and empathy, it is implicit in such a remark is the assumption that the lived experience of the person with CFS/ME is accessible to the other; that what they are experiencing has been experienced by others as part of their healthy, everyday lives. The assumption that the fatigue experienced by those with CFS/ME is phenomenologically alike the tiredness, fatigue, or even exhaustion experienced by the general population is harmful and false. Indeed, this frustration has motivated patient activism: some have expressed dissatisfaction with the label "Chronic Fatigue Syndrome" since it allows those ignorant to the condition to assume that fatigue, understood in the general sense, is the sole affliction of the condition. Over the years, this has motivated attempts to revise the label of the condition, such as to replace "Chronic Fatigue Syndrome" with "Myalgic Encephalomyelitis" (ME), or "Systemic Exertion Intolerance Disease" (SEID).[13] As one EFQ participant commented:

> I also feel the illness isn't taken seriously, by doctors or by people generally, and is often misunderstood. It has some stigma attached to it, which I think mainly comes from the name

[13] At first glance, one might suppose that the diagnostic label "Myalgic Encephalomyelitis" is interchangeable with "CFS". Sufferers of ME also often cite viral triggers for their illness. Unlike "CFS", however, the term "ME" implies a physiological disruption: encephalitis is inflammation of the brain and spinal cord. On this alone, then, CFS and ME are not equivalent diagnoses. However, the distinction between ME and CFS is contentious and so in practice, they are generally given together; one is offered a diagnosis of "CFS/ME" (or "ME/CFS").

> Chronic Fatigue Syndrome - people assume you are just tired, and that they might have it too. It isn't taken as seriously as it should be. (#24)

This questionnaire response articulates the difficulty that people with CFS/ME face having their experience understood by others whose first introduction to the condition is by way of hearing the label "Chronic Fatigue Syndrome". In everyday contexts, "tired", "fatigued", and "exhausted" can be used to refer to a range of states, and can sometimes be used interchangeably. Of course, "tired" and "exhausted" are not exact synonyms, and suggest at least differences in degree, and likely qualitative differences too. It is not at all clear where "fatigued" would fit on that scale. In various contexts, one can identify trends of subtle differences in use. For example, a small group of athletes who train together might subconsciously develop a linguistic consensus on "fatigued" referring to the build up of lactic acid and muscle weakness after intense physical activity, and reserve "tired" for descriptions of being under-slept or otherwise lacking in a feeling of bodily energy or vitality. We might expect to find countless small linguistic communities across the world, such as families, colleagues, and professional bodies, to use these terms differently. The looseness of these terms creates a linguistic predicament for people with CFS/ME.

In his work on the experience of survivors of the Holocaust, Martin Kusch identifies a linguistic predicament which he calls "linguistic despair" (Kusch, 2017). Given that this work refers to phenomena situated in a radically different context, there is a need for caution here. I suggest, though, that the broad notion of linguistic despair can offer useful insights to the domain of illness and pain more broadly.[14] Kusch describes the struggle experienced by survivors to communicate how markedly different one's experience was from ordinary taken-for-granted life. He quotes from the following passage from Elie Wiesel:

> I had many things to say, I did not have the words to say them. Painfully aware of my limitations, I watched helplessly as language became an obstacle. But how was one to

[14] Something similar may have been picked up by Elaine Scarry in her discussion of "verbal unanchoredness" in her book *The Body in Pain* (1985). Here Scarry discusses how descriptions of events in various contexts of "strategy, alliance and history" as well as "daily conversation" can find themselves "submerged in obscurity" (pp.133-136).

> rehabilitate and transform words betrayed and perverted by the enemy? Hunger— thirst—fear—transport—selection—fire—chimney: these words all have intrinsic meaning, but in those times, they meant something else. (Wiesel, 2006)

And the following, from Charlotte Delbo, regarding the term "thirst":

> Otherwise someone [who was in the camps] who has been tormented by thirst for weeks would never again be able to say: 'I'm thirsty. Let's make a cup of tea.' … 'Thirst' [after the war] has once more become a currently used term. On the other hand, if I dream of the thirst that I felt in Birkenau, I see myself as I was then, haggard, bereft of reason, tottering. I feel again physically that real thirst, and it's an agonizing nightmare. But if you want me to speak to you about it …" (Quoted in Langer, 1991)

Matthew Ratcliffe discusses a similar predicament in the context of trauma. He describes the structure of situations in which one finds oneself in a new context in an enduring way, thus experiencing a gulf between one's own context and that of others:

> To describe Context A to those residing in Context B, one relies upon words such as x, y, and z, which are familiar to interpreters situated in B. However, those words have importantly different connotations in A, which are obscured by their employment in B. Hence, in order to describe something, one must use words that someone else understands, but that same understanding eclipses the phenomenon in question. (Ratcliffe, 2021)

These considerations begin to scratch the surface of the difficulty of capturing the phenomenology of the fatigue experienced by people with CFS/ME. Equipped only with familiar, mundane terms, people with CFS/ME do not have the linguistic tools to offer descriptions which can reliably distinguish between fatigue of various types and degrees, some of which may or may not be unique to CFS/ME experience. Terms like "fatigued" drastically understate the experience, yet one has to use familiar terms in order to attempt to describe something which markedly departs from the familiar; this language is all patients have.

Moreover, even between people with CFS/ME, there are significant differences in the way the fatigue is experienced. It would be a mistake to assume that there are just two distinct experiential states which are to be distinguished, one of which is associated with a given

pathological state, and the other which is not. Nonetheless, it does appear to be the case that there is something distinctive about instances of fatigue characteristic of CFS/ME compared to various other instances of tiredness or fatigue. This is particularly salient in people's comparisons of their CFS/ME fatigue with previous experiences from before they fell ill. When asked how their experience makes their body feel, some EFQ participants did in fact compare bodily feeling in CFS/ME to other experiences such as sugar crashes, hangovers, over-exercising, or mild illness, but not without qualification:

> It can be similar to experiencing a sugar crash where you might feel faint, except with fatigue crashes you generally don't actually faint, just feel completely exhausted to the point your mind and body shuts off. (#6)

> The only way I can describe it is it is like a mixture of feeling like your body is shutting down all the time. It is almost like you have been to the gym and massively over done it, with your whole body aching and in pain constantly. Then on top of that it is like having the world's worst hangover. (#11)

When describing body feeling in CFS/ME, respondents were often describing much more than the state of fatigue alone. As might go under-recognised given the emphasis on fatigue in the condition's name, CFS/ME generally involves more than just fatigue. Rather, CFS/ME experience for many also involves additional discomfort and pain as well as multiple other multi-system symptoms. As some EFQ participants make clear:

> Like I have been beaten up / run over / have bad flu. I have symptoms constantly, and so severely that I cannot even sit up or feed myself. Light feels like daggers hitting the back of my head, and sounds (eg peoples voices) also cause physical pain. I often choke on food (even though it is pureed), struggle to catch my breath, and often have vertigo (so it feels like I am on a boat even lying still in bed). (#13)

> My body feels exhausted and achy, as though I have just run a marathon, even when I am well rested. I often cannot think straight, or focus on anything. I fall asleep at my desk or watching television. I am only young but I imagine this is what it feels like to be very old, aches, pains, stiffness. (#17)

Fatigue is, however, a hallmark symptom of CFS/ME for many, and does feature heavily in many EFQ responses accordingly. Fatigue stands out as an aspect of the experience that is either difficult to describe, or which it is important for other reasons to try to explain adequately – perhaps to ward off the aforementioned tactless comments from others. Potentially in an attempt to get across the distinctiveness of experiences of fatigue in CFS/ME, some respondents were careful to distance their experience of CFS/ME fatigue in particular from other experiences. For example:

> I don't remember what being normal tired is like. I am like an on and off switch. As soon as warning signs come I need to stop immediately. Its never a nice "sleepy" feeling, always an "I can't cope with being awake any more". Even so I have a lot of struggles falling asleep. Sometimes I have been exhausted but ME has kept me awake the whole night - especially when I start stressing I can't sleep/am over excited about the next day. (#9)

> Not a natural tiredness from exercise or fatigue but an ingrained fatigue that your body has 24/7. (#18)

> In the initial acute phase, I felt as though some alien being had entered my body - such strange sensations - certainly far worse than "just fatigue." (#19)

"Sleepy" is another interesting relevant adjective. The description of "a nice sleepy feeling" paints a picture of getting home after a long day, and wrapping oneself up warm ready to fall into a restorative sleep. This has clear phenomenological distance from other descriptions of CFS/ME fatigue such as not being able to "cope with being awake". There is also an interesting distinction being made here between fatigue which feels natural, proportionate or otherwise "makes sense", from that which is more pervasive, disproportionate or sinister. Other responses emphasise the pervasiveness of the fatigue, describing their body as feeling broken, drained, weak, heavy, sluggish:

> Heavy, like sinking. My muscles (particularly legs) feel like they are being dragged/are falling out of the body. It becomes so difficult to move, like walking through treacle. (#9)

One might also distinguish between states which are unpleasant given one's current context, and states which are intrinsically unpleasant or distressing. It might be unpleasant

for me to experience significant tiredness in the context of it being only 3pm on a weekday, knowing that I have to attend a meeting at 5pm before I can go home. However, when I am finally home and lying on the sofa, I might come to experience this tiredness in a pleasant way. However, should I be in the midst of a norovirus infection, the exhaustion I am experiencing is unpleasant regardless of the fact that I am at home and lying on the sofa: there is no sufficiently un-demanding situation that detracts from the unpleasantness of the bodily feeling.[15]

Moreover, unlike some but not all other experiences of tiredness or fatigue, another common description of CFS/ME experience is of being "tired but wired". This means that despite exhaustion, one finds it difficult to fall and/or stay asleep and is in some sense wide awake or stimulated. This is not a symptom shared by all people with CFS/ME, however; as highlighted in the NICE criteria, sleep problems of many kinds, such as hypersomnia, contribute towards a CFS/ME diagnosis. The vast heterogeneity here makes clear that there is not just one single experience of fatigue characteristic of CFS/ME which can be pinned down to reveal the true nature of the experience. Instead, experiences will vary significantly between people depending on a variety of different factors, some of which we can pin down (such as comorbid diagnoses and social support), others we cannot (such as personality-shaping past experiences, hidden premorbid mitochondrial dysfunction or nutrient deficiencies). There is a sense in which this is not surprising: one would expect similar variation in reports of symptoms of pains, nausea or fatigue as part of certain experiences such as pregnancy or viral infection. For instance, the diversity in reported experiences of

[15] It would be interesting to empirically test whether the fatigue associated with CFS/ME consistently comes under the category of "unpleasant". It is not clear that experiences of acute illnesses like influenza would: though unpleasant in other ways, one might enjoy aspects of the floating, directionless state of fatigue that might accompany influenza. It is plausible that, should the *same* phenomenology persist for a sufficiently long period of time, it would cease to be in any way pleasant, thus changing it. This suggests that, consistent with other arguments in this thesis, that temporal experience is important in affecting the phenomenology of illness. One might consult the literature on illness perceptions in CFS/ME to investigate the impact of differently affective valanced bodily states (Moss-Morris, Petrie & Weinman, 1996; Moss-Morris, 1997; Dickson, Toft & O'Carroll, 2009).

SARS-CoV-2 is a salient example. In which case, why does this ambiguity create a particular problem for people with CFS/ME?

3. The feeling of being unwell

In the context of attempting to make a diagnosis, the difficulty linguistically conveying the kind and degree of fatigue experienced by patients becomes especially salient where one recalls that there are no biomarkers or other physiological clues to arbitrate between diagnoses. Based on description alone, it might not be possible to distinguish between a broad range of conditions, such as the fatigue described by a patient with depression and a patient with a live Epstein-Barr Virus infection. In cases like this, however, blood tests can arbitrate.

Things become more difficult when one faces the challenge of differentiating between the diverse and heterogeneous set of experiences associated with CFS/ME, and other illnesses with similarly heterogeneous symptom profiles *and* similarly uninformative biomarkers. Depression is a salient example of one such condition. First, though countless biomarkers for depression have been identified over time, none have proved particularly informative so far (Strawbridge, Young & Cleare, 2017). Second, influential though diagnostic criteria for depression are, there has been wide-spread criticism of how cursory and under-descriptive they are (see Andreasen, 2007; Ratcliffe, 2015; Fernandez, 2019; Jackson, 2019).[16] Recall that one of the necessary criteria for a diagnosis is either "depressed mood" or "loss of interest or pleasure". Not unlike the issue with "disabling fatigue" which I discussed in the previous section, it is not at all clear what a "depressed mood" and "loss of interest or pleasure"

[16] As well as being under-descriptive, it is also sometimes unclear what diagnostic criteria are expected to do. There are various ways of understanding this, and it is being increasingly highlighted that there is a conflation of different approaches (see Kendler, 2017; Fernandez, 2019). We can identify the currently popular operational approach, as well as the typification approaches often preferred by phenomenologists. As laid out by Fernandez (2019), the typification approach can fall into smaller subcategories still, such as ideal types (Weber, 1949; Schwartz & Wiggins, 1987), essential types (Parnas & Zahavi, 2002), and prototypes (Parnas & Gallagher, 2015), though ambiguities are common in the details of these approaches. Phenomenological approaches to classification claim to better accommodate how clinicians intuitively diagnose patients (Fernandez, 2019, p.5). I will be non-committal on this matter here (see Fernandez 2019 for discussion).

amounts to phenomenologically; plausibly, a broad range of experiences could be described in these terms (Ratcliffe, 2015, p.66; p.95).[17]

Amidst more obviously cognitive and affectively-loaded symptoms, recall that fatigue features in the DSM criteria for depression too. This suggests that depression can involve bodily phenomenology. Indeed, Ratcliffe, Broome, Smith and Bowden (2013) reported on a study in which people were asked how their body feels when they are depressed. Of 136 respondents, 96 offered descriptions which involved one or more of the words "tired", "heavy", "lethargic" and "exhausted". As well as this, it appears that depression can involve a broad range of other bodily phenomena including pain and cold and flu-like symptoms. Consider the following responses to Ratcliffe's Depression Questionnaire (DQ):[18]

> Slow, heavy, lethargic and painful. Every morning I wake with a sore throat, headache and blocked nose. Everything feels 1000 times harder to do. To get out of bed, hold a cup of tea, it's all such an effort. My entire body aches and feels like it is going to break. (#14)
>
> When I first started to suffer from depression I always used to say that it felt as though something 'wasn't quite right' in that I generally felt under the weather. It felt as though I was always coming down with a cold in that I felt 'below par'. My swings in mood are generally accompanied by headaches, sometimes quite bad, and I will always wake up with them. If that is the case I know that my mood is changing and that my headache will not go until I go to sleep that night. (#334).

These responses make for striking comparison with the following EFQ responses:[19]

> Most of the time there will be symptoms similar to the start of a flu or a common cold, your glands will feel sore and swell, maybe your throat will hurt slightly, you may become

[17] As Ratcliffe writes: "What is lacking from the world of depression is not simply the anticipation and/or experience of pleasure, but a sense that there could be meaningful change, change of a kind that matters. This is different from anticipated or actual pleasure; meaningful change might bring pleasure but it is not meaningful in virtue of its relationship to pleasure" (2015, p.66).

[18] The full data set for this is not publicly available, but selected responses feature in Ratcliffe (2015).

[19] Interestingly, like some EFQ responses (see #11 above), some DQ respondents compared their experience to a bad hangover. One DQ respondent described depression as a "permanent hangover" and another said that depression is "like when you have just had a load to drink the night before and just woken up with a desire to stay put and sleep" (Ratcliffe, 2015, p.91).

> light sensitive and you'll be prone to headaches. All of this around a feeling of generally feeling sluggish and tired, your mind does not process quickly and your memory may feel impaired. Thinking and doing cognitive work may feel harder than physical. These experiences may be from the moment of waking up all through the day, and it is there to some extent every single day. Joints may ache and muscles cramp and feel unnaturally uncomfortable after exertion. My muscles are more prone to tension and getting "knots" which is worsened by having to spend much time in seated or lying positions. This in itself can cause problems with tension headaches. (#6)

> It makes me feel heavy and inflamed. I feel achey all over but particularly joints, and my skin is sometimes so sensitive that even light touch can be painful. I often feel as though my brain hurts, my thoughts are blurry. Overall, I feel weak. (#24)

> Like I cannot move and everything hurts. As though my back and other parts are on fire, I cannot think. The pain and fatigue is all consuming and very little and sometimes even breathing and speaking feel overwhelming. (#26)

At the descriptive level, this is suggestive that both experiences of CFS/ME and of depression can involve a broad range of bodily symptoms typically associated with general "illness" such as cold and flu. Moreover, as well as descriptively, the picture painted by descriptions of experience here can be offered support at a different level of explanation, namely, by contemporary research in immunopsychiatry.

The past two decades have seen a significant interest in the possibility that depression, in at least in some cases, has its roots in an inflammatory immune response. For instance, Harrison et al (2009) have shown that in some instances, there is a common pathophysiological basis for both major depressive disorder and sickness-associated mood change including depression. In such cases, the excessive release of particular pro-inflammatory cytokines is causally involved in experiencing the sickness response which is characterised by lethargy, low mood, a lack of vitality, inability to concentrate, a diminished inclination to act and a sense of being disconnected from things. This sickness response is not pathogen-specific, and can arise in the prodromal period, that is, before the emergence of specific symptoms, and can linger afterwards. This suggests that despite being classified

differently, some of these experiences which involve certain bodily phenomena might not only be phenomenologically indistinguishable in some cases, but also that where they are, they might also have shared pathophysiology.

It will not be the case that this mechanism explains, in full, all cases of depression. A weaker claim, that this mechanism might be suggestive of an inflammatory sub-type of depression, is much more plausible. Contemporary work in immunopsychiatry supports the view that differential responsiveness to antidepressant treatment is suggestive of this inflammatory subtype. For instance, Cattaneo et al (2013) found that depressed patients who did not respond to escitalopram and desipramine had higher baseline mRNA levels of inflammatory cytokines IL-1, MIF and TNF-alpha. The levels of these three cytokines predicted around 50% of the variance in response to the antidepressants.

Unusual cytokine activity in people with CFS/ME has been found (Montoya et al, 2017; Groven et al, 2018; Jason et al, 2021). Importantly, some evidence suggests the same cytokines are implicated, yet it is not consistently the case: some data finds higher levels of anti-inflammatory cytokines such as IL-10 (ter Wolbeek et al, 2007), and reduced levels of pro-inflammatory cytokines such as IL-6, where some find the opposite (Montoya et al, 2017; Groven et al, 2018). Moreover, it is also not always clearly evidenced that cytokine levels in the CFS/ME population are consistently higher than controls (Corbitt et al, 2019), nor whether the differences are sufficient to play a role in diagnosis or treatment (Yang et al, 2019). Despite these limitations, there is early evidence to suggest that the pathophysiology of at least *some* cases of depression, then, might be shared with at least some cases of CFS/ME.

However, even if all cases of depression appear to be principally attributable to inflammation, which we are not currently in a position to assert, depression of course remains causally diverse since there are multiple factors that can cause this inflammation response. As I have outlined, the same appears to be true of CFS/ME given its heterogeneity. Given this, it might be that in some cases one experiences CFS/ME which is distinct from depression, but also has comorbid depression which is arises by a different mechanism. In such a case, the CFS/ME *causes* the depression, but is distinct from it. As

Ratcliffe, Broome, Smith and Bowden (2013) note in the context of depression, the sickness response alone might not be sufficient for depression: perhaps the initial sickness feeling instead predisposes one towards other phenomenological changes that are. There are many options here which I will critically discuss later (see Chapters 2, 3).

These considerations might be suggestive of the idea that the category "depression" is so broad as to fail to pick out anything particularly informative, and as such is just a place-holder for a number of predicaments whose explanation is "pending". Indeed, Ratcliffe, Broome, Smith and Bowden (2013) suggest that this is the case. Based on our current understanding of the condition, it might also be true of CFS/ME. As in depression, the diagnostic category "CFS/ME" likely accommodates a range of different predicaments. Extant scientific and phenomenological research does not allow us to make sharp distinctions between at least some cases of CFS/ME and depression, and work is needed in order to discern ways of distinguishing between a variety of broad categories such as depression, the general sickness response associated with inflammation, *and* pathophysiological mechanisms which might be unique to CFS/ME. Though we should expect vast heterogeneity in CFS/ME experience, doing more phenomenological work to better understand the structure of such experiences will be an important task for better managing them clinically.

4. Phenomenology and the body

Philosophical phenomenology encompasses a variety of movements and methods. In what follows, I will not follow a particular method, but will instead will draw on various insights from the tradition which are relevant to my analysis. Of central importance here is the body. The phenomenological approach to bodily experience shows how experiences of the body such as illness are not solely confined to the body, but instead involve much more. This perspective can offer some illuminating tools for engaging with the *experience* of illness, showing for instance the impossibility of distinguishing between disturbances of psyche and soma. Phenomenologically-grounded ways of describing illness do not need this category, and hence can make salient various under-recognised dynamics which can inform a rich study of how illness affects not only the ways that one's body is experienced as a result of

symptoms, but also crucially, how changes to one's bodily feeling also affects one's wider experience of self and world.

The body here is to be understood as that *through which* one's environment is experienced; it is a medium of perception. Thomas Fuchs describes the role of the body here as follows:

> The lived body means not only the felt body, the subjective space of bodily sensations, but comprises my prereflective experience as a whole, insofar as it is conveyed by the medium of the body, by its senses and limbs. I act through my body, perceive and exist through it, without explicitly reflecting on it. (2002, p.224)

In the classic text *Phenomenology of Perception* (PoP), Maurice Merleau-Ponty refers to "the darkness of the theatre required for clarity of the performance" (1962, p.103). The thought here is that in good health the experience of the body is "transparent", and thus allows one to move through the world in a fluid, pre-reflective way, allowing the world to be experienced with a sort of background certainty. One does not carry out a movement after conscious consideration and planning, checking where one's arm is and then preparing to move it through one's surroundings in a particular way, say, directed at the light switch on the wall. Rather, one's body moves fluidly, pre-reflectively, to carry out the intended action:

> …my body appears to me as a posture toward a certain task, actual or possible. (1962, p.102)

To carry out these tasks in this way, the body depends upon a certain unity. Merleau-Ponty expresses that a certain arrangement of movements directed towards some chosen end comes together organically; there is no explicit calculation over which particular parts of my body should to come together to carry out this particular task effectively. Rather, my body does this calculation for me:

> I desire a certain result and the tasks divide themselves up among the segments in question, and the possible combinations of movements are given in advance as equivalent: I could remain leaning back in my chair provided that I extend my arm further, I could lean forward, or I could even partly stand up. All of these movements are available to us through their common signification. (1962, p.150)

The lived, feeling body [*Leib]* can be contrasted with the anatomical, corporeal body understood as an object of third-person study and observation [*Körper]*. Some more recent phenomenological work has involved accounts of a *shift* from experiencing the body as a fluid, "invisible" entity, to experiencing the body as a brute physical object. The process, referred to as "corporealisation", involves a disruption to the pre-reflective fluidity of the lived body, instead replacing this with a sense of the body as awkward, heavy, rigid, and object-like, with the "thing-like" properties of the body thrust into awareness (Ratcliffe, 2012a). There is a variety of experiences which can affect the experience of the body in this way. Fuchs (ibid) lists some examples which can dispose one towards corporealisation, such as: injury or illness (including fatigue); typical clumsiness; shame (for instance when under examination by a doctor). The process of corporealisation has been given its own analysis in multiple particular contexts of psychiatric illness, such as depression, schizophrenia (Fuchs, 2005b) and anorexia nervosa (Bowden, 2012).

As shown by the various examples mentioned by Fuchs, one can experience the body as corporealised either acutely or chronically. Not all such experiences need be associated with pathology. I can stumble on the stairs, and thus experience my body as corporealised and negatively so, yet only for a second or two. Even if this is experienced over a longer period of time, not all experiences of corporealisation need be experienced negatively.[20]

Depending on various factors, chronic illness can be a context in which the corporealisation of the body is chronic, and felt painfully. Being under frequent medical scrutiny and examination might be one such factor which disposes one towards this. For instance, S. Kay Toombs writes that illness involves a sort of ambiguity of one's own body: she describes experiences of being looked at as an ill person as forcing the subject towards recognition of

[20] As well as taking various different temporal structures, it is worth noting that experiencing one's body as an object need not be distressing or unpleasant. Iris Marion-Young discusses pregnancy as a context in which the body can be enjoyed as a physical object, without suffering a breakdown of one's relationship with the world which leaves one feeling alienated and estranged (2005). Instead, according to Young, the "fleshy relation to the earth" re-established in pregnancy is one that can foster "a sense of power, solidity and validity" (ibid). See Freeman (2015) for a different view on body experience in pregnancy.

the brute fact of being "physico-biological stuff" (1988, p. 216). Toombs writes that experiencing this facticity of the self, in existing for the other as the object-body under scrutiny, the body as "other than me" amounts to an experience of alienation. There is a felt tension in being both oneself, united, and the brute anatomical object-like thing that is thrust into awareness by illness.

Even when one's body is not under medical scrutiny, though, illness of course involves significant disruption to the way that the body is experienced. Consistent with the experience of the body as corporealised, Havi Carel has developed an account of *bodily doubt* which can occur in serious, chronic illness. In line with phenomenologists before her, she argues that in good health we operate with a tacit sense of bodily certainty that characterises our normal everyday experience as embodied subjects: we have trust in this relationship, and it is not the subject of our explicit reflection (Carel, 2013, p. 2). We have implicit faith, for instance, that our legs will support us when we walk up the stairs, or that we can reach to take a book off a shelf without pain or discomfort; the body is the "faithful ally" of the person in good health (van den Berg, 1966). Serious illness disrupts that bodily certainty. The faith in one's body that had previously gone unquestioned is now under scrutiny, and one is forced to confront the reality that one's bodily scope is restricted. Here, attention is withdrawn from the world and thrust onto the body (Carel, 2013, p.6). One EFQ questionnaire respondent describes an experience of the body losing its fluidity, instead replaced by calculated movement:

> At its worst, even lifting an arm can be a project that needs careful calculation as to what resources it will need (#30)

As implied by Toombs, the type and frequency of medical intervention and scrutiny in illness can affect the subsequent phenomenology of the body. Other features of temporal experience are clearly important here too. For instance, one would not expect to experience bodily doubt in the relevant pervasive sense during a brief period of acute illness such as a common cold or food poisoning (see Chapter 4). It is also plausible that even just knowledge that the bodily disruption is temporary can influence whether or not one experiences corporealisation. Indeed, Carel acknowledges that the experience of bodily

doubt may be less pervasively world-altering where there is an understanding that one's experience is temporary (2013, p. 7).

CFS/ME is a case of illness which is often long-lasting, unpredictable or progressive. It is also important to recognise that an experience of CFS/ME is often highly changeable over time. It may be that, within a given course of illness, the body will be experienced in a variety of different ways. For instance, transparency of and trust in the body may be restored when symptoms are sufficiently mild. For illnesses which are highly changeable, constant oscillation between various ways of experiencing the body might constitute an additional pressure. The following EFQ response describes this oscillation:

> It is constantly fluctuating. I never know how I will feel when I wake up in the morning. Every day is different and unpredictable. Sometimes I am pleasantly surprised and my tolerance levels are much higher than expected and other days I feel the opposite. My emotions tend to ride the wave of my symptoms. Strangely this rollercoaster of emotion can be exhausting in itself. (#31)

Plausibly, where a case of CFS/ME is long-lasting, unpredictable, or consistently getting worse, this might dispose one towards a more pervasive sense of doubt in the body. This inability to engage with the world in a way which was once habitual can create a feeling of bodily failure. Consider:

> I feel as though my body is letting me down again. I feel defeated. (#26)

The notion of one's body letting oneself down is illustrative of the fact that the body is often what allows oneself to carry out certain desired actions. Where one is defeated by the uncooperative body, this is suggestive of being resigned to something less, something smaller. This sense of no longer being able to do what is desired can force a significant readjustment of one's existential orientation in the world. This can involve radical upheaval: a once habitual, confident anticipation of possibilities in the world is lost.

4.1. Body and world in CFS/ME

Where bodily capacity is radically restricted, one's sense of what the world offers can be restricted with it. Recall that the body is understood as that *through* which the things in

one's environment are experienced. Through the body, one experiences things as being imbued with possibilities for action; these possibilities reflect the things that matter to us, that is, our projects, concerns, commitments and values. The character of the world, then, specifies what thoughts, feelings and courses of action are experienced as possible, and which stand out as desirable, disgusting, dangerous, and so on. As Husserl writes: "World is the universal field into which all our acts, whether of experiencing, of knowing, or of outward action, are directed." (Husserl, 1954/1970, pp.142-144).[21]

In *On Being Ill,* Virginia Woolf writes that "the world has changed its shape" (1930/2002, p.8). There are a variety of different ways that the world can be affected by illness. EFQ responses to the question "In what ways, if at all, does your experience of CF/CFS/ME make the world seem different to you?" were amongst the most striking in the data set. These responses illustrated how living with the condition can involve a radical change in world-experience, and also that there is often a painful awareness of this. The following responses strikingly illustrate how world-experience colours perception and dictates what actions, thoughts, and even feelings are experienced as possible:

> My world has shrunk - before the world was my oyster, full of light and colour, opportunity and laughter. Now I live in a dark room, unable to leave my bed. It feels like I am tethered and incarcerated by invisible chains in a barren prison cell. (#13)[22]

> Hills are higher, ski slopes a distant memory, horizon has closed right in. (#20)[23]

[21] For Husserl, "world" is not to be thought of as an explicit object of attention in the way that I perceive a flickering candle on the bookcase or a big, leafy cauliflower on the table. A cauliflower sat on the table presents itself as an obvious, conspicuous object of my attention. Obvious, indeed very obvious, but markedly inconspicuous, is the world. Husserl writes that, "more than anything else the being of the world is obvious. It is so very obvious that no one would think of asserting it expressly in a proposition" (Husserl, 1931/1960, p.17).

[22] This response is also discussed in Chapter 4.

[23] "Hills are higher" can be interpreted in a variety of different ways; it is plausible that two people could make the same remark, but with markedly different phenomenology behind it. By reflecting on these testimonies, and perhaps with certain qualifications added (such as cause), we can still learn something about the world of the person. See Ratcliffe (2015, p.40) for a discussion of the role of metaphorical language in phenomenological inquiry.

The evocative description of being "tethered" shows how bodily feeling plays an important part in how the world is experienced. Indeed, bodily feeling and world-experience are importantly related; a sense that one's body can or cannot do certain things affects how and whether certain possibilities are experienced. As JH van den Berg writes:

> The body forms itself in accordance with the world in which its task lies […] But one is equally justified in saying that the world is changed by the body moving about in it. Objects take on different shapes, working shapes, fighting shapes, loving shapes. Do objects not look different to the fighter and to the peaceful person? Objects *are different* to them. Thus, prereflective body and prereflective world are united as in a dialogue. (1972, p.58)

Toombs points out that where one experiences profound bodily disruption, one becomes confined to the present, preoccupied with the demands of one's current state, instead of seeing the world as imbued with possibilities for future action. She writes, "life projects must be abandoned, postponed or modified" (1988, p.212). Future possibilities for joy, fulfilment and excitement now seem beyond reach, and the world feels different as a result. Experiencing a chronic illness like CFS/ME which has little promise of cure can create a sense that one is confined to a world which is small and drained of possibilities. Consider the following EFQ responses:

> It makes me feel frustrated because I can't do a lot of things. It is difficult to stay positive when your world has shrunk so much and you can't do the things that used to give you pleasure. I feel this is more like an 'existence' than a 'life'. (#13)

> Everything slowed and stopped. I was planning to have a family, and that proved impossible. I became poorer. All the external props for my identity were removed. (#30)

Response #13 is indicative of a relationship between *doing* particular things and *feeling* particular things. As I will argue in detail in Chapter 3, a restriction in one's bodily capacities can constitute a barrier to various affective states, dispositions and attitudes. This can also colour the world:

> Now, it takes me much more energy to actively seek the best that the world has to offer and when I don't have that energy, it feels like a very grey and draining place. (#31)

As I have suggested, there are a variety of ways that the world can change. Participant #13 describes the world as having shrunk. This is familiar from some existing phenomenological work on illness: "I have ceased to belong; I have no part in it; the world has shrunk to the size of my bedroom, or rather my bed." (van den Berg, 1966, pp.26–7). However, as I will argue in detail in Chapter 4, illness can change the world in a variety of other ways. In some cases, one is painfully aware that the world carries on, but also that no longer has one's place in it. One is therefore stuck, hovering between different worlds:[24]

> Memories of what used to be possible and frustration at the gap between what used to be possible and what now is are a frequent presence. (#7)

Unlike the description offered by respondent #31, this response describes an experience where certain possibilities from before one's illness remain in sight, and remain desired; however, they are now experienced as painfully out of reach. Here one is still drawn to possibilities, but is unable to engage with them.

A phenomenological perspective on CFS/ME experience can also illustrate the extent to which the interpersonal can be implicated in the person's world-experience. After all, the world is not experienced solipsistically, at least not in good health (Sass, 2014; Sass et al, 2015). Rather, one belongs to a shared, intersubjective world (Sartre, 1992; Zahavi, 2003). One experiences illness alone, however. Where one's world has changed as a result of being ill, this can lead to a sense of being cut off from the rest of the world and the people in it who appear to continue on unaffected (see Chapter 3).

There are various social and political dynamics typical of an experience of illness like CFS/ME which can exacerbate this experience of being cut off and alone. Where one experiences stigma and relatively little social understanding or support, feelings of being alone can be more extreme and pervasive. Where one once implicitly functioned with a background sense of being a member of a shared world, this is replaced with a jarring sense

[24] In the context of grief, Ratcliffe and I describe something similar in terms of an experienced "gulf" between worlds (Ratcliffe & Byrne, 2022; Ratcliffe, 2022).

that one is different to others. Sometimes one can remain in the shared world, but loses one's way in it:

> The world seems to be going at a million miles an hour whilst I crawl along at a snail's pace. Some things 'normal' people do seem impossible to me (#1)

Alternatively, one can lose a sense of being part of that world at all, instead becoming entirely detached from it:

> My world feels very small like being in a bubble. A lot of what goes on in the rest of the world feels more detached as if it's in a TV show or an alternative reality. (#7)

Both of the shifts in world described in these responses implicate a shift in temporal experience. Just as we exist in a shared world, in good health we operate with a basic, implicit background feeling of being synchronised with others, existing in intersubjective, shared time (Fuchs, 2001, p.181). Under certain states (Fuchs focuses on depression, or melancholia), one instead painfully experiences an inward-directed rigidity, falling out of sync with "the movements of life going on in his environment." (p.183).

This framework helps us to understand how experiences of the body in CFS/ME can involve much more than just bodily experience. As a consequence of one's bodily restrictions, one can be forced out of sync with various socially-shaped rhythms such as times for waking, eating and sleeping (p.181). One has to radically adjust to a new way of life, and so can find oneself cut off from the intersubjective world which operates on intersubjective time.

Such temporal desynchronisation can also relate to disruptions to sense of self and agency in CFS/ME. The following EFQ response is suggestive of a feeling of loss of agency, replaced with a sense of powerlessness over the actions that take place within the shared world:

> Your ability to act is much reduced and you are more susceptible to its action on you. (#30)

One can take certain behaviours, actions and even thoughts to be an important part of one's sense of identity in a world. Before becoming ill, one's actions might have reflected one's roles or duties to oneself or to others, such as to be a good colleague or parent. The

bodily restrictions associated with CFS/ME can then leave one unable to act in such a way that honours those roles:

> I have lost my career, hobbies, ability to attend my children's activities. (#21)
>
> I used to be extremely fit & healthy, and used to spend a lot of time outside in the hills. All this has been stolen from me. (#13)

As I will show in detail in Chapter 4, no longer being able to engage in the world as one did before can have significant consequences for one's sense of self and identity. One's identity can be dependent upon what one does for oneself, but also what one does for other people. All of these aspects of experience considered shows that a significant process of existential reorientation can therefore be demanded by an experience of CFS/ME. Emphasising the interrelated aspects of experience which can all be affected by CFS/ME shows that a disruption to bodily experience has effects which can be incredibly existentially disruptive. It is not the case that the body alone experiences radical upheaval, leaving other aspects of one's life and world preserved. Rather, one's entire world can be turned upside down.

Just the very beginning of this phenomenological inquiry illustrates the restrictiveness of the distinction between the bodily and psychological dimensions of illness which is so often employed in research into CFS/ME. If we pay closer attention to the details of the lived experience of CFS/ME, it becomes clear just how restrictive some of our existing ways of understanding illness are. In what follows for the remainder of this thesis, I will use this phenomenological framework in order to provide detailed analyses of a range of different aspects of CFS/ME, thus illuminating features of it which have so far been missed. In the following chapter, I turn to an in-depth discussion of the ubiquity of loss in CFS/ME, suggesting that pervasive and deeply-felt experiences of loss associated with the illness can constitute experiences of grief.

Chapter Two: Grief

1. Introduction

Some existing qualitative work suggests that people with CFS/ME can grieve over losses associated with the condition. The aims of this chapter are two-fold. The first aim is to offer support for this hypothesis by illuminating under-appreciated structural features of typical grief which are shared with grief in CFS/ME. The second is to explicate some of the clinical challenges that arise should this hypothesis be embraced. Rates of comorbid depression in CFS/ME are estimated to be exceptionally high. Accepting that people with CFS/ME can grieve over losses associated with the condition might suggest that rates of comorbid depression are inflated, however, the challenge of distinguishing between healthy and pathological grief arises in its place. Successfully diagnosing and treating grief in CFS/ME therefore requires clinically recognising it and distinguishing it from other predicaments.

Some philosophical work has attempted to pin down the "essence of grief". Whilst reluctant to define it, there have been various attempts to explicate its distinctive features. Peter Goldie, for instance, maintained that the grieving process involves "characteristic thoughts, judgments, feelings, imaginings, actions, expressive actions, habitual actions, and much else besides, unfolding over time, but none of which is essential at any particular time" (Goldie, 2011). What has received less philosophical interest so far, is the scope of grief. Does grief necessarily require a bereavement, or can one grieve over any loss provided that the experience takes a certain structure? In lay contexts, one might be inclined to think the former. If a colleague were to take time off work because their spouse had died, they would be considered to be taking time off because of their grief. If a colleague were to take time off work because they had *divorced* from their spouse, they would be considered to be taking time off because of their distress, sadness and so on.

However, increasing work on grief is suggestive of the latter view that one can grieve over various non-death losses. In a variety of therapeutic contexts, and sometimes colloquially, we are already comfortable referring to grief to describe emotional processes in contexts other than bereavement. For instance, a counsellor might discuss a process of grieving the

breakdown of a marriage, a job, or a home. Researchers are also having conversations about grief over things like climate change (Cunsolo & Ellis, 2018) and loss of social resources such as during the Covid-19 pandemic (Richardson, Ratcliffe, Millar & Byrne, 2020; Froese, 2021).

Talk of grief in the context of illness is not unseen in illness literature (Doka, 2006; George et al, 2007); indeed, some within psychiatry have called for such instances of grief to be validated within psychiatry (Godress et al, 2005). However, such experiences are still generally not clinically recognised. This might seem odd given that experiences of grief in bereavement are of interest to the psychiatrist, with some forms of grief making it into the DSM.

Despite it being a very common form of chronic illness, very little has been written about the presence of grief in CFS/ME in particular. While grief in the CFS/ME patient community might go informally recognised privately, in support groups, patient fora, informal conversations between patients and their family and friends, and counselling contexts, it is not recognised academically, especially not clinically.

An exception, one recent paper suggested that grief is a cardinal "element of suffering" in CFS/ME, and that supposed depressive symptoms might better be attributed to grief (Fennell et al, 2021). This is but one paper, and moreover, like most of the aforementioned research on grief over illness, it is without theoretical defence of whether or not patients are *really* grieving, that is, whether the grief they are experiencing is *really* grief as opposed to grief-like, whether "grief" here is used metaphorically, or whether "grief" here refers to something different in kind to grief over bereavement.

In the following section, I offer such support for the claim that grief can be an important aspect of CFS/ME experience in attempting to deflate assumed structural asymmetries between typical grief over bereavement and grief in CFS/ME. This allows us to better recognise shared features between typical and atypical cases. I also offer some empirical support for the view that CFS/ME experience can take this structure by considering some responses to the EFQ.

Having made plausible that people with CFS/ME can really be grieving, closer inspection of the clinical consequences of taking such experiences to be genuine experiences of grief is warranted. With this in mind, in the second half of this chapter I go on to consider how such experiences of grief ought to be distinguished from other predicaments. It is important to consider whether patients are experiencing (i) healthy grief (ii) depression, not grief or (iii) grief, but of the psychopathological kind. Tackling these issues is by no means straightforward, nor is it obvious that there are clear answers. However, being in a position to better navigate the conceptual landscape here has potential benefit for both patients and clinicians.

2. The structure of grief

A significant number of respondents to the EFQ described a process of grieving. In response to the question, "Has your experience involved any sense of loss?", 87% of participants answered affirmatively. Moreover, 40% of those participants explicitly went on to describe a process of grieving. For instance:

> When I first got sick and also again when I was diagnosed I went through a period of grieving. Like the former me had died, I was grieving my old life and my old plans. (#14)

The grief that is being described here is, of course, not grief over the loss of a person in the context of the death of a loved one. In bereavement, the obvious candidate for the object of loss is simply the person who has died. In contexts other than bereavement, a different object of loss needs to be identified. It remains to be clarified what exactly, then, participants are grieving over in such cases. More precisely, the object of the loss is unclear. Moreover, it is not clear whether there need be just one object of the loss, or whether a process of grief can unite multiple losses which hang together in some meaningful way. There are certainly a number of objects of loss which are possible candidates here, for example: the loss of one's health, one's relationships, one's identity, or one's future plans. Indeed, participants mention multiple of these:

> I am grieving for the loss of my old self, my old life, and my old health. (#24)

Here, the grief in question has no bereavement trigger, however there is still a clear sense of loss. Intuitions about grief over bereavement might be that there is one intentional object of loss, that is, the person who has died. As well as there being a clear object of loss, there is generally a clear temporal structure to that loss; one can easily map the loss on to a particular event, that is, a death.

It is doubtful that grief over bereavement really does generally have such a straightforward structure. Rather, closer inspection suggests that both the intentional and temporal structure of grief experience is considerably more dynamic. There exist types of cases in which the death of the loved one is not experienced as one event in time, but is instead dragged over a longer period. For instance, Kitzinger and Kitzinger (2014) discuss the experiences of family members of those in Permanent Vegetative States (PVS). Participants in this qualitative research describe going through the grieving process, despite the fact that their family member is not yet, biologically speaking, dead. Consider the following quotations:

> I only thought in terms of life and death…not this, this in-between.
>
> It's like a bereavement but you can't grieve and they [care staff] keep telling me he's not dead.
>
> It would've been a tragedy that Mum had died […] but it would've been…we would've been able to go forward. As it is we're stuck, all of us, behind this glass wall and when she dies…although it's been so long, you kind of imagine it's all going to be okay when she dies.

Though Kitzinger and Kitzinger are discussing exceptional circumstances, other much more common bereavement circumstances plausibly take a similar structure, such as neurodegenerative disease like Alzheimer's. This motivates open-mindedness about two aspects of grief's structure even in "typical" cases. One, that the starting point of grief needn't be as straightforward as immediately following a bodily death. Rather, grief's temporal structure is far more dynamic than this. Two, relatedly, that what is lost in bereavement is far more than just the living person. Rather, it appears that one can grieve over various losses spread over time, all of which are associated with a person with whom

one's relationship has changed (Cholbi, in press). For instance, when one's partner is in PVS, one loses the ability to communicate with them, engage in activities with them, and a whole range of activities important to the relationship and the system of meaning that relationship is tightly woven into, all before the person has actually died.

There is also an important but messy distinction to be made between suffering new losses over time, and the surge of emotions associated with a loss under certain conditions. For example, the resurgence of a strong grief response on the anniversary of the death of one's loved one might not be classified as a new loss, but a circumstance in which existing losses are felt painfully. However, circumstances might arise such that the original loss gains a new dimension, thus catalysing grief over a new aspect of loss. For instance, somebody who is bereaved of their partner might suffer a new loss (which is nonetheless parasitic on the loss associated with the death) when their baby is born. So here, as well as losing a partner, one has now lost a co-parent. It would miss something to understand this as merely a resurgence of emotions associated with the initial loss. All that was lost under the most general object of "my partner" has now changed, rather than just having been reminded of it.

Granting this dynamic structure is surely required in order to claim that the experiences that the participants in Kitzinger and Kitzinger's research are experiencing are in fact experiences of grief, rather than just sadness, depression or some other state. Moreover, revising how we assume a wealth of other grief experiences to be structured allows us to identify structural similarities with not only typical and atypical bereavement experiences, but also cases of non-bereavement grief such as grief over loss in chronic illness like CFS/ME. We are distracted from such structural similarities in bereavement and non-bereavement cases of grief by assuming that bereavement grief has such a clear structure.

As well as there being multiple losses spread over time, it is also important to recognise that the intentional object of the losses can be difficult to pin down. In her book *Ambiguous Loss* (1999), Pauline Boss describes losses which "defy closure", in which the status of a loved one as "there" or "not there" remains indefinitely unclear. Boss describes ambiguous losses as confusing, immobilising, and resistant to being worked through. This is, in part,

because it is unclear whether such losses are final or temporary: "If they have not already closed out the person who is missing physically or psychologically, they hang on to the hope that things will return to the way they used to be" (1999). This highlights that one need not grieve over that which has already been lost, but that one can also grieve over things which threaten to be lost. Accordingly, grief is not necessarily just past-directed, but can be future-directed too. Such dynamism in CFS/ME experience stands out in the EFQ:

> I went from being very active to being bedridden. I lost all my hobbies, all my friends as I can't really socialise, I lost what future I could have had. I lost my life. I had to grieve for my own life. I remain in the four walls of my house while the world goes on without me. (#29)

Not only does this response illustrate striking intentional dynamism, that is, the sheer number of things that are lost in CFS/ME, but also the non-linear temporal structure of these losses. This participant describes losing their friends and hobbies, losses which are directed at the past in that one is no longer able to engage with the world in the way that one did before the illness. However, "I lost what future I could have had" has a rather different temporal structure. This loss is future-directed; one can no longer *expect* to engage with the world in the way one had done before. One cannot anticipate exciting, fulfilling and positive experiences within the world anymore, now that the tools required to have those future experiences are gone.

The notion of anticipatory grief is relevant here in fleshing out this temporal dynamism. Anticipatory grief refers to the process of grieving and adapting to impending losses.[25] Therese Rando (1997) has suggested that anticipatory grief often meets the criteria for post-traumatic stress. Interestingly, three EFQ respondents mentioned trauma, each time in the context of loss:

> …psychological difficulties too […] even though these are a natural result of the traumas and losses associated with such a debilitating condition. (#13)

[25] See Robert Fulton (2003) for an interesting critique of this concept. For the purposes of this thesis, though, it suffices to clarify that what I am interested in here is the idea of grieving in advance of an actual, but anticipated, loss.

> Since I became seriously ill the losses have been dramatic and traumatic: most upsettingly the losses of many relationships including my marriage a number of friendships my relationship with my brother and to some extent to my father and even my mum that relationship has changed. My loss of my former understanding of myself and what I was capable of and everything that I hoped to achieve in the world is a massive one that is very difficult to quantify. (#25)

> The sense of loss of my former self is the most traumatic element of the condition, for me. […] The loss of my cognitive function is one of my biggest stresses. I feel as though I have lost my 'clever' and any prospects of success in life. I can manage the tiredness and the physical symptoms, but the lack of cognitive function has the biggest impact. I want, more than anything, to have the old me back. (#31)[26]

These responses indicate losses from one's past, but also the anticipated losses in one's future; one has to adapt to the loss of that which was previously taken for granted to be part of one's future. For instance, regardless of the course of one's life, there might have nonetheless been a background assumption of some constants: one's intelligence, one's cognitive functions, one's relationships with family members, and so on. Moreover, as well as discussing that from the past which has been lost and that from the future which threatens to be lost, other responses demonstrate the tension described by Boss whereby it is not clear whether one ought to accept a loss, or instead understand it as temporary:

> It fluctuates, some days my normal me is back and then the next day I am deep in CFS. This makes the grief perpetual with very big low points. (#27)

This response is suggestive of the unpredictable, episodic nature of CFS/ME being a barrier to overcoming or accepting one's losses; here it is not clear whether or not losses are temporary, and one ought to hope to return to one's normal self and one's normal life, or whether one should begin the process of assimilating to a "new normal", or as Attig (1996) described the work of grief, "relearning the world" (see Chapter 4).

[26] This quote is also discussed in Chapter 3 in the context of loss of cognitive function.

These responses highlight that the losses in CFS/ME are not associated with one event, such as becoming ill, or being diagnosed, but rather with multiple losses of different kinds and over time. Nonetheless, there is a general sense in which all that is lost can be summed up as "one's health". Grief in CFS/ME shares structural features with grief over bereavement in that there is both a very general object of loss, as well as countless more specific ones particular to a given situation. In bereavement, one loses a person, but one also loses a wealth of other things which that person's existence was a precondition for.

The social context in which people grieve also plays an important role in shaping its distinctive phenomenology. Some forms of grief, or grief within certain contexts, are better recognised than others. Disenfranchised grief is understood as grief which "falls outside of society's grieving rules" (Doka, 2002, p.8). Multiple contexts of loss which can produce disenfranchised grief have been recognised by grief scholars, for instance, where the person died by suicide or drug use, or where the relationship between the person who died and the person who is bereaved was turbulent and difficult, or even kept secret. Jody Day, author of *Living the Life Unexpected*, describes the process of adjusting to a life involuntarily without children as a form of grief which goes under-recognised in society, giving rise to high rates of disenfranchised grief in such women (Day, 2016).

Ambiguous losses are also more likely to be disenfranchised since there is no official or community verification of what is lost. As Boss writes, "their experience remains unverified by the community around them, so that there is little validation of what they are experiencing and feeling" (Boss, 1999, pp.6-8). One would not be surprised to find high levels of disenfranchised grief amongst people with CFS/ME who are grieving. Whether or not CFS/ME patients are depressed is given considerably more attention than whether or not they are grieving (see Chapter 1, 3). Moreover, unlike grief, scientific discourse about the relationship between CFS/ME and depression has bled into media and political discourse. Hence, to interpret emotional distress in CFS/ME as depression is the most available framework by which to explain the experience of patients who are exhibiting relevant symptoms.

As a result of the stigmatisation of psychiatric illnesses like depression, and the blame associated with them, people with CFS/ME can easily face accusations of malingering or suffering from an ailment "all in one's head" (see Chapters 5, 6). In consequence, people with CFS/ME can ignore or hide their experiences, expecting not to be believed or understood:

> Also others say 'well you were fine at the time...' because they never see us at our worst. So we have a chip on our shoulder from doctors implying that we just need to 'think ourselves better', and another from the friends that only see our good days (and not the price we pay afterwards for over-exerting ourselves), and another that we generate for ourselves when we try - and fail - to actually think ourselves better / manage to do x,y,z. And then we get frustrated and blame ourselves, which can lead to depression / etc, but because we have spent so long fighting to be believed, it is then much harder to admit that we now have psychological difficulties too. (#13)

> Also, I often do not tell friends in case they do not understand/think that I am lazy. I feel like I am very secretive about a huge part of my life which I would not have been before I was ill. (#17)

> Very few people who do not have ME can imagine it accurately. It's hard for them not to blame the victim - who cannot even be consistent in his/her illness. That is a terrible burden, to never be fully understood or believed. (#30)

Where people with CFS/ME do not have supportive relationships with other people who they can discuss their experience with, and the role of grief here goes under-recognised, there are substantial obstacles to recognising or working through one's grief. People with CFS/ME who may be grieving can then find themselves without support networks and other resources for understanding their experience such that they might not even suspect that they are grieving. Moreover, where the objects of loss are ambiguous, it may be even more difficult to understand one's experience as an instance of grief. As Boss writes: "Ambiguous loss can cause personal and family problems, not because of flaws in the psyches of those experiencing the loss, but because of situations beyond their control or outside constraints that block the coping and grieving processes. Therapy based on the recognition of the

ambiguity of the loss frees people to understand, cope, and move on after the loss, even if it remains unclear." (Boss, 1999, p.7).

Better attending to the nuances of grief experiences in bereavement motivates a more expansive view of grief as to accommodate non-bereavement grief. Furthermore, recognising that some people with CFS/ME are experiencing grief might help to support patients to navigate their own experiences of loss. Moreover, as will be my focus for the remainder of this chapter, recognising grief in people with CFS/ME might also help us to better navigate relevant clinical issues.

3. Grief and depression

The exact rates of comorbid psychiatric illness, particularly depression, are not clear in CFS/ME. They have been extensively studied, however. Even at the lowest estimations, comorbid psychiatric impairment in CFS/ME is significant. For instance, Fuller-Thomson and Nimigon (2008) found that 36% of Canadian individuals with CFS were depressed. Matsuda et al (2009) found that over 47% of Japanese patients with CFS had comorbid psychiatric diagnoses, with over 25% of those being Major Depressive Disorders. The prevalence of depression in paediatric CFS has also been found to be considerably higher than in the general population (Bould et al, 2013; Loades et al, 2018).[27]

If one accepts that (a) people with CFS/ME can grieve, though this has gone under-recognised, and that (b) grief and depression can appear very similar, we might have reason to think that the statistics of comorbid depression/psychiatric disorder have thus far been over-estimated. Paula Clayton (1974) has commented that, although there are some differences, there is sufficient overlap between the symptoms of grief and depression such

[27] Different authors have suggested different causal explanations for why these rates are so high. For instance, Bould et al (2013) found that rates of depression in CFS/ME are associated with markers of disease severity. Others have suggested that it is due to exceptional levels of stigma in CFS/ME compared to other diseases (Devendorf et al, 2020). There is an implicit suggestion here and elsewhere that the depression is therefore secondary to the physical impairment; that is, if the primary disturbance (medical condition) was resolved then the secondary dysfunction (the depression) would be rectified too. I offer an in-depth discussion of this in Chapter 3.

that the two groups cannot be satisfactorily differentiated for research purposes without the bereavement trigger. Of course, grief is generally identified where a certain set of symptoms follow a bereavement. Yet without an identifiable bereavement trigger in CFS/ME, one is reliant on differences in symptomatology and phenomenology to distinguish between grief and depression.

What are the differences, then? Clayton found that that 53% of depressed patients expressed symptoms of worthlessness compared to only 3% of those grieving (ibid). Interestingly, a similar asymmetry has been picked up by various others over the years. For instance, it is echoed in Freud's *Mourning and Melancholia*:

> The distinguishing features of melancholia are a profoundly painful dejection, abrogation of interest in the outside world, loss of the capacity to love, inhibition of all activity, and a lowering of the self-regarding feelings to a degree that finds utterance in self-reproaches and self-revilings, and culminates in a delusional expectation of punishment. This picture becomes a little more intelligible when we consider that, with one exception, the same traits are met with in grief. The fall in self-esteem is absent in grief; but otherwise the features are the same. (Freud, 1917)

Interestingly, one study suggests that CFS/ME patients do not show the same levels of "self-reproach" typically seen in depressed patients (Hawk, 2006). In my view, this supports the hypothesis that at least some patients might be grieving, thus, statistics of comorbid psychopathology in CFS/ME might in fact be inflated. What predominantly has prevented the recognition of grief here is the lack of bereavement trigger. When one appreciates the extent to which people with CFS/ME experience significant loss, grief shows itself to be a salient aspect of CFS/ME experience which requires further recognition.

In the same study, Clayton also found that 65% of depressed patients showed symptoms of hopelessness compared to only 6% of those grieving. To my knowledge, there is no empirical data on hope in people with CFS/ME. My own data paints a varied picture:

> I find it difficult to see much light at the end of the tunnel, but clinging to hope is largely what keeps me going - hope that things WILL eventually get better / that science will eventually find some answers. (#13)

> CFS makes me feel extremely frustrated. There is so much I want to do in my life and I feel so held back by my illness, both physically and mentally. I know I have the ability to do well in my degree, but I am too tired to do the work I need to. This has lead [*sic*] to severe depression, having feelings of extreme hopelessness. (#17)
>
> I hope that I never relapse and that for the future I will be fine but the possibility is always there of having to live years of my life under the shadow of ME (#18)
>
> I grieve for the person I used to be but can't be any more, and all the things I lost. I feel hopeless and depressed at continuing living. (#29)
>
> After trying to deal with it in every possible way, every treatment, it's hard not to become hopeless, and so tired. This is sometimes mistaken for depression. (#30)

It is not clear from these excerpts which respondents would meet the criteria for comorbid depression and which would not, and furthermore, whether or not grief might be a better explanation for why some do when they would not otherwise. There are clear differences between respondents with regards to whether and to what extent they retain hope for the future. To assume that we can distinguish between grief and depression in patients by virtue of whether or not they seem to have retained a degree of hope for the future would be hasty, crude, and likely inaccurate.

It is important to consider whether, and if so in what way, people with CFS/ME might exhibit hopelessness. It might be possible that one can separate aspects of experience which are attributable to depression from aspects which are attributable to grieving, where one experiences feelings of hopelessness on top of grief. It is important to consider the effects of the contexts in which people with CFS/ME suffer. Treatment options are limited, and many cite constant disappointments with exploring various potential avenues for treatment which fail to help. Moreover, cycles of remission which are only ever temporary can erode hope in eventual recovery:

> No treatment has worked that I know of, and the improvement is partly through learning how to manage effort and partly time. But relapses are always a minute away. (#30)

Related to the consideration of that which a given person with CFS/ME might be hopeless over, is the question of how that loss of hope is structured. That is, the question of what type of hope is lost in particular cases. Ratcliffe makes an interesting distinction between loss of intentional hopes and loss of existential hope. An intentional hope is a hope directed at something, for instance, "I hope that x". Loss of such hopes can be understood in the following way:

> [L]oss of hope over p is a matter of 'it will not be the case that p' or, alternatively, 'p is not the case, even though I don't have confirmation of this yet'. Losing the hope that p sometimes involves adopting a different attitude towards p, such as 'I am resigned to the fact that not p'. In this case, the proposition p (or not p) continues to feature as the content of some attitude. (Ratcliffe, 2015, p.104)

In the context of CFS/ME, a relevant intentional hope might be "I hope that I will recover". There can be retention of hope even where those hopes are fragile or modest:

> My future is uncertain, I am still determined to follow my plans but to what extent I am unsure. I refuse to give up though. (#1)

> Pretty positive, though the current worsening of polyneuropathy (Pain & numbness in legs & feet) which appears to be part of "my ME" is a bit scary. I enjoy time with my grandchildren & look forward to seeing them grow up - if the grand lottery that is life happens to be kind to me. (#19)

> I am optimistic that there will be a treatment and cure someday. (#19)

In contrast, to lose intentional hopes of this sort might look like the following:

> I do not feel particularly hopeful about the future - any time I seem to make any progress with my health, I catch an illness and then am set back again. (#17)

> After trying to deal with it in every possible way, every treatment, it's hard not to become hopeless, and so tired. This is sometimes mistaken for depression. (#30)

Loss of intentional hopes is contrasted with loss of existential hope. It is possible, Ratcliffe writes, to lose all intentional hopes, even a system of hope, but to retain existential hope. Ratcliffe writes, in the context of grief:

> Suppose a person has spent the last thirty years in a loving relationship with a partner. It could well be that all or almost all of her activities and projects (other than mechanical routines that would not ordinarily be associated with attitudes such as 'hope') make explicit or implicit reference to the partner in some way, take on the significance they do because of the relationship, and are regulated by the relationship. […] The contents of all the person's hopes, all her aspirations, thus involve the partner in one way or another. For someone with that kind of life, the partner's death could, I think, impact on all hopes. It is not that she would cease to hope for various states of affairs, but that these states of affairs would no longer make sense. (ibid, p.106)

This amounts to the loss of a system of meanings, and a system of hoping that is built into that system of meanings. Still, one must differentiate between the loss of a system of hopes, and loss of the *capacity* to hope and find meaning. That capacity to find hope and meaning was described by Jonathan Lear as *radical hope* (Lear, 2006). Contrary to Lear, Ratcliffe argues that radical hope is not something people have on occasions where systems of intentional hopes are lost, but instead, radical hope is a constant backdrop against which hopes can be formed, maintained and lost:

> It is not the bare appreciation that 'something is coming', but a more specific kind of anticipatory structure that includes possibilities such as 'things could change for the better' and 'bad things might not happen'. (Ratcliffe, 2015, p.109).

Ratcliffe claims that many experiences of depression involve this loss of existential hope, rather than just the loss of a system of intentional hopes which can be dashed without significant disruption to one's existential landscape. On his view, typical instances of grief, rather, include openness to the possibility of positive change, and thus the ability to engage in a process (ibid, p.107). Some experiences of profound grief, however, can involve a loss of the sense that anything could ever be significantly different from the present, at least in a positive way (p. 199). Though it is of course not possible to offer an assessment of a particular individual based on an excerpt alone, one EFQ response which is more suggestive of this more pervasive loss of hope is the following:

> I grieve for the person I used to be but can't be any more, and all the things I lost. I feel hopeless and depressed at continuing living. Physical suffering on its own brings emotional problems with it and makes me feel irritable, sad and I will always spend hours crying at random times for no reason at all. (#29)

Ratcliffe's position is broadly compatible with Victoria McGeer's account of the role of hope in our lives; indeed, she writes that "hopes for particular ends may be dashed without compromising our basic ability to live in the light of hope" (2004, p.109). McGeer developed an account of not just what it is to hope, but what it is to hope *well*. Crucial to "good hope", according to McGeer, is the ability to shift one's target of hope when one's circumstances frustrate particular hopes.

In the context of CFS/ME, there may be past hopes which in the light of one's illness are no longer sustainable. For instance, to sustain the hope to one day run a marathon might be, in McGeer's vocabulary, an instance of "bad hope". For McGeer, good hope requires sensitivity to one's changing circumstances and adjustment to the possible. Or, in Ratcliffe's terminology, good hope requires assimilation to a new system of meanings and hopes that is reflective of one's circumstances. This sort of adaption is clear in some people with CFS/ME:

> Initially my world shrank enormously, but I found even in the early days that I was able to reinvent myself by discovering things I COULD do - specifically watercolour painting in which I became a pretty proficient amateur, selling prints & greeting cards as well as originals, several of those commissions. This became the "silver lining in the cloud" for me, just 2 years into the illness. (#19)

This respondent describes redirecting their energy towards that which is possible, but that which might not have earned attention or interest before becoming ill. That is, things that did not feature as salient or attractive possibilities for action before becoming ill, later became ways to regain a sense of agency and future-directedness. One here might not be able to sustain hopes of keeping a job where one is required to stand up all day, but can replace such hopes with hopes of selling a painting, or receiving a commission. As McGeer writes, hope offers a *direction* in which one can navigate through the world: "In hoping, we

create a kind of imaginative scaffolding that calls for the creative exercise of our capacities and so, often, for their development." (McGeer, 2004, p.105).

Maintaining and sustaining good hope can be exceptionally difficult for people with CFS/ME. People with CFS/ME can face an incredibly difficult epistemic predicament whereby there is no clear fact of the matter as to which hopes are "good" and which are "bad" until one is able to look back in retrospect. Some hopes, such as the hope that one can one day run a marathon, certainly *might* be a "bad hope", or might at least seem like one, but it is important to note that, though rare, there are people who make exceptionally good recoveries to the point where activities like this are possible again. For instance:

> My mother has been a rock throughout the whole experience. She herself had the illness and is now a triathlete. (#9)

It might have seemed that somebody with CFS/ME who clung onto the hope of being an international triathlete might have been nurturing bad hopes. It is only that exceptional circumstances allowed this hope to be realised that it appears, or perhaps shows itself, to have been a good hope all along. Where the trajectory of any given person's illness is so unclear, knowing how radically to readjust one's hopes can be impossible: there are countless possibilities for the direction in which one can navigate the world, but it is entirely opaque which of these directions are viable, and which are futile, until it is too late.[28]

With all of this in mind, further questions arise as to how we understand the patient who loses all hope, compared with the patient who retains some hopes, but which are unhealthily at odds with one's circumstances and what is now possible given one's bodily limitations. These issues invite consideration of something more in order to help to unpick and distinguish between hypothetical patient predicaments: the possibility of psychopathological grief in CFS/ME.

4. Pathological grief

[28] This relates to the discussion of transformative experience discussed by L.A. Paul, as I discuss in depth in Chapter 4.

Recall that earlier in this chapter I contemplated whether or not estimations of comorbid psychopathology in CFS/ME, especially depression, might have been over-stated as a result of failing to recognise similarly-presenting experiences of grief. There are, however, other complications which must be considered before one can be confident that the statistics of comorbid psychopathology have been over-estimated, even if patients are grieving. After all, the presence of grief alone is not sufficient to rule out psychopathology, since there can be pathological forms of grief. An outstanding important task then becomes to develop criteria for distinguishing between healthy grief and pathological grief in the context of CFS/ME. Martha Nussbaum describes the task of distinguishing between healthy and pathological grief as follows:

> We might add that what distinguishes normal from pathological mourning is, above all, this change of tense: the pathological mourner continues to put the dead person at the very center of her own structure of goals and expectations, and this paralyzes life. (Nussbaum, 2001b, pp.82-3).

Psychopathological grief reactions feature in both DSM-5-TR and ICD-11, as proposed by a group of researchers who had long worked on a set of criteria to take to the relevant workgroups to make a case for its inclusion (Prigerson, 2021). The DSM-5 included Persistent Complex Bereavement Disorder (PCBD) as an "emerging diagnosis" requiring further research. The ICD-11 included Prolonged Grief Disorder (PGD), with DSM-5-TR later following suit and including PGD in 2019 (ibid). The ICD-11 requires a certain set of symptoms for at least six months after the loss (WHO, 2018).[29] DSM-5-TR requires a certain set of symptoms following the loss of a loved one for at least 12 months following the loss. The criteria are as follows:

> A. The death, at least 12 months ago, of a person who was close to the bereaved (for children and adolescents, at least 6 months ago).
> B. Since the death, the development of a persistent grief response characterized by one or both of the following symptoms, which have been present most days to a clinically significant

[29] To compare additional differences between DSM-5-TR and ICD-11 criteria for pathological grief reactions see Comtesse et al (2020).

degree. In addition, the symptom(s) have occurred nearly every day for at least the last month:

1. Intense yearning/longing for the deceased person

2. Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)

C. Since the death, at least 3 of the following symptoms have been present most days to a clinically significant degree. In addition, the symptoms have occurred nearly every day for at least the last month:

1. Identity disruption (e.g., feeling as though part of oneself has died) since the death

2. Marked sense of disbelief about the death

3. Avoidance of reminders that the person is dead (in children and adolescents, may be characterized by efforts to avoid reminders)

4. Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death

5. Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursuing interests, or planning for the future)

6. Emotional numbness (absence or marked reduction of emotional experience) as a result of the death

7. Feeling that life is meaningless as a result of the death

8. Intense loneliness as a result of the death

D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

E. The duration and severity of the bereavement reaction clearly exceeds expected social, cultural or religious norms for the individual's culture and context.

F. The symptoms are not better explained by major depressive disorder, posttraumatic stress disorder, or another mental disorder, or attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.[30]

(APA, 2020)

[30] In this case, if the symptoms are better explained by another medical condition, namely CFS/ME, that counts against a diagnosis of PGD. I suspect that this exclusion criterion is victim to the same issues raised by Zisook, Shear and Kendler (2007). It suffices to say, however, that if diagnostic criteria for an illness-inclusive form of pathological grief were to be developed, that it would not include such criteria.

In the context of CFS/ME, one possibility to consider is that there are indeed significant rates of grief, yet some of those experiences of grief still warrant categorisation as pathological. If this is the case, then it would not be the case that the earlier quoted estimations of comorbid psychopathology in CFS/ME are inaccurate, but rather, that some cases of psychopathology have been mis-attributed to depression where they would in fact be better classified as cases of pathological grief. A natural place to begin investigating this possibility is to consider whether the existing ways of distinguishing between healthy and pathological grief might clarify matters in the context of CFS/ME.

Katherine Shear comments that PGD is best understood as an unusually severe and prolonged form of acute, healthy grief, rather than a separate entity (2015, p.156). Hence, the difference between healthy and unhealthy grief is to be understood as one of degree, albeit with some qualitative differences, rather than a marked difference of kind. Accordingly, in the context of grief over bereavement, a key way of distinguishing between healthy grief and pathological grief is time passed since the death, that is, whether or not the grief has persisted for longer than a certain time following the death of the person.

If an experience of CFS/ME involves grief which is the same in kind, and which persists for longer than what is deemed healthy, this would count towards the grief being judged pathological. What length of time after the death a grief response is considered healthy is a judgement about what a given society and culture deems normal: lasting for "longer than is expected according to social norms" (Shear, 2015, p.154). The time-frame of a grief response which is judged to be healthy differs across cultures, and the DSM-5-TR (12 months) and the ICD-11 (6 months) differ in judgement here.

Temporal passage does not seem particularly helpful as a criterion for screening for pathological grief in CFS/ME. Provided symptom criteria are sufficiently met, it is unclear whether it is reasonable to judge a grief response to be pathological where one has been ill for twelve months, and has been showing a grief response since becoming ill, but where there have been multiple triggers for grief over time. Consider somebody who has been ill for twelve months, was diagnosed eight months ago, lost their ability to work six months ago, their ability to read books two months ago, and their ability to walk only one month

ago. Each of these changes can involve different set of losses. The grief of people with CFS/ME ought not be assumed to begin at any given time, such as at the prodromal period, at early stages of serious illness, or at diagnosis. Rather, the experience of being ill with CFS/ME is often slow, non-linear, and highly variable such that different things are lost at different times, some of which losses will be felt more painfully than others:

> I think there are cycles that repeat - the sense of loss when I loose [*sic*] something else (eg the ability to chew), interspersed with periods when I feel calm / accepting of my situation and better able to focus on the positives (even just the sight of a bird in the garden, or pleasure of a nice taste, or the joy of a hug from my spouse). (#13)

> Loss has been a continuing process over the course of the almost 15 years now that I have had ME […] The daily griefs are also numerous. Every small thing you have to give up, whether it is a particular food or a particular activity is one more loss added to the sum total of losses. There are really too many losses to be able to describe here in any way adequately. (#25)

However, as discussed earlier in this chapter, there is an extent to which this a shared feature of grief over bereavement. Bereavement involves one very specific object of loss, that is, the person who has died; however, it also involves a variety of sometimes diffuse, all-encompassing losses which can unfold over time. For instance, one can lose a parent, a concrete entity, but also one's identity as a daughter, and various imagined future possibilities in which the person was implicated. The efficacy of temporal criteria here are dependent on understanding grief as having a clear "event" from which to start measuring time lapsed. It is unclear whether the shared structural qualities I have proposed are sufficient to bring into question the role of the temporal criteria in all cases of grief. I do not think that there is a clear answer here, and rather, the answer is likely to be as unsatisfactory as: it depends on the case. For instance, grief over the death of a relative who died after a short period of illness will likely be easier to measure in this way than cases such as a partner in a minimally conscious state, or a missing child. The structure of loss in CFS/ME has more in common with these latter cases.

As discussed earlier in this chapter, another feature of ambiguous loss is that one often does not know if something is gone forever, or if the loss is temporary. This is a salient feature of experience for some people with CFS/ME. For some, it is not clear whether or not the losses they feel are permanent, to be adjusted to, or are temporary. Whether or not CFS/ME patients recover, in part or in full, is highly variable. Accordingly, patients can find it difficult to know whether to accept their losses and adjust to a new life with lifelong illness, or whether to resist the illness and stay hopeful for recovery. It is easy to understand how this can be an obstacle to the process of forming new goals and new expectations: if there is a chance that one's old world could return, why would one give up on it? Understood this way, this also helps to make sense of why the type of "good hope" described my McGeer can be difficult for people with CFS/ME to maintain. It is a challenge that cannot be over-stated to be responsive and adaptable to a new set of circumstances, and a new set of abilities, when it is not at all clear what those circumstances and abilities are from one day to the next. Whether or not one judges that these temporal criteria are appropriate in the context of bereavement, it is much harder to make compelling the view that these temporal criteria are appropriate in the context of grief in CFS/ME.

Meeting symptomatic criteria is also important for a diagnosis of pathological grief. Some, notably Shear, have suggested that it is possible to distinguish healthy grief from pathological grief by symptoms as well as timeline (Shear, 2015). Additional features of complicated grief might include, she writes: preoccupation with the circumstances of the death; preservation of the deceased person's belongings exactly as they were before death; oscillation between excessive preoccupation and avoidance of reminders of the deceased; difficulty accepting the loss; difficulty coping without the loved one; difficulties recalling positive memories of the deceased; difficulty engaging with social activities; feeling that life is meaningless; and substance abuse or suicidal ideation (ibid, p.155).

These differences are informative in the context of bereavement. For instance, there is a fact of the matter as to whether the bereaved person has preserved the deceased person's belongings just as they were before death; difficulties recalling positive memories of the loved one can likewise, if imperfectly, be measured. However, without the death of a

person, these features are not easily transferrable to non-bereavement contexts such as chronic illness like CFS/ME. One could attempt to reframe some of these features for the relevant context, such as whether one finds it difficult to accept the losses associated with one's illness, hanging on to, for example, gym memberships or plans to run a marathon. This reframing would require serious clinical work. As it stands, neither existing temporal criteria nor symptom differences appear to be particularly informative in this context. The challenge of distinguishing between healthy and pathological grief in CFS/ME based on current criteria is therefore not feasible.

Importantly, it is also noted in the criteria that the construction of pathological grief depends upon what society deems normal, that is, whether it violates cultural expectations or not. Arguably, grief in CFS/ME automatically violates cultural expectations insofar as it is disenfranchised: it is plausible that society, at its broadest, would not deem normal an experience of grief caused by a chronic physical illness. With these considerations in mind, it is far from clear how to distinguish between healthy and pathological grief in CFS/ME beyond differences like "intensity" which are so vague as to be uninformative.

5. Conclusion

In this chapter I have illuminated good reason to focus on grief in clinical and therapeutic contexts for people with CFS/ME, and potentially more broadly. I have also raised some complicating factors that need to be considered should clinical work on this receive attention and investment such as the temporal and intentional dynamism in such cases. Moreover, the causal sequence of various aspects of depression or grief experience would likely be important for clinical practice. We might distinguish, for example, between a patient who is depressed as a result of a felt accumulation of losses, and a patient who is only experiencing certain losses painfully as a consequence of being in a state of depression. The same could be true of experiences of fatigue and bodily pain. The answers to such questions have potential to influence what is understood as the target of treatment in any given case.

It remains unclear what the role of grief might be in typical cases of depression; plausibly depression can involve loss, and if we have expanded grief to accommodate some non-bereavement cases, does it continue to expand? What if we could distinguish between instances of depression that involved grief, and instances that didn't? One consideration here, is that if a grief-focused sub-type of depression is developed, what its temporal criteria will be. The symptom duration required to warrant a depression diagnosis is considerably shorter than the duration required to warrant a diagnosis of pathological grief under both the ICD-11 and DSM-5-TR. As discussed in this chapter, ascertaining a "starting point" from which to measure grief in CFS/ME can be difficult.

Another consideration is how the distinction between primary and secondary psychopathology maps onto this discussion. Prima facie, it seems as though granting that CFS/ME involves grief commits one to the claim that the grief is secondary to an organic, or at least a separate, dysfunction. That is, grief in CFS/ME arises as a consequence of suffering with an illness. This might appear to be in tension with the view that depression-like experience in CFS/ME is, in some cases, part of the primary dysfunction: such experience cannot easily be "explained away" as grief *over* something else if it is primary. This, as I will show, is a false dichotomy. This leads me nicely onto the next chapter, in which I will say more about the relationship between bodily and emotional challenges involved in CFS/ME.

Chapter Three: Emotion Regulation and Affective Scaffolding

1. Introduction

Here I will detail the ways in which CFS/ME can affect a person's ability to make use of environmental scaffolding both privately and in the context of interactions with other people, thus impeding emotion regulation. To illustrate the various different factors at play and the effects they have, I will look closely at dynamics of stigma around CFS/ME as well as three of its hall-mark symptoms. I will also show that the type of regulatory resources a person employs before becoming ill affects how and whether those regulatory resources will be impacted by illness. My analysis puts pressure on the assumed distinction between "primary" and "secondary" psychiatric dysfunction in CFS/ME.

I will begin by outlining some recent work on emotion regulation, broadly construed. I introduce some recent literature on emotion regulation and affective scaffolding, and engage with some contemporary work on how emotion regulation is impeded in psychopathological conditions, namely depression. Various existing philosophical accounts of depression focus on challenges to emotion regulation and a sense of being connected to others, supporting the general idea that depression is "an illness of isolation" (Karp, 2017).

In Section 3 I introduce CFS/ME to the debate to show that the extent to which this literature on emotion dysregulation in depression describe a process unique to depression, or even to psychopathology, is not clear. Indeed, drawing on data from the EFQ, I go on to show that similar emotion dysregulation appears to be an important part of some people's CFS/ME experience. This much has not gone entirely unnoticed, and there have been various hypothesised causes for apparent comorbid depression in CFS/ME. Some have suggested that loss of social support is responsible for the particularly high rates of comorbid depression. Inadequate support from family members, friends, employers or even medical professionals all contributes to this. Some have suggested that emotional dysregulation in CFS/ME ought to be understood as *secondary* to the bodily impairment, and thus distinct from it. Does this causal explanation hold in all cases? I suggest not.

In Section 4, I show that some challenges to emotion regulation are in fact inextricable from the bodily impairment, and as such, ought not to be understood as "secondary". I illustrate this by focusing on two of three hallmark symptoms of CFS/ME. I discuss extreme fatigue and "brain fog" to show how the relevant emotional difficulties can be much more tightly bound to the body than can be accommodated by the model of "secondary" emotional difficulties. In Section 5, I offer an analysis of the emotion regulation challenges posed by the third hall-mark symptom, post-exertional malaise (PEM), which is more complicated. This is an especially salient example of the restrictiveness of the distinction between primary and secondary psychiatric symptoms. Attending to this messiness motivates a more nuanced understanding of depression-like experiences in CFS/ME.

In Section 6, I look at the concept of the "resilient personality" discussed as a protective factor for the development of chronic illness. I show that whether and how people experience certain interpersonal challenges is, to a significant extent, importantly affected by a person's existing regulatory repertoire. I suggest from this that supplementing the concept of resilience with an acknowledgement of context-dependent access to certain types of regulatory resources could have important consequences for the development of well-targeted therapeutic practice. I also draw on Tom Roberts and Joel Kruger's (2021) account of chronic loneliness and the corresponding "affective flattening" that can be part of such an experience. The structure that Roberts and Krueger identify for experiences of chronic loneliness is compatible with my claims here about the various ways in which emotion regulation can be impeded in CFS/ME. One need not understand loneliness as "secondary", purely psychological phenomena, then, but instead can better appreciate the extent to which one's bodily situation can affect what social goods are experienced as within reach.

2. Emotion regulation

Emotion regulation is an important part of our everyday lives, and healthy mental and physical function, in part, depends upon our ability to carry out emotion regulation

effectively (Grillon et al, 2015; Gross, Richards & John, 2006).[31] James Gross describes the regulation of emotion as that which involves either enhancing or diminishing one's emotional responses (2014). A range of "instrumental motives" can be involved in emotion regulation, meaning that it is more complex than simply enhancing "positive" emotions and suppressing "negative" ones (p.13). For instance, rather than seeking to straightforwardly suppress a negative emotion such as sadness, we might instead be motivated to "cry out" inchoate sadness by listening to a certain piece of music, or looking at a particular photograph. Moreover, Gross's conception of emotion regulation accommodates everything from non-conscious processes, such as avoidance of certain situations, to processes that we consciously and deliberately engage in (p.7).

Emotion regulation processes need not, and often do not, take place privately. Rather, they are deeply interpersonal in structure, often relying on specific patterns of interaction with particular individuals, spaces or objects in one's environment. Indeed, Campos et al go so far as to suggest that we and our interpersonal environments are "necessarily entwined in the generation of affect" (2011, p.27). Here the notion of "scaffolding" is useful. Krueger (2020) distinguishes between three forms of affective scaffolding: embodied, social, and material. Where embodied scaffolding takes place, affective experiences are scaffolded by physical processes and resources, and "some regulative processes likewise loop through this affective scaffolding and modulate the character of our experience" (p.599). Krueger claims that how an affective experience feels is often a function of how it is regulated, and this regulation can implicate bodily features such as agency, expression and attention.

Social scaffolding makes use of bodily processes like motor mimicry and movement synchrony, such that the individual becomes "absorbed by a socially distributed co-regulatory system" (p.600). These processes are largely involuntary, but individuals can exert some strategic control. Material scaffolding, on the other hand, involves making use of particular things, spaces and even sounds in order to regulate. Colombetti and Krueger have

[31] Here I am working with a permissive view of emotion regulation which can encompass both episodic emotions and longer-lasting affective states and processes.

argued that central to affectivity is the active modification of one's environment in order to scaffold certain affective states (2015, p.1160). Here, scaffolding can encompass sustaining, amplifying and even diminishing certain emotions by exploiting one's environment. As Krueger writes, "enjoying reliable access to the things and spaces of our material culture — being able to actively integrate with them in an immediate and spontaneous way — Is crucial for our ability to stabilize and regulate our affective life." (2020, p.600).

Colombetti and Krueger's position here was motivated by a broader view of scaffolded cognition which was put forward by Kim Sterelny (2010). Sterelny defends a multi-dimensional view of the scaffolded mind; one such dimension is trust. Here, trust refers to a sense that some environmental resource is reliable, or can be accessed reliably. We might have a high level of trust in the train timetable listed on our mobile phone app, for example. We might trust that it is usually accurate, and that it can be checked quickly and easily to monitor delays, platform changes, or cancellations. Building upon this, Colombetti and Krueger offer a picture of the affective function of environmental resources which they argue brings to light a subtly different sense of trust. Some resources, they claim, are trusted in that one has confidence that they will have a certain effect on one's affective state (p.1162). For example, I might trust that playing with the dog at the local pub will lift my mood, or that listening to a *Misfits* album will purge my feelings of irritability (DeNora 2000).

As well as material objects in one's environment, Colombetti and Krueger also discuss how interpersonal interactions can be trusted in the context of affective scaffolding (p.1167). That is, we can interact with other people in such a way as to bring about certain affective states. For example, we can choose to spend time with a reliably contagiously jolly friend when we are feeling sombre, while we can instead choose to spend time with a friend who is a good listener when we are in need of advice. Thus, the interpersonal is implicated in our goal of emotionally regulating insofar as we "engage in joint activities that are qualitatively enriched by the presence of others" (p.1166).

Thus, there are various ways in which one can be deprived of regulatory resources. In the context of illness, it might seem that we can pull apart some distinct regulatory challenges.

We might distinguish between challenges to regulating one's relationships with others, as we might distinguish between challenges to regulating one's bodily condition from regulating one's affective life. However, as the above suggests, each of these regulatory challenges are interrelated, dependent on one another, such that to draw too strong a contrast between them would be to lose sight of the pervasiveness of the illness experience.

There are various forms of emotion dysregulation associated with psychopathology, particularly depression. Various authors have written about aspects of this emotion dysregulation and how it colours one's experience of the world and other people. Ratcliffe, for example, has argued that central to depression is a sense that certain types of interpersonal connection are no longer possible, that others just cannot offer you what they did before (2015; 2017; 2018b). In depression, one loses a sense of things as contingent and filled with possibilities, which is instead replaced with a sense of stasis, inescapability and impossibility. A change in interpersonal experience is inextricable from this, since a sense that things can change for the better implicates other people and the possibilities for thought and action which other people are perceived to offer.

Being unable to be moved by other people importantly implicates the experience of one's body. Fuchs describes the person affected by depression, or melancholia, as having become confined to the spatial boundaries of her material body (Fuchs, 2005b; 2010). Described by Fuchs as triggering *corporealisation*, this frustrates the body's fluidity, spontaneity and transparency which is characteristic of the body in good health (Fuchs, 2002; 2005b; 2010). Here, the body is experienced as a heavy, burdensome object which puts up resistance to the individual's intentions and impulses, and this is felt painfully (2002, p.99). This experience of one's body affects experience of one's wider environment, including one's experience of other people. As Fuchs describes:

> [T]here is also a more subtle loss of transparency: It concerns the bodily resonance or affectability that mediates our experiences of emotions and atmospheres, and is also required for our affective attunement with others. In melancholia, the corporealized and frozen body loses this capacity for emotional resonance. […] They are no longer capable of being moved and affected by things or persons; the attractive and sympathetic qualities of

> their surroundings have vanished. Thus they speak of a "feeling of not feeling" and complain of not even being able to experience feelings for their family any longer. (Fuchs, 2005b, p.100.)

Where one's "affectability" is compromised, one no longer has reliable access to various affective states; instead, they are out of reach. A loss of trust can be implicated in this. On Colombetti and Krueger's account of affective scaffolding, trusting something or someone involves having confidence that something or someone will have a particular effect on one's affective states. Colombetti and Krueger offer examples of a localised loss of trust, such as an infant temporarily losing trust in a care-giver (p.1168). They also, however, suggest that trust *in general* might be compromised by loss of previously trusted regulatory resources, shattering "pre-reflective patterns of reliance" (2015, p.1167).

Loss of trust in a particular resource need not involve the broader, more pervasive loss of trust which is characteristic of a loss of trust *in general*. Of course, one can lose trust in a particular resource for a given period of time, without losing trust in and connectedness with that resource permanently, or in people in general, in the world, or in one's self. For instance, I might lose faith in the train timetable on my mobile phone app after experiencing some glitches, yet be able to trust it at a later date once the problem appears to be fixed; I can also trust an alternative resource in the mean-time. Where the experienced loss of trust is more pervasive, however, one's ability to exploit a wide range of artefacts (including people) in order to scaffold certain affective states will be impeded.[32] This more foundational, pervasive loss of trust is described in detail by Ratcliffe:

[32] I do not want to commit myself to the claim that in cases where foundational trust is lost, all localised trust is lost without exception. It might be the case that though one has lost trust in general, there might remain a particular person or resource that remains "safe". Consistent with this, Ratcliffe (2018b) has argued that there might be particular people who are exempt from a general feeling of distrust. Second, one might be cut off from people in general, but be able to sustain connections under certain circumstances. The former seems to be supported by people's apparent reliance upon support groups and patient networks. A person might, for example, have lost trust in people in general, but be able to maintain trust in other disabled people; people that "get it". For example, one EFQ respondent wrote: "The relief when I walked into my first meeting [at] the [redacted] Fatigue Group was huge. Suddenly there was a group of people who "got it"." (#20)

> If you cannot depend on other people, then you cannot depend on social norms, items of equipment maintained by others, information they provide, and so forth. Erosion of trust can also extend to the efficacy of one's own actions, to one's bodily functions; to the reliability of one's thoughts and feelings; and to the integrity of one's sense of self. (Ratcliffe, 2017a)

It is plausible that a string of disappointments leading to broken trust in localised cases might lead to a more pervasive sense that the world is not to be trusted. For instance, where infants are repeatedly let down by their care-givers, this can lead to the loss of trust in other people in general, or even in features of one's environment. The relationship between these types of losing trust will be relevant for later discussion.

3. Secondary psychopathology

These insights into emotion dysregulation in psychopathology provides a strong foundation for developing my account of the challenges to emotion regulation that people with CFS/ME can face. It is not an altogether natural springboard, though: one thing which is not clear is to what extent the structural features described here are unique to psychopathology.

Though multiple psychiatric illnesses might share these structural features, one might not expect them to be shared with conditions which are thought to be somatic or "organic" in nature. According to Fuchs, in diseases like Parkinson's, it is typically the case that one is more or less able to separate the feeling of bodily impairment from one's sense of self, thus avoiding "corporealisation" and the emotion dysregulation that comes with it (Fuchs, 2005b).

As I discussed in Chapter 1, it is not clear that people with these other illnesses are not vulnerable to this too. Rather, in addition to specific, localised lesions or changes on the physiological level, the whole of consciousness becomes vulnerable in illness (Merleau-Ponty, 1962, p. 138). It is not clear how Fuchs' view of corporealisation in melancholia, then,

teases apart bodily experience in the melancholic from the generally unwell.[33] [34] Implicit in this discussion is the view that challenges to emotion regulation are not a constitutive part of "somatic" illness in the same way that they are for psychiatric illness. Under this assumption, recognising such challenges in an ill person might seem to be indicative of some psychopathology. Indeed, this is relevant to some existing clinical work on the much-contested relationship between CFS/ME and psychopathology, particularly depression.

If one looks uncritically at assessments of comorbid depression in CFS/ME, we see that people with CFS/ME have been identified as having higher rates of comorbid depression than other chronically ill people (Loades et al, 2019). One popular way to understand this is to take the view that high rates of comorbid depression in CFS/ME are attributable to poor social support and distress over bodily limitations and the subsequent negative impact on quality of life. For example, Taylor et al (2017) claim that depression, while common in CFS/ME, is *secondary* to the impairment, and arises because of the impact CFS/ME has upon quality of life. They argue that the bodily limitations imposed by CFS/ME restricts valued activities, which causes patients to feel depressed. On this view, to provide an account of obstacles to emotion regulation in CFS/ME might be taken to fail to reveal much about CFS/ME experience itself, but instead might be taken to reveal something about the impact of living with a chronic illness in a society which is not disability-friendly, and where understanding and social support is poor. Here, then, the regulatory challenges are not seen as directly attributable to the bodily dysfunction, but to psychopathology which is secondary to it.

[33] In defence of the view that bodily experience in somatic and psychiatric illness is often phenomenologically indistinguishable, see Chapter 1 for a discussion of this. See also Ratcliffe, Broome, Smith & Bowden (2013).

[34] An alternative view to the corporealisation view of bodily experience in depression has been put forward by Osler (forthcoming). On Osler's view, rather than necessarily experiencing the body as object-like, the depressed individual's bodily is saturated with experiences of lethargy, tiredness, heaviness, sadness, hopelessness and so on, to the exclusion of being able to connect with others on a bodily level. This analysis is more permissive, and closer to a view of bodily experience in bodily illnesses such as CFS/ME. This alternative conception makes it no clearer what separates bodily experience in CFS/ME from bodily experience in depression. This is not a problem for the analysis per se; it appears, however, that it also captures more than depression.

A small number of studies have directly investigated emotion regulation in CFS/ME and related conditions such as Fibromyalgia, finding a variety of results and proposing a variety of hypotheses which are suggestive of a more complex interaction between fatigue and emotion dysregulation. Though this has not yet been found to be true of people with CFS/ME, pronounced deficits in positive affect have been identified in people with Fibromyalgia; this is thought to increase the risk of depression in response to illness-related stressors (van Houdenhove & Luyten, 2008; Zautra et al, 2005).

A study into the neural correlates of fatigue in CFS/ME found that though CFS/ME patients tend to fail to down-regulate emotional responses to *fatiguing* situations, they tend to over-regulate emotional responses to general emotional stimuli (Caseras et al, 2008). Consistent with this, there is some evidence for increased emotional suppression in people with CFS/ME compared to healthy controls (Creswell & Chalder, 2001; Rimes et al, 2016). It is hypothesised that this may be associated with negative beliefs about the acceptability of emotional struggle, as has been found in studies of depression and anxiety (Spokas et al, 2009).

Rimes et al (2016) suggest that low observer-rated emotional expressivity could result in others failing to identify the individual as being in need of support, thus potentially contributing to the development or maintenance of the fatigue. Rimes et al hypothesise that *the fatigue itself* may contribute to reduced outward displays of emotion, and call for research into this hypothesis (2016, p.10). To my knowledge, there is not yet any empirical work to suggest that this is true, however, there is good evidence to suggest that emotion dysregulation has negative consequences for one's physical health (Fernandez & Turk, 1989; Gross & Munoz, 1995).

We can be confident at the outset that for many, stigma and the resultant relationship pressure is a highly challenging aspect of having CFS/ME for many. This is supported by various recent studies; for instance, one study defends that the high levels of depression, anxiety and suicidal ideation in CFS/ME is attributable to secondary stressors such as stigma, interpersonal conflict and lack of viable treatment options (Devendorf et al, 2020). There is also empirical support for the hypothesis that the strength of one's support networks has

an effect on well-being in chronic illness (Petrie & Jones, 2019). Before I show that this is not an exhaustive explanation of the relevant regulatory challenges which people face in CFS/ME, I want to offer some support for the role that such dynamics can play in emotion dysregulation.

Recall Colombetti and Krueger's expansion of the notion of trust offered by Sterelny. A resource, be that an object or a person, is trusted where one has confidence that the thing will have a certain effect on one's affective state (2015, p.1162). We also saw from Ratcliffe's discussion of depression that a more foundational trust can be lost, such as in depression, where not just particular resources cease to be trusted, but trust *in general* is compromised. Living with a heavily stigmatised illness such as CFS/ME is a plausible example of where trust of either type might be lost.

For instance, before becoming ill, one might have trusted a friend insofar as being confident that should they feel lonely, they could talk to them and feel understood, thus diminishing feelings of loneliness or being misunderstood by others. There are various ways in which living with CFS/ME can test or shatter trust in other people as resources with which to regulate. For one, public understanding of CFS/ME is poor, and often saturated with stigma, such that one can cease to feel understood by even those closest to them. Loved ones might, perhaps for the first time in a particular relationship, fail to understand, fail to ask the right questions, or fail to avoid hurtful comments. Someone who has *always* been trusted to "get it", now, might for the first time, fail to do so, shattering a sense of being understood, at least *by them*. The following EFQ response illustrates the suffering that can result from not feeling understood by those close to you:

> I am much more emotional than I used to be and often do not feel good enough anymore, especially when others do not understand the condition and do not know just how debilitating it can be. For example, when my 75 year old grandma says that I should be able to do something physically because she can when she does not realise that I no longer can just makes me feel even worse. (#11)

One might also have trusted a friend as a regulatory resource insofar as being confident that in times of low mood, one could take part in a shared activity together which would allow

oneself to better regulate one's mood, such as playing tennis together or going for a drink at the local pub. Now one faces bodily restrictions, shared projects with others that once reliably scaffolded particular positively valanced affective states may no longer be viable. Moreover, where these projects were an important part of one's relationship with the other person, it can be unclear what the relationship now consists in, creating a sense that those relationships are now compromised:

> I can't do things with my friends that I would like to; I can't go clubbing all night, go on days out shopping. I feel like I would be a lot closer with my friends if I could partake in all the activities. (#17)

> I lost all my friends because many people define themselves by what they do, so when that is the focus and you can't do anything, it feels so alienating from everyone. (#29)

A feeling of not being able to rely on other people in a once habitual way can contribute to a sense that one is alone. Moreover, where trust in others in general is lost, pre-emptive withdrawal from other people can follow. If one no longer sees people as beholding possibilities for positive, meaningful exchanges, one can retreat, instead choosing not to seek engagements with others. As one respondent writes:

> I often do not tell friends in case they do not understand/think that I am lazy. I feel like I am very secretive about a huge part of my life which I would not have been before I was ill. (#17)

The notion of secretiveness here is interesting. There is a distinction to be made between selective secretiveness, such as in the face of a particular person or group of people, and secretiveness in general as a default way of approaching other people. The latter is suggestive of finding oneself in a world where other people *in general* are not to be trusted. It is not just the loss of trust in a particular person with whom one could be completely honest, and hide nothing from, but the loss of pre-reflective trust in, and the anticipation of other people as potential providers of a certain type of connection which can scaffold positive affective states. Instead, others are anticipated to be unkind, judgemental, or just fail to understand.

Living with CFS/ME does not just challenge close personal relationships. Wider interactions with other people with whom one is not closely acquainted can contribute to the transformation of the world into a hostile place, where people do not care, do not understand, and where nobody is to be trusted — potentially even oneself. This might be a candidate for a case of localised loss of trust disposing one towards a more pervasive loss of trust. For example, as is well documented, people with CFS/ME cite difficult interactions with GPs, friends, employers and family, principally in the context of either not being believed or not being understood (Blease et al, 2017). Ceasing to feel supported by any group over any domain of one's experience can lead to a more pervasive loss of trust in others. Moreover, where scepticism about one's illness is expressed from those in a position of epistemic authority, this can even predispose one towards a loss of trust in one's own judgement. One respondent describes the difference that this can make:

> Having a very supportive GP and specialist has been hugely helpful - and a sharp contrast to interactions with previous doctors who believe we are all just whingers, or who believe it is purely psychological - which adds hugely to the sense of guilt/blame and self doubt that is so easy to develop and so hard to get rid of in this condition. (#14)

Though vitally important in many cases, dynamics of stigma do not offer an exhaustive explanation of challenges to emotion regulation posed by CFS/ME. This will be shown by a closer inspection of the challenges that can arise in direct result of the bodily predicament. In what follows, I want to highlight another aspect which is, to some extent, independent from actual and anticipated stigmatising experiences with other people, but that still implicates the interpersonal. That is, where one's bodily condition directly brings about an obstacle to emotion regulation. Dynamics of stigma alone do not capture the fact that one's bodily condition is sometimes inextricably linked with having access to various affective states, dispositions and attitudes (see Chapter 1). Where the body becomes vulnerable, so too can one's relationship with the world and other people as part of that world. We might then be in a position to say that unpleasant and stigmatising interpersonal interactions exploit this vulnerability, exacerbating feelings of disconnectedness, but there is more that

remains to be said about the nature of that vulnerability which is a constituent part of one's bodily condition.

In what follows, I focus on extreme fatigue and "brain fog" as features of bodily impairment in CFS/ME, a constitutive part of which can be emotion dysregulation. I then consider another hall-mark symptom, "post-exertional malaise" which I suggest paints a more complicated picture. For instance, one ought to distinguish between the regulatory obstacles faced by somebody who suffers recurrent episodes of post-exertional malaise, but is not currently experiencing it, and somebody who is in the midst of an episode of post-exertional malaise (and is thus likely to also be experiencing extreme fatigue and "brain fog").

Recognising intra and interpersonal variation highlights that understanding these predicaments in CFS/ME as either primary or secondary is unhelpfully restrictive. The dynamic interplay between causation and constitution here will become clearer in the following consideration of three hallmark symptoms of CFS/ME and how they affect one's ability to emotionally regulate.[35]

4. Extreme fatigue and brain fog

Earning its place in the most common label for the condition, fatigue is a (but not necessarily *the*) fundamental symptom of CFS/ME. Though a hallmark symptom of CFS/ME for many, it is not a particularly informative one, since fatigue is a symptom shared by countless illnesses, somatic and psychiatric (see Chapter 1). David Healy (1993, p.29) reported on a study of depression where the three most commonly reported symptoms were lethargy, a sense of detachment (especially from other people), and physical changes described in terms of feeling that the subject was coming down with a viral illness like flu or

[35] The relationship between causation and constitution is much-disputed in the extended cognition debate (Adams & Azaiwa, 2001) and more widely in the philosophy of science (Krickel, 2018). Some have defended a more dynamic, diachronic approach to the metaphysics of constitution (Kirchhoff, 2015), yet it is possible that some may take some of my claims of constitution to instead pick out a particular type of causal relation. That is fine; my argument can accommodate either metaphysical view while preserving the idea that the primary/secondary distinction in this context is restrictive.

glandular fever. As discussed in Chapter 1, a particular group of generic sickness symptoms of which fatigue is often principal, can be understood as indicative of an inflammatory immune response: here, the body's inflammation response serves a regulative role which is widely recognised to result in changes in behaviour and mood such as a feeling of being disconnected from the world and from others, as well as bodily fatigue. Some scientists have labelled this the "sickness response", and the phenomena is elsewhere described at a different level of explanation as the "feeling of being unwell" (see Ratcliffe, Broome, Smith & Bowden, 2013). As is recognised in countless somatic illnesses, it is becoming more widely recognised that some cases of depression are likewise associated with the release of high levels of inflammatory cytokines by white blood cells in response to stress, suggesting an inflammatory sub-type of depression (Pariante, 2017; Bullmore, 2018). Some research into CFS/ME has produced similar findings which is suggestive of shared pathophysiology in at least some cases.[36]

There is some evidential support for the hypothesis that there is some change on the physiological level which is causally responsible for a loss of access to certain affective states, constituting an obstacle to emotion regulation by way of change to extra-neural processes which are implicated in embodied scaffolding (Krueger, 2020, p.598). Where the body is fatigued (either by the aforementioned inflammatory mechanisms, or otherwise), and this results in a sense of detachment and disconnectedness from other people, it is woven into one's bodily condition that certain interpersonally-nurtured affective states are no longer possible. One therefore has diminished access to certain affective states not because of stressors secondary to the impairment, but because of features constitutive of it. It therefore seems that extreme fatigue can present a direct challenge to emotion regulation in CFS/ME. However, it is not clear that it presents a distinct one, since this much is shared with many other cases of illness which can appear to involve similar pathophysiology. That is

[36] I discussed limitations of this research in Chapter 1. Moreover, it is important to note that this is just one promising live empirical hypothesis to explain the biological mechanism behind the apparent relationship between illness, fatigue, and a feeling of being disconnected from other people. My account is not dependent on this mechanism being accurate, for it maybe that other mechanisms are identified which better explain the apparent phenomenon.

not a problem per se, but there is more that can and should be said about the challenges to emotion regulation which people with CFS/ME can face.

Looking into another hallmark symptom of CFS/ME, brain fog, might help to illuminate further nuances here.[37] Clouding mental activity and limiting attention span, brain fog is another very common symptom of CFS/ME, and is thought to affect around 85% of patients (Komaroff & Buchwald, 1991). Experiencing brain fog can threaten the cognitive and emotional life of patients, causing significant distress. This can lead to challenges to patients' sense of self and identity (see Chapter 4). Brain fog was a commonly-discussed experience in the EFQ. For instance, some respondents wrote:

> My ME has firstly made thinking much harder, I have constant brain fog and focusing makes the fatigue worse. (#1)
>
> My feelings become numb and especially when interacting with others I no longer have any energy or spark […] I get complete brain fog where I can't even order words properly anymore (articulation is difficult) and instructions are impossible to follow. (#9)
>
> There is a certain brain fog that I have which means I can't necessarily think everything through to the best extent. (#10)
>
> I'm sure I would now be diagnosed as suffering with depression. I had brain fog all the time and struggled to think clearly and to focus. (#15)[38]
>
> Some tasks, that I could once do in my sleep, are now painful and very difficult, even the things I used to do for pleasure, such as reading a book. The loss of my cognitive function is one of my biggest stresses. I feel as though I have lost my 'clever' and any prospects of success in life. I can manage the tiredness and the physical symptoms, but the lack of cognitive function has the biggest impact. (#31)

[37] Moreover, this serves to show how thinking of the illness only in terms of fatigue limits one's understanding of the world of the patient. This point has been made politically, which I touch on in Chapter 1.

[38] As this participant acknowledges, brain fog is a symptom shared with depression. Like fatigue, this feature of experience might have its physiological basis in an inflammatory sickness response. We might therefore identity a similar pathophysiology here in both CFS/ME and depression, where in both cases reduced capacity for interpersonal engagement is a constitutive part of the bodily change. The phenomenology of brain fog in depression and CFS/ME might also therefore be shared.

Some of the effects of brain fog described by respondents implicate other people in various ways. For instance, an impeded ability to articulate oneself to others, or follow instructions, will surely affect the ways in which it is possible to interact with other people. If one cannot articulate oneself to others, this creates limits to the type and depth of the interpersonal interactions which are possible.

Respondent #9 explicitly described the numbing of one's feelings. This suggests that brain fog, by way of affecting bodily resonance, appears to affect *emotional* resonance too. Where one's affectability is impaired, certain environmental resources cannot elicit certain affective states in the same way that they did before. Even scaffolding affective states by listening to certain pieces of music might be achievable if the impairment to attention is sufficiently severe; the sounds which might previously have given you to access certain affective states might instead just "wash over" in the way that they might if you were especially distracted, tired or unwell. Understood this way, it becomes clearer how brain fog can directly obstruct access to various affective states.

Grillon et al (2015) found that mental fatigue plays a key role in emotion dysregulation, supporting the view that higher levels of cognitive resources are required for successful emotion regulation (Opitz et al, 2012). They suggest that successful emotion regulation depends not only on individual differences in capacity, but also on the extent to which these resources are depleted over time (Grillon et al, 2015, p.5). As one respondent describes, in the context of challenges to information processing:

> Everything is effort. Optimism can seem a reckless energy that will backfire. When things go down I cannot process information and have no access to the energy of charm and empathy - I become cranky even as I try to avoid acting it out. Love is difficult – it's hard to present a stable self, and to be able to do things for others when you want. (#30)

Having "no access to the energy of charm and empathy" is highly illustrative of the pervasiveness of the obstacle posed by suffering from brain fog. Moreover, it illustrates that this is not a merely personal problem, but an interpersonal one too: where one's capacity for empathy is compromised, so too is one's capacity to connect with other people on a certain level. Brain fog, therefore, can have a direct effect on one's ability to make use of a

whole host of environmental resources. For instance, a kind friend who might once have been a reliable facilitator of a balanced, empathic approach to a family quibble might no longer be able to facilitate access to those affective states in the same way that they did before. One's bodily condition can therefore be an obstacle to being affectively moved by others, removing or compromising previously established routes for accessing to various affective states.

As well as obstructing one's ability to make use of other people as emotional regulators, one's bodily condition might also obstruct one's ability to self-soothe. As well as depending upon resources within one's environment external to oneself, one can also depend upon one's own cognitive capacities in order to self-regulate. One might, for instance, rely upon various solitary thought processes or cognitive strategies in order to enhance or diminish particular affective states. For example, one might rely upon one's problem-solving abilities to navigate and mitigate feelings of distress or anxiety, or take comfort in being able to cognitively map out the schedule of one's busy working day. The limitations imposed upon oneself by brain fog can make it the case that exploiting such cognitive and affective processes is no longer possible. If I cannot hold clear and sufficient information to cognitively "hold" the details of my day's work schedule in mind, this provides an obstacle to accessing the positively valanced affective state.

5. Post-exertional malaise

The term "post-exertional malaise" is used to describe the symptom whereby patients experience an intensification of symptoms after a period of exertion. "Exertion" is to be understood broadly here as to encompass cognitive, emotional and physical exertion. Post-exertional malaise affects the majority of patients, hence the motivation to rename CFS/ME "Systemic Exertion Intolerance Disease" (SEID) (See Chapter 1). However, post-exertional malaise is heterogeneous in terms of onset trigger, gestation period, and duration. In a patient survey into post-exertional malaise in CFS/ME, 84.9% said there were instances in which the precipitants of their post-exertional malaise could not be identified. 78.2% also identified "basic activities of daily living" as triggers (Holtzman et al, 2019). Participants in the same study also overwhelmingly reported that the severity and duration of their post-

exertional malaise was out of proportion to the type, intensity, duration and frequency of the exertion, with over 50% of participants consistently selecting that this is true "all of the time" for each of these variables.

Not only does post-exertional malaise significantly vary between patients, any given individual's experience can vary similarly over time. Asked how they would describe the course of their illness, only 15.4% of participants described it as "persisting"; the remaining participants described their illness as changing in some way, whether that be "fluctuating" (46.2%), "getting worse" (29.3%), "relapsing or remitting" (7.4%) or "improving" (1.4%). Managing this symptom requires many people with CFS/ME to avoid activities that could potentially trigger a period of malaise. As this data shows, which particular activities are to be avoided is not always clear. This uncertainty can impose significant restrictions on daily functioning, meaning that even seemingly harmless activities are seen to pose risk.

Even for the patients with the mildest cases of the condition, managing this symptom involves having to avoid particular activities, either in general or under particular conditions. Moreover, given the fluctuating nature of symptoms in CFS/ME, managing and preventing post-exertional malaise can involve having to decide not to engage in a particular activity, *even if* one feels perfectly able and willing at the time of making the decision. For instance, one EFQ participant wrote that they, as a matter of course, cannot engage in social activities during the week since they would be unable to work the following day:

> Relationships with my friends have broken down, as I often have to cancel plans last minute and I am unable to take part in activities that they want to do- such as going to a class at the gym, going to the pub, anything in an evening during the week is a huge no. (#11)

Such intrapersonal variation here can lead to a sense that no activity is safe, even if it is desired. Recall that the breadth of what constitutes "exertion" here has scope over cognitive, emotional and physical exertion. Thus, depending on the severity of the individual's condition, even certain moods or emotions can be considered unsafe, and so activities which elicit them have to be avoided. Where one need not only avoid certain activities, but also states such as excitement, one's incarceration is even more profound. Where such emotions to be avoided include positive ones, this hugely restricts the world of

the patient, making previously positive, desirable emotional states dangerous and potentially regrettable. For example:

> Excitement takes energy and is the enemy and you learn to tone it down (#30)

The challenge that this poses for emotion regulation has its root in the fact that ways of interacting with the world and other people in order to scaffold certain affective states are now no longer viable or safe; instead, they are out of reach or are filled with risk. A broad range of activities, behaviours, and pastimes can support affective scaffolding, and each of these can be made difficult to the person with CFS/ME. Having to mitigate against post-exertional malaise can affect material scaffolding, for instance, no longer being able to play one's musical instrument should it tire your muscles or leave you short of breath, or no longer being able to wear one's favourite but "less sensible" shoes should they leave you unable to walk home. Mitigating against post-exertional malaise can also affect social scaffolding to the detriment of interpersonal connection with others. In good health, for instance, if you want to express gratitude to a friend, you might take them for dinner. For a person with CFS/ME, such activities and the interpersonal engagement they bring might still be desired, but be sacrificed at the expense of managing one's symptoms. One has to make a conscious decision to restrict desired activities in the knowledge that is necessary for one's health.

Crucially, then, withdrawal from regulatory resources here does not always reflect (a) first-order desire or (b) bodily ability at the time of decision. Rather, withdrawal can be a decision based on forward-thinking and vigilance. Here all of the needs, desires and complexities of emotional life which existed before the illness remain, but previously relied-upon regulatory resources are no longer exploitable. For instance, anxiety is still felt, but going on a run to diminish or "sweat out" the anxiety is no longer an option. Some participants of the EFQ describe this inability to engage in regulatory activities:

> I am not able to engage in certain activities I might have done before to pick up my mood (for example feeling bored/lonely I cannot always just go have some excitement or interact with others) […] I have also experienced a few stages where I've needed to focus all my

> energy on work where I have felt depressed because I have not engaged in any "fun" or social activity other than chatting to housemates or my partner for a month or two. (#6)
>
> Lovemaking depends on health. (#31)

Lack of access to affective scaffolding here relates to the challenge that CFS/ME poses to one's sense of identity. Due to the restrictions of one's bodily impairment, it might no longer be possible to honour parts of one's identity which have long been valued; this can lead to a felt loss of self (see Chapter 4). Certain qualities might remain part of the description under which one values oneself, though one can no longer reliably "act out" those qualities. Important features of one's identity might include things that one does for oneself and for others; both of these can be frustrated in CFS/ME. For instance, qualities like diligence and ambitiousness might be exercised in relation to one's own personal projects, hobbies or goals. Likewise, I might consider myself a good friend to the extent that I can do particular things *for* them. CFS/ME can frustrate these actions. Some responses to the EFQ speak to this incongruence powerfully. Consider:

> I cannot choose what I would like to do, I have to choose what is realistic. This means that I am occupying myself with activities which do not fit who I am. As I have had the condition for years and have much changed since, I find it hard to know who I really am or what I would choose to do if I had the freedom to do so. (#6)
>
> When really bad it stops me from doing the things that make me who I am. I had to stop dancing and singing for a year when I got it initially. It was difficult staying optimistic when you can't socialise with people that make you happy or do the things that make you happy. (#9)
>
> I have always been incredibly ambitious, and desired a fast-paced life and career, involving lots of travel. Now, I know that at least for now, and likely in the future, I am unable to have the type of career and lifestyle that I have always wanted. I was always the positive person, extremely outgoing and constantly busy. I now spend most of my time at home, having to refuse or cancel social plans because I don't feel up to it or I know that I will be too ill the next day if I did go. (#24)

Aspects of one's identity, in part, depend upon being able to interact with other people in a particular way. For instance, qualities like dependability, reliability and generosity depend upon being able to employ those qualities interpersonally. For instance, the second participant quoted above describes previously being "the positive person". One can certainly be privately positive, but often, being "the positive person" picks out the quality of being one of the more positive people within a group of people who inhabit a shared world. The same participant writes, when asked how their experience has affected their relationships:

> It has mostly negatively affected relationships - I am no longer reliable as I often have to cancel plans, or refuse to commit in the first place. (#24)

Here the problem is that while the identity description remains valued and in place, as does the desire to maintain it, one cannot reliably act in such a way that is congruent with it. Maintaining one's practical identity here requires action, but it requires action which is either no longer possible or no longer reliably possible. One is then forced to act in ways which are incongruent with one's identity description.

Looking closely at the problems posed to emotion regulation as a result of post-exertional malaise illustrates some important inter- and intrapersonal variation in CFS/ME. I have highlighted how some of the experienced challenges to emotion regulation are more or less constitutive of the bodily impairment. The reality for many people with CFS/ME is that the condition fluctuates, meaning that certain symptoms are not constantly present, at least in their most severe and debilitating form, but are a constant threat to be avoided. When one is not in the throes of a crash, one can still be denied access to scaffolding by virtue of having to sacrifice certain behaviours in order to prevent one. When one *is* in the throes of a crash, and symptoms are severe and debilitating, one faces an intensification of symptoms like extreme fatigue and brain fog; and as I detailed at the beginning of Section 4, experiencing these symptoms can leave one unable to scaffold certain affective states which support regulation.

This is not to be understood in dichotomous terms, however. There are not merely two states, in a crash or not, but instead the illness experience is often much messier. In a crash, one experiences a disabling intensification of symptoms, but there is often a base-level of symptoms, such as fatigue and brain fog, which can impede emotion regulation. So even if one is not currently in a crash, one can still face problems accessing scaffolding in a way that is tightly bound to the bodily impairment say, as a result of persistent fatigue. In this state, though, one still exercises judiciousness over activity which could trigger further intensification of symptoms. This, as I have outlined, has its own consequences for accessing affective scaffolds. There is an important dynamic interplay of factors here which cannot be accommodated by the distinction between primary and secondary emotion regulation dysfunction. Even if there are particular instances where one can more easily attribute a certain emotional *episode* to primary or secondary factors, this is not to say that this explanation will hold over time (thus differing intrapersonally). Moreover, this explanation will almost certainly differ between people (thus differing interpersonally).

6. Resilience and loneliness

What has come up a few times so far in my discussion is the strain that CFS/ME can have on one's relationships. It is important to note that not everybody with CFS/ME experiences the same strain on relationships. For some, all relationships are affected, while for others, some are under strain and some are preserved or even strengthened. Of course, where relationships come under strain, this can cause significant emotional disruption in some of the ways I have so far outlined.

Whether and how people experience emotional difficulties in the face of hardship is often discussed in terms of "resilience". Accordingly, resilience can also be discussed as a risk factor for disease, especially psychiatric or "functional" disorders. For instance, Casale et al (2019) found that a "resilient personality" is relevant to the development of Fibromyalgia. The authors pick out difference-makers which can increase one's chances of developing the condition, and acknowledge the breadth of the concept of resilience:

> [There was] a scientific debate as to whether resilience was a personality trait or a dynamic process, and this led to it being considered an ability that develops during life on the basis of existential circumstances. […] The level of individual resilience can be increased by having access to social resources, being a member of a community, cultivating social relationships, having a supportive family, and maintaining affective bonds, and is also influenced by attachment, social learning, socio-economic status, religion and culture. (Casale et al, 2019)

Scaffolding is a useful framework for looking more closely at these factors. In their work on emotion, Griffiths and Scarantino (2005) highlighted a distinction between synchronic and diachronic environmental scaffolding. Synchronic environmental scaffolding is concerned with supporting particular emotional performances, that is, certain emotional episodes such as an instance of anger or joy. Diachronic emotional scaffolding is concerned with the way in which the environment supports the development of a repertoire of emotional abilities which can be drawn upon over time (p.12). With the aforementioned difference-makers for resilience in mind, this distinction serves as a useful springboard to look in greater detail at the variation in disruption to relationships in CFS/ME.

People's regulatory resources are crafted over time. These resources can involve different styles of engaging both with people in general and with particular people. Plausibly, then, the nuances of people's emotional repertoires are will affect how and whether they are disrupted in a given context. This is compatible with some formulations of pre-morbid risk in CFS/ME (Harvey & Wessely, 2009). It is important to emphasise that these diachronically-nurtured factors are essentially interpersonal and circumstantial in nature. One participant in the EFQ picked up on something like this:

> It's very hard for others to continually adapt to unpredictable changes unless there is already a strong relationship. (#30)

If we carefully consider all that can be captured by "unpredictable changes", we can see that certain styles of interacting might be made more vulnerable than others by illness. Earlier in this chapter I discussed testimony from a participant who expressed a sense that they would be closer to their friends if they could partake in certain shared activities. Relationships that are maintained by actions and behaviours, such as fast-paced intellectual

discussion or shared physical activities, will inevitably suffer if one's symptoms mean that those things are no longer possible. One might hold dear a relationship with an elderly relative which is maintained by an informal caring role; potentially not particularly compatible communicators, reliable action is what is important for the expression of love and maintenance of a sense of closeness. Where those actions are no longer possible, how or whether one can maintain the relationship might be unclear, thus putting pressure on close relationships.

Particular relationships require particular things for their maintenance. Some close relationships may only require subtle gestures like exchanging a knowing look, physical proximity or touch. Plausibly, such a relationship can more easily be preserved, whatever the severity of the bodily impairment.[39] The maintenance of other relationships may require something more effortful (whether that be cognitive or physical), such as intellectual conversation, quick-witted humour or joint activity. Of course, different symptoms will put different strains on relationships here too. For instance, where one suffers from severe brain fog, certain types of conversations will no longer flow like they may have done before. Depending on what types of conversations one has, either in general or with particular individuals in order to scaffold certain affective and regulatory states, an experience of severe brain fog will have a more or less pervasive impact on a sense of closeness to other people.

Close examination of such factors is another possible way of better understanding the mechanisms behind lack of access to scaffolding that people might experience. Interpersonal variation can be appreciated by recognising heterogeneity in symptomatology, as outlined above, but also by recognising how relationships, and the type of affective support they

[39] It is important to note that there are some cases of CFS/ME which are so extreme that exposure to even a small degree of light, sound or touch are all intolerable. As I mentioned in the Introduction, my data sample does not accommodate such cases. It would be interesting to see how relationships are affected in these kinds of cases, where a family member often has to take on a care role. This role might involve maintaining strict conditions for the patient's care, potentially involving monitoring and control the patient's interactions with others.

offer, differ qualitatively.[40] This also puts pressure on the distinction between primary and secondary dysfunction: such factors shape the terrain on which the subsequent bodily disruption takes place. If feeling close to others and using them as regulators requires exactly those things which are no longer possible in illness, one will sooner experience challenges accessing interpersonal scaffolding. These factors are not strictly primary nor secondary; rather, they are pre-morbid, yet they play a role in shaping the phenomenology of the subsequent condition.

Earlier I suggested that a succession of unpleasant experiences over time can dispose one towards a more general sense of being cut off from others. I have also just discussed how premorbid factors such as what kind of existing regulatory resources one has before becoming ill can have an impact on whether and how one subsequently loses access to interpersonal scaffolding. These factors, I suggest, can be instrumental in whether the person with CFS/ME experiences what Roberts and Krueger have called *chronic loneliness* (2021).

Roberts and Krueger make a structural distinction between loneliness and chronic loneliness. For them, loneliness requires a pro-attitude towards some missing social good coupled with awareness that the missing thing is somehow out of reach. This type of structure appears to fit neatly with many of the testimonies offered in the discussion of post-exertional malaise: here I engaged with testimonies which describe a painful awareness that certain shared activities are no longer possible, despite the fact that they are still desired. Chronic loneliness, on the other hand, does not require this pro-attitude. This means that the person in question might cease to yearn to be understood, or cease to want to take part in shared activities with friends, meaning that, as Roberts and Krueger put it,

[40] There is also something to be said about the regulatory impact of having *so few* interactions. As one participant writes: "I have found that if others insult me I am far more sensitive to it than I would have been and my self-worth is far more affected, this is because I have so few social interactions that even one person's opinion or one bad experience is significant." (#6).

the person ceases to be concerned with "social goods" (p.200). This brings about an *affective flattening* by which social ventures will not arise as attractive possibilities for action. An experience of chronic loneliness, the authors write, has an impact on how one experiences the surrounding world and one's body. They write:

> A person for whom the goods of social interaction have lost their allure will, for instance, not be motivated to pursue the range of everyday social activities in which we usually participate. She will […] be less attuned to social affordances like facial expressions, gestures and intonation patterns that animate social interaction. Her "bodily-affective style" […] is subdued, undemonstrative, and closed to others. In making plans and surveying the future, new and complex social ventures […] will not arise as salient options — they will not emerge within the space of credible possibilities for action. (p.200)

I suggest that people with CFS/ME can experience something like this for a variety of reasons. For instance, the severity and time-frame of the impairment can be instrumental here. In more acute episodes of symptoms like fatigue or brain fog, it might be that trust has not gone, but there is some obstacle in place which frustrates the desired effect of the resource being achieved. An everyday experience with a similar structure might be the difference between ceasing to feel moved by an old sentimental record, and not getting what you once did from it because the record keeps skipping as a result of a scratch. In the latter case, one still considers oneself to be in the same relationship with the object, that is, having the same pro-attitude towards it, despite there being some obstacle in the world which prevents one from enjoying that relationship in the same way. If symptoms of extreme fatigue and brain fog are severe and prolonged, over time this can strip the person of their capacity to yearn for the restoration of certain activities or interpersonal connections, and also of their trust in once-reliable regulatory resources. This sense of being cut off from the world and the things in it might exacerbate feelings of isolation, hopelessness and loss, making them more profound and depression-like (see Chapter 2).

It might have seemed intuitive to categorise loneliness as a secondary feature of CFS/ME. Prima facie, one might assume that somebody with CFS/ME is lonely because the restrictions on their bodily capacity prevents them from engaging with the relevant social

goods which foster a sense of connectedness to others. However, understanding how the persistence of symptoms such as fatigue and brain fog can leave one in a state of chronic loneliness shows that this is to miss nuances in the structure of the experience. One need not understand loneliness as secondary, purely "psychological" phenomena, rather, there is an important extent to which one's bodily situation directly affects what social goods are experienced as within reach.

At the close of their paper, Roberts and Krueger suggest that this analysis of loneliness would be useful to the continued study of psychiatric disorders, potentially having clinical and therapeutic significance here. I think this is right. I also think it is right to develop a better understanding of how experiences of these structures can affect people with illnesses outside of classical psychopathology. Their account of chronic loneliness, I think, offers a structural framework by which to understand the ways in which people with CFS/ME can be cut off from others and the world by way of being denied access to scaffolding. This can have potential clinical and therapeutic benefits for people with CFS/ME, too. Recognising that CFS/ME patients might be suffering from chronic loneliness does not rule out that they are suffering from depression, however being more attentive to the structure of experience here can, I suggest, promote greater understanding of the causal mechanisms behind depression-like shifts in experience which can illuminate potential therapeutic targets for CFS/ME where it involves emotion dysregulation.

7. Conclusion

What I have said in this chapter might appear to bring CFS/ME, at least at some times for some people, closer to depression than further away from it. I think that need not be a problem. There are various existing approaches to matters which I think are compatible with the view I have put forward here. For instance, Harvey and Wessely (2009) suggest that diagnostic criteria for CFS ought to be made more permeable, with relaxation of existing psychiatric exclusion criteria. On their view, crucially, this need not undermine the diagnosis of CFS itself; here, one need not advocate that CFS ought to collapse into depression, but instead one ought to recognise that some that features of experience which are typically associated with depression might also be intrinsic to CFS/ME experience.

In my view, it is crucial to recognise shared features with depression, but it is also crucial to continue to investigate particular ways of measuring aspects of CFS/ME experience that may illuminate some important nuances and differences. Here I have outlined some differences between a variety of ways that one can be cut off from scaffolding, such as the difference between making a judicious decision to avoid certain actions despite that being against one's wishes, and merely *being* cut off from scaffolding by virtue of one's bodily impairment, consequently feeling cut off from the world and unable to access certain affective states which are instrumental in emotion regulation. Better recognising these nuances can, I think, facilitate the development of more effectively-targeted treatments for restoring emotion regulation and providing novel and creative affective scaffolds for those who require them.

Chapter Four: Practical Identity and Transformative Experience

1. Introduction

Built into existing philosophical work on transformative experience is the assumption that a transformative experience results in a new experiential world, and with it, a new identity. In this chapter, I contribute to the project of refining the concept of transformative experiences by using the example of CFS/ME to show that this assumed structure fails to accommodate certain types of transformative experiences. There is, I suggest, an important family of transformative experiences that do not involve stable adjustment to a new practical identity, but instead involve various under-recognised and more complicated changes in one's relationship to the world.

In particular, I suggest that some transformative experiences are structured such that they leave the person stuck in a world of indeterminacy, with their practical identity unresolved. Here, one is unable to stably inhabit a new experiential world in which to replace meanings lost, and thereby adjust to a new identity. Other transformative experiences involve a radical shrinking of one's world and identity, where one lacks the sense of possibilities required for a transformative experience, at least as they are typically characterised. Instead, one world is irrevocably gone, and nothing promises to replace it. CFS/ME, I argue, can involve transformative experiences of any of these structures. I suggest that this can also be true of other types of experiences such as various other illnesses, grief and trauma.

Some background will be helpful before I proceed. First, I will discuss the concept of transformative experience as first developed by L.A. Paul (2014). I then turn to an expanded

taxonomy of transformative experience recently proposed by Carel and Kidd (2019). One notable aspect of this proposed expansion of Paul's account was to better accommodate the "facts of life" by opening up the framework of transformative experience to include involuntary and non-voluntary cases.[41] Paul's original account was primarily focused upon voluntary cases such as choosing to try to become a parent, or somewhat less familiarly, a vampire. The inclusion of involuntary and non-voluntary cases is a welcome one: under this broadened taxonomy, experiences like illness and trauma can be understood under the framework of transformative experience, allowing for a better understanding of how these experiences affect us. Building on this, I propose that (i) there is a family of transformative experience which has been excluded from analyses to date and that (ii) some paradigm cases of transformative experience are more complex than has been appreciated thus far.

2. Transformative experience

L. A. Paul's notion of transformative experience has been highly influential. Originally a challenge to the notion of rational choice discussed in decision theory, the concept has since seen application to multiple different areas of philosophy (Barnes, 2015; Chan, 2016). A transformative experience, on Paul's picture, is both epistemically and personally transformative. An *epistemically* transformative experience is an experience such that the only way to know what it is like is to have it yourself. Paul gives an example of tasting a Durian fruit for the first time. This appeal to "what it's likeness" is familiar from the classic

[41] Carel and Kidd describe the distinction between involuntary and non-voluntary by way of examples (p.206). The non-voluntary example is described as something that one did not and would never choose, such as being attacked, whereas the involuntary case is one in which the agent is causally responsible for the outcome, but the outcome was not intended, such as being hit by a car in an attempt to save a child.

Knowledge Argument: Mary the colour scientist, stuck in a black and white room, has an epistemically transformative experience when she experiences red for the first time (Jackson, 1982). A *personally* transformative experience changes one's core preferences, values, desires, or outlook. An experience that is personally transformative then, meaningfully transforms one's identity. For example, if I read Anna Karenina and come away with a radically different perspective on love and marriage, then I have had a personally transformative experience.[42]

Becoming a parent is a particularly salient example of an experience which is both epistemically and personally transformative. You could never have known what it was like to be a parent before you had experienced it, and becoming a parent brings about substantial changes to your identity. Paul writes "[w]e only learn what we need to know after we've done it, and we change ourselves in the process of doing it" (2014, p.4). In the remainder of her book, Paul pursues the challenge that this "hiddenness" poses to the requirement of informed choice for rational decision making. How can I calculate the utility of possible outcomes, and the expected value of those outcomes? Put otherwise, how can I rationally volunteer for an experience without knowledge of what it will be like, and what effect it might have on me? How can I, rationally, make a decision based in line with my preferences, when it is hidden to me what my preferences will be afterwards, compared to now? How

[42] This might sound like a suspiciously "every day" type of experience which does not deserve to be considered properly transformative in the relevant sense. However, it is an interesting part of Carel and Kidd's account (2019) that mundane experiences, at least accumulatively, can be transformative in the way that we are interested in here. I am sympathetic to this view.

can I make an informed choice about whether to try to become a parent, since I cannot know in advance what it will be like, and what I, as a parent, will value?

This has raised many rich and interesting problems in many areas of philosophy and beyond. Here I build on the notion of transformative experience as broadened by Carel and Kidd (2019). This revised taxonomy of transformative experience set out to accommodate a wider range of cases, namely involuntary and non-voluntary ones. The subject of Paul's original analysis, decision theory, is of course all about making rational decisions. However, it seems that not all transformative experiences are ones that we volunteer for. Illness is an obvious example: typically, I do not make or fail to make a rational decision about whether or not to become ill, rather it is something that is sprung upon me nonvoluntarily or involuntarily.[43] There are many cases in which either one does not volunteer for the experience, or where an action has unanticipated transformative consequences. In fact, Carel and Kidd claim that few transformative experiences are voluntary, and are instead "imposed on us by the contingencies of life" (p.206).

Moreover, Carel and Kidd emphasise that transformative experiences are not rare, once or twice in a life-time events, but are instead a common part of human life. It is in acknowledging this that the "facts of life" become salient. All of our epistemic and practical agency takes place in the context of these facts; they are an essential part of human life.

[43] Illness can be both nonvoluntary and involuntary. One might develop heart disease caused by having worked as a firefighter, which might be understood as an involuntary consequence of a choice. However, I suggest that our everyday way of making sense of illness fits more comfortably with the view of it as nonvoluntary. Our lives are complex webs of causes and effects; while we can understand choices we have made as whole or partial causes of illness, it is still reasonable to say that, for the most part, people do not choose to become ill in the relevant sense.

3. The facts of life

The facts of life are to be understood as features of life upon which many transformative experiences are premised. Building on Alasdair MacIntyre's *Dependent Rational Animals*, Carel and Kidd describe the facts of life not as "periodic features of the lives of certain unfortunate human beings, but universal features of human life" (p.201). The proposed facts of life which are part of the essence of what it is for us to "be" as humans are contingency, vulnerability and subjection. Carel and Kidd acknowledge that, in line with Paul's original account, some transformative experiences are in fact volunteered for, such as making the decision to get married or to try to have a child. However, they emphasise that many other types of transformative experiences can be better recognised by acknowledging the extent to which these facts of life shape us.

The vulnerability built into human life means that such decisions which involve voluntary choice can have wildly unanticipated consequences which amount to a transformative experience. In the case of deciding to try to have a child, then, we may learn that we are infertile, or suffer repeat miscarriages. Moreover, insofar as we are bodies, we are vulnerable to falling ill, ageing, and becoming injured. Insofar as we are social animals, we are vulnerable to emotional and physical abuse at the hands of others. All of this is part of human life, our manner of being. Nussbaum describes similar effects of the reality of the facts of life:

> Greek tragedy shows good people being ruined by things that just happen to them, things that they do not control. This is certainly sad; but it is an ordinary fact of life, and no one would deny that it happens. (Nussbaum, 2001a, p. 25).

Many other types of experience which are often hugely transformative, are not ones that we have elected for in any sense. Consider bereavement, subjection to violent assault, or sudden injury as obvious examples of this kind. In her recent book about grief following the death of her husband, Juliet Rosenfeld describes coming to terms with this deep vulnerability: "We were both about to see that all this attention and care could be suddenly and violently sabotaged by an illness that does not reward the careful or the diligent." (Rosenfeld, 2020, p.39).

One can also be forced to make difficult decisions one would never have wanted to make. Nussbaum considers many such cases from Ancient Greek literature in her book *The Fragility of Goodness*. For example, Aristotle's discussion of a captain who chooses to throw his cargo overboard in order to save lives. He must make a choice, but will regret it: "he will go on regretting that he threw it into the ocean — that things turned out so that he had to choose" (p. 27). This is a theme familiar from the famous passage of Kierkegaard's *Either/Or*: "Believe a girl, you will regret it; if you do not believe her, you will also regret it; if you believe a girl or you do not believe her, you will regret both; whether you believe a girl or you do not believe her, you will regret both" (1992, p.54).

As well as bereavement, illness is, of course, one such fact of life. It is common to think of illness as something that one is subjected to, as something that is "sprung upon" a person. There are instances of illness whereby one is forced to choose between options, all of which have consequences that are either clearly regrettable, or opaque but potentially regrettable. In Jean-Luc Nancy's essay *L'Intrus*, he offers a detailed account of his experience

of surviving a heart transplant.[44] He writes "who can say what is "worth the trouble," and exactly what "trouble"?" (2000, p.5). Here the consequences of each of the available choices are opaque, but each option is undesirable, and would never have been freely chosen. Though a decision has to be made on whether or not a particular surgery is "worth the trouble", this decision is made in the context of the knowledge that the only other option is death.

4. World and identity

Recall that transformative experiences are *personally* transformative, meaning, they transform your identity. To motivate my account, I ought to first clarify the way in which one's identity is constrained by the experiential world that one inhabits. I broadly adopt the notion of practical identity as put forward by Christine Korsgaard (2009). For Korsgaard, a practical identity is a description under which one values oneself. Conceptions of practical identity can include a mixture of one's projects, concerns, values and commitments such as ethnic or religious groups, professions, sex or gender, or relationship roles such as partner or parent. As well as our projects, concerns and values coming to shape our practical identities, our practical identities also shape what actions appear salient or worth doing:

> Our conceptions of our practical identity govern our choice of actions, for to value yourself in a certain role or under a certain description is at the same time to find it worthwhile to do

[44] I owe thanks to Havi Carel for making the striking connection between Nancy's essay and the transformative experience debate in her talk at the Northern Network for Medical Humanities Congress in Sheffield in 2020.

> certain acts for the sake of certain ends, and impossible, even unthinkable, to do others. (Korsgaard, 2009, p.20)

Here, then, practical identity is constructed and maintained by action. A person might conceive of their practical identity in terms of their role as a loving parent, a musician, or as a person who is very health-conscious, and as such is drawn to certain actions and repelled from others. For instance, if it is integral to H's practical identity that she is timely and reliable, she will find it unthinkable to fail to let her inbox go unchecked for days on end; conversely, she will be drawn to certain tasks that appear to her as ways of honouring that identity, such as making sure that she keeps an eye on the time when she is on her way to meet a friend or attend a meeting.

Recall that existing accounts of transformative experience require a transformation of values. Adopting a new set of practical concerns, values, projects and dispositions constitutes a changed canvas against which one engages with the world: certain projects which would once have failed to appear salient now attract attention and are experienced as enticing. Conversely, values and projects which once structured somebody's life might cease to appear salient, instead replaced with new ones. If H undergoes a transformative experience, say, as a consequence of taking psychedelic drugs, she might cease to care about attending meetings precisely on time in favour of taking her time and feeling unhurried; her values and commitments have changed, and so have her behaviours accordingly. In this sense her world has transformed. A transformative experience transforms one's world, that which constitutes the backdrop against which certain affective states, attitudes, dispositions, and projects are experienced as possible or impossible (see Chapter 1).

It is important to acknowledge that what you do is constrained by what it is *possible* for you to do, and that what it is possible for you to do depends upon your capacities and the circumstances of the world that you act within. For instance, a practical identity that involves being a loving parent is only possible when acting as a loving parent to a child is supported by the world one inhabits. A practical identity that involves being an athlete is only possible where one has the capacity to train. How do we understand, then, cases in which one's practical identity is at odds with the world one inhabits? This brings me on to my primary focus for the chapter, namely that not all transformative experiences involve adjustment to a new world and practical identity, but instead, can leave one's practical identity confused, divided or otherwise compromised.

In what follows, I will focus on CFS/ME in order to illustrate various under-appreciated structures that experiences can take — experiences which I think ought to still be classed as transformative. Much of this analysis might apply to other chronic illnesses; as Toombs writes, "illness is not just a threat to the body, but is also a threat to the self in seeing oneself as "less of a person"" (1987, p.23). I suggest that other similarly-structured experiences might be found in cases of serious injury such as a limb amputation, neurological disorders such as Multiple Sclerosis or Spinal Cord Injury, or various forms of grief and trauma.

Existing accounts of transformative experience assume a structure of a neat and tidy transformation. One previously inhabited world A, and a transformative experience carries one to world B, voluntarily or otherwise. It is plausible that this "A to B" structure is indeed the structure that some paradigm cases take. An experience which triggers an abrupt and

deeply-felt appreciation of the hardships of a particular marginalised group W might be one such example. Here, various aspects of one's previous practical identity might be replaced: an easy-going attitude to crude pub humour at the expense of group W might suddenly fail to tickle you, a laissez-faire attitude instead replaced with a desire to educate or challenge. You might then dedicate your time to a set of new projects in support of group W instead, and describe yourself in terms of being committed to W's liberation. A different set of possibilities for action are now made salient.

Experiencing the world as one full of possibilities for action for is tightly bound up with one's practical identity. Recall that on Korsgaard's notion of practical identity, to value yourself in a certain role, or under a certain description, is to find it worthwhile to do certain things for the sake of certain ends. What follows when what the world offers has radically changed against one's will? When one remains committed to the actualisation of valued projects X, Y, and Z, but changes in circumstance mean that one cannot stably maintain a sense that those hopes for the future might be actualised, this poses a challenge to practical identity. How can I act with certain worthwhile projects in mind, when I no longer know which possibilities the world incorporates? To lose a world which affords certain actions can involve experiencing a tension between the person one takes oneself to be, and one's current predicament. The world no longer allows one to maintain a particular conception of a practical identity that is nonetheless still valued and desired.

There are a number of different ways that this predicament can play out, and there are multiple things which can affect the outcome, such as the actual or expected timeline of the change, or the type of one's interpersonal support (see Chapter 3). In cases where the

change is understood as temporary, one need not revise their practical identity. A brief period of non-threatening illness or injury is a good example of this. If I fall ill with norovirus, there will be a period of time in which I am unable to act in particular ways that are congruous with my sense of practical identity. For instance, I will be unable to enjoy my hobbies, see my friends, or work on a paper. However, since I know this to be a temporary obstacle, I need not worry that my ability to commit to certain valued projects will be irretrievably compromised.

5. Between worlds

CFS/ME is a salient example of an experience where the temporal structure of the disruption is remarkably less clear. Where this is the case, one's sense of practical identity can be thrust into uncertainty. One might not be unable to trust with any great certainty that certain actions, which are in line with certain values and goals, will again one day be possible. Despite this, these projects might not be experienced as absolutely and irretrievably lost.[45] That one's old sense of identity really might be irretrievably lost may be experienced as a threat, yet the uncertainty functions as an obstacle to the adjustment to a

[45] Another particularly timely example of this sort of uncertainty is the Covid-19 pandemic. Recent journalistic and academic articles have suggested that people might be grieving non-death losses associated with "lockdowns" and other disturbances to normal life (Richardson, Ratcliffe, Millar & Byrne, 2021). The changes to how our lives are structured have involved cycles of restrictions, tightening and then relaxing and then tightening again, with little promise of the pandemic being near an end (or here to stay permanently). Qualitative research into experiences of the restrictions to ordinary life associated with the pandemic could show us some interesting things about whether and how this experience has affected people's sense of personal identity. One interesting hypothesis would be that where one's social interactions are dramatically restricted, one might come to experience a diminished or sense of self. We might also expect certain goals and projects to be perceived as unintelligible, since the world that ordinarily supports such goals and projects is so unstable. See Froese et al (2021) for some striking collaborative work of this type. Further theoretical and empirical research into this will be an important part of understanding and supporting those who have been adversely affected.

new system of hopes and meaningful projects, and correspondingly, the development of a new practical identity.

The notion of acceptance is interesting here. Where one struggles to accept that the change in one's circumstances is permanent, one might continue to understand oneself a certain way but recognise that one's actions can no longer honour that description. Here, what was expected, desired or hoped for oneself is drastically at odds with what one is currently faced with. As Nancy writes:

> This was always, more or less, the life of the infirm and the aged: but, precisely, I am neither one nor the other…Just as I no longer have an occupation, although I am not retired, so too I am nothing of what I am supposed to be (husband, father, grandfather, friend). (Nancy, 2000)

This type of in-between state is powerfully illustrated by reports of family members of people in vegetative and minimally conscious states (Kitzinger & Kitzinger, 2014). When interviewed, family members often took explicit positions about whether their relative is dead or alive, but stumbled over their words when trying to explain the situation, sometimes referring to the relative as dead and then correcting themselves, or speaking about their relative as dead and alive in the same sentence (p.256). This illustrates a tension between the recognition of propositional facts such as "this person is still alive" and the experiential world which is in conflict with that (Ratcliffe, 2019; 2022).

In such cases, one's life-structure has radically changed as a result of a loss which is somehow "incomplete". A range of projects, pastimes, habits and expectations which implicated that person are no longer possible, yet the lack of closure is an obstacle to

"moving on" and coming to build a new life-structure and a new practical identity. Here, one is stuck hovering between worlds A and B which each incorporate a vastly different system of salient projects, values and possible courses of action. Certain experiences of bereavement can also take this structure as part of the process of the death "sinking in", potentially due to the contexts of the death(s) (Ratcliffe & Byrne, 2022).[46] This is powerfully illustrated by the memoir *Wave* by Sonali Deraniyagala, who lost her parents, her husband and both of her children in the 2004 Boxing Day tsunami:

> I trip up constantly, between this life and that.
>
> Their promise, my children's possibilities, still linger in our home.
>
> (Deraniyagala, 2013)

Here there is a clear tension involved in existing between worlds, where one is suspended between different lives, and with it, between different practical identities. Being a parent, for instance, involves commitment to a range of projects and values, shaping the way that one navigates the world. A parent bereaved of their children is forced to consider "Is "parent" still a description under which I value myself? How could it possibly cease to be? If not, what else of myself crumbles?". Possibilities that cease to make sense in the context of the loss remain diffusely present despite recognition of what has changed.

It is thus not clear what of a person's practical identity from before has survived, now that one inhabits a radically different world, with a radically different system of affordances. It is as though emerging from a wreckage and being forced to consult what of you remains.

[46] Something similar is described in the "dual process model" of grief proposed by Stroebe and Schut (1999). Here one oscillates between the habitual world and the new world in which the loved one has died.

Recall that an important part of one's practical identity can be certain social roles which involve duties to and relationships with other people such as one's partner, one's children, one's friends, employer, or even strangers. In CFS/ME, one can lose one's ability to attend to and honour those roles, causing self-defining structures of meaning and purpose to be brought into question.[47] Some EFQ respondents describe something like this:

> It has left me feeling I don't know who I am. I used to be a doctor. I used to do lot for charity. I used to be a 'doer' and a 'giver'. (#13)

> I can't do things with my friends that I would like to; I can't go clubbing all night, go on days out shopping. I feel like I would be a lot closer with my friends if I could partake in all the activities. (#17)

These participants express a tension between what is desired and valued, and what is possible. One's identity is in one sense unchanged, in that what one values is preserved, but certain aspects of one's identity can no longer be "lived out" by action.

One might distinguish between (a) experiences where one is *chronically* stuck between worlds and (b) experiences which involve a longer-term adjustment to new habits, values, commitments and projects. The latter may involve a period of varying durations which resembles (a) however, it is plausible that experiences of type (b) involve this as a necessary part of the journey to properly assimilating to the transformation that one has gone

[47] This is also a striking theme in bereavement. As Deraniyagala writes: "What I did for my boys never stopped. Now I have to give that all up?" (p.43).

through. Some EFQ responses indicate the dynamism between experiences of type (a) and (b):

> There is still disparity between who I see myself as and my abilities, although this is starting to become more unified. (#6)

> I feel a little lost recently, trying to find a new version of me that I am content with and that is at peace with my illness and limitations - but I don't know if I will ever get there. (#24)

These responses indicate that there can be, at some level, acceptance of the requirement to assimilate to a new practical identity, coupled with an awareness that this process is protracted and difficult. Thinking back to my discussion of pathological grief in CFS/ME in Chapter 2, attending to how people can engage with this process might have important practical consequences for how we understand and treat responses to distressing upheaval, even if this does not allow us to distinguish tidily between "healthy" and "pathological" responses.

In the following section, I turn my focus to structures of experience whereby one attempts to resist the transformation that threatens to take place, and instead holds on to a particular practical identity despite the fact that the world one now finds oneself in is not hospitable to this identity.

6. Resisting a new world

Another under-appreciated structure that transformative experiences can take, involves the person "clinging on" to a world that offers things which are no longer possible. Here, a sense of another world to replace the previous one might be experienced as a possibility,

but a threatening one which is to be resisted. Here, one is not "working through" a period of adjusting to a changed world or adopting a new identity as above, but is instead actively trying to preserve the world and the identity which threatens to be lost.[48] One is not hovering between worlds A and B, but is clinging to world A in the face of something which threatens it.

People with CFS/ME are, I suggest, particularly vulnerable to experiences of this structure. There are a number of reasons for this, including but not limited to the fact that CFS/ME considerably fluctuates over time. As discussed in Chapter 3, one of the hall-mark symptoms of CFS/ME, "post-exertional malaise" is incredibly unpredictable (Holtzman et al, 2019). On a "good day", one might be able to engage in activities that one enjoyed before becoming ill. As is the unpredictability of post-exertional malaise, one might suffer the consequences of doing so in the next few hours, days or even weeks; alternatively, one might get away with it.

Where one doesn't get away with it, this behaviour is discussed in the context of "boom and bust" cycles which lead to further disability in CFS/ME. Interestingly, one study found that of a sample of people with CFS/ME, those who were classed as engaging in "boom and bust" behaviour were significantly younger than those that were classed as "indeterminate"

[48] One might distinguish between (a) a failure to accept a change, coupled with a failure to adjust one's life accordingly and (b) fondly remembering the past in a way that might serve various regulatory roles. It is likely that there is a grey area between (a) and (b). Recent work on "continuing bonds" in grief is relevant here. For instance, some research suggests that more externalised expressions of continuing bonds were more so associated with complicated grief than internalised expressions, where the latter might be understood as part of a healthy process of growth (Field & Filanosky, 2010; Scholtes & Browne, 2015; Klass & Steffen, 2018).

(King et al, 2020). It is plausible that youth is a risk factor for transformative experiences of this structure in CFS/ME, given the sense of invincibility that can come with youth as well as expectations about lifestyle and physical ability which young people are exposed to.[49]

In transformative experiences of this type, one remains committed to the identity that one had prior to becoming ill, despite the fact that it threatens to be no longer sustainable. People are faced with an incredibly difficult predicament here, since recovery and a "return to normal" might still be considered possible, if unlikely. Despite the fact that one has undergone radical upheaval, self and world as it was known before becoming ill may not be experienced as irrevocably gone. This provides room for resistance against a narrower, bleaker world which threatens to take its place.

As well as factors relating to the symptoms of CFS/ME, there is a related epistemic predicament which disposes people towards experiences of this structure. There are many dissenting voices about the most appropriate way to treat and cope with CFS/ME. Subsequently, people can experience conflicting advice from others about how to handle their condition, in particular, whether to "give in" to it or not. This is picked up on by one EFQ participant:[50]

> I think there are better / worse ways to respond (both your own response to being ill and the response you get from others), but it is very individual and even then can change with

[49] If this is right, it would likely be true for other illnesses too. An interpretive phenomenological analysis (IPA) of young people with thyroid cancer found that a key theme was a "loss of youthful immunity" and a "shift in life perspective" (Smith et al, 2018).

[50] See Jackson (2017) for a discussion about a similar predicament in depression, where people find it difficult to arbitrate between different voices such that it is unclear how to live a fulfilling life.

> time. I think it is important to feel accepted and empowered to function as best we can, but how to get there isn't always straight forward. (#13)

Some people with CFS/ME are exposed to both perspectives which insist that assuming one's illness to be permanent is bad for recovery, and on the other hand, perspectives which insist that accepting that one faces a life-long challenge is an essential part of learning how to manage the condition and live well again. People with CFS/ME themselves can take different views on the matter. In the EFQ, a variety of attitudes were endorsed by participants:

> The only thing there seems to be is patience and truly giving into it. I think you need to straight away appreciate/be realistic that you will live with it for the rest of your life but what you can do is learn how to manage it and prevent a "crash". (#9)

> In terms of how to conduct yourself in the world, you should be aiming for - at all costs - to keep everything to how it was. Otherwise the world will wash you up and you will fall far behind. I'm not saying that it's not incredibly difficult but either way you will suffer. Either suffer at home unemployed or suffer more at work but at least you're making some sort of difference to the world. (#16)

The second of these responses might be understood as a resistance case. In such a case, the world that one finds oneself in no longer offers what it did before, and engaging with the world as one did before is no longer possible. Despite this, one remains committed to certain projects insofar as one remains committed to the world that existed before the change. Even though it will be replete with suffering, at least this world offers *something;* the other option is too bleak to entertain. The same participant writes:

> I have never made a choice based on CFS […] I do not factor in CFS when considering my future, I just put up with the suffering regardless. [...] I do not want to wash away because of something out of my control. (#16)

We might understand cases like this as an attempt to *avoid* a transformative experience. After all, an experience of this type might fail to satisfy the conditions originally associated with transformative experiences such as a transformation of personal values. Nonetheless, it seems right to attend to experiences which take this structure since they involve drastic upheaval in the sense that is relevant to the crux of the transformative experience literature.

The language of "washing away" is striking here. This is suggestive of a desire to remain part of a *shared* world, a world which will carry on with or without you. The alternative is to enter into a narrow, solitary world in which one's capacity to act and make meaningful differences to the world, and everything and everyone in it, is restricted.

7. Shrunken world

The final structure of transformative experience I will focus on here is shrinking cases, where people have been resigned to this narrower world, and that this is felt painfully. Plausibly, this is the type of existential shift that people whose experience takes the "resistance" structure are trying to avoid. Yet, these experiences might be closer in structure than one might think: in being imprisoned by a commitment to the old self and old world, one is unable to inhabit or even entertain a new, different world which might offer vastly different possibilities for positive change. In a steadfast commitment to the old world, the alternative is unthinkable. Plausibly, then, if resistance becomes increasingly

untenable, one might come to experience the world as having shrunk (hopefully impermanently).[51]

Not all transformative experiences which do not take the paradigm "A to B" structure need involve various forms of being *between* A and B. Rather, some transformative experiences involve the shrinking of one's world coupled with a lack of a sense of the possible which is required for even the initial stages of the construction of a new world. Here, the old world, and the old self, is experienced as irrevocably gone and nothing promises to replace what is lost. Consider Robert Stolorow's description of how emotional trauma can involve a destruction of certain "absolutisms":

> When a person says to a friend, "I'll see you later" or a parent says to a child at bedtime, "I'll see you in the morning," these are statements whose validity is not open for discussion. Such absolutisms are the basis for a kind of naïve realism and optimism that allow one to function in the world, experienced as stable and predictable. It is in the essence of emotional trauma that it shatters these absolutisms, a catastrophic loss of innocence that permanently alters one's sense of being-in-the-world. Massive deconstruction of the absolutisms of everyday life exposes the inescapable contingency of existence on a universe that is random and unpredictable and in which no safety or continuity of being can be assured. (Stolorow, 2007, p. 16)

[51] I would imagine that there are a range of different experiences which might go through similarly structured processes. A qualitative analysis of women's experiences of domestic violence identified four phases which are strikingly compatible with this suggestion (Kearney, 2001). The first phase involved women discounting violence in favour of commitment, followed by demoralisation and affected sense of self, then an acknowledgement that the situation as untenable, and eventually working towards a new life.

In "between worlds" cases, one is extricated from world A, recognises that one must move towards world B, yet is unable to stably habituate it. This predicament, however, is devoid of the sense of potential for positive change, coupled with a sense that no new project could ever be sustainable.[52] This profound loss of access to the possibility of meaningful change can be experienced as "futurelessness".

Here, one's practical identity is experienced as compromised along with the world which has shrunk so significantly as to eclipse all possible projects, goals, commitments and values. Some EFQ responses are illustrative of this type of experience:

> I used to be so active and cheerful, now socializing can be a struggle, sports are a no go and no I see myself as broken. (#14)

> There is nothing left of my old self. No work, sport, social contacts etc. (#23)

These responses illustrate how the acts one engages in are implicated in one's practical identity such that no longer being able to do those acts is experienced as a loss or destruction of that identity; one is left "broken". The notion of "futurelessness" conveys how experiences which take this structure threaten imagined future projects, as well as destroying the "old self". Consider the following EFQ responses:

> If this is all I am able capable of then it really isn't a future. (#8)

[52] See Ratcliffe (2019b) for a discussion of something similar in depression.

> I'm scared I'll have to drop out of college, will never make it university, will never be able to have a proper job that I love, not being able to have a social life, not be able to move out, not be able to live 'normally' again. (#14)

> I was very limited in what I could do so lost a lot of potential. (#18)

These responses describe a loss of not just pastimes, but also a loss of that which was anticipated, expected, and hoped for in one's, sometimes distant, future. One's practical identity does not just include past and current projects, commitments and values, but also has scope over the future that is to be expected for oneself, such as to have a career committed to helping others or which depends upon cognitive sharpness.[53]

CFS/ME, much like other chronic illnesses with similarly opaque trajectories, is a poignant example of an experience which can eliminate one's previous sense of the future, making it difficult to envisage anything to take its place. The unpredictable rollercoaster of symptoms and relapses is also important here. There may be periods in which one's condition might have temporarily stabilised to the point where one might *almost* have a grip on a new set of possibilities, only for these to show themselves to be untenable once another relapse or additional debilitating symptom arises. This throws one back into a world devoid of future possibilities for positive change. The following EFQ response illustrates this powerfully:

> Just as you begin to think you might be moving forward and to be able to see some kind of life being possible, some other thing comes in and throws you right off course and forces

[53] It is also interesting how the future that others expect of a person might be relevant in shaping their experience. Carel, Kidd and Pettigrew (2016) have discussed how the notion of illness as transformative experience might be used as a springboard to discuss the happiness that might be found in "off-script" futures.

> you back into living from day to day again and making few if any plans more than a day or two ahead. (#25)

Again, we should distinguish between the shrinking of one's world which subsequently involves (a) a long-term process of re-establishing a system of values, goals, projects and possibilities and (b) a chronic loss of access to types of possibilities required for the formation of any such replacing system. Discussing the latter type (b) in the context of depression, Ratcliffe has argued that a series of disappointments can result in a restriction of one's world such that the future does not offer the possibility of positive change or support the maintenance of stable expectations (2015, p.151).

Plausibly, something like this can take place in CFS/ME where one's condition involves unpredictable relapses and frustrated attempts at re-orientation.[54] Indeed, empirical work suggests that people with CFS/ME generally experience a bigger hit to their quality of life than those with other chronic illnesses (Taylor et al, 2017; Loades et al, 2019). Some people with CFS/ME continue to experience the world as hostile and devoid of possibilities:

> I used to see the world as something I wanted to explore and something really exciting and now I see the world as a constant barrier and I am constantly seeing things I am unable to do or achieve rather than seeing the positive. (#11)

[54] As with the distinctions I made between processes of adjusting to loss in Chapter 2, we should expect to find it difficult to make sharp distinctions between these types of experience in practice, but the distinction may nevertheless be instrumental in therapeutic contexts.

> My world has shrunk - before the world was my oyster, full of light and colour, opportunity and laughter. Now I live in a dark room, unable to leave my bed. It feels like I am tethered and incarcerated by invisible chains in a barren prison cell. (#13)

These responses are suggestive of a restricted world which does not hold any sense of possible future adjustment to a new system of possibilities, values and commitments. The powerful description of being incarcerated in a prison cell strikingly communicates an experience of inescapability, where there is no sense that the current predicament is something that could ever be adjusted to or escaped from. What hopes, commitments, projects and expectations could possibly be formed in the context of such a world?[55]

Ratcliffe has argued that expressions of futurelessness can generally be distinguished from a sense of a future which does not incorporate the possibility for *any* kind of positive change. Where the former can be a typical, and temporary, experience when one has undergone drastic upheaval, the latter is typical of experiences of depression. He writes:

> There is a difference between inhabiting a world where the future offers no prospect of significant change (or no prospect of positive change, at least) and feeling "lost", insofar as the future is no longer experienced in the light of a specific system of projects. (Ratcliffe, 2019b, p.543)

[55] Bereavement can also take this structure. In the context of the loss of a child, one can lose the future imagined for oneself as indefinitely committed to the role of parent for that child, leaving one with a sense that there is nothing to be done, and nowhere to go next. In the context of the death of her son, Denise Riley powerfully wrote in *Time Lived, Without its Flow*: "His sudden death has dropped like a guillotine blade to slice through my old expectation that my days would stream onwards into my coming life…this cut through any usual feeling of chronology leaves a great blankness ahead. (2019, p. 31)

In Susan Brison's *Aftermath*, she describes a process of rebuilding after violent sexual assault which, in its early stages, is suggestive of a "blankness ahead", where the future that lies ahead is entirely unrecognisable: "Although I had always been career-oriented, always planning for my future, I could no longer imagine how I would get through each day, let alone what I might be doing in a year's time" (Brison, 2002, p.15). The following quote illustrates a recognition that what was lost was a *system* of possibilities, however wide-raging that system was:

> I protested that I had lost so much: my security, my self-esteem, my love, and my work. I had been happy with the way things were. How could they ever be better now? [...] I have had to give up more than I would ever have chosen to. But I have gained important skills and insights. (2002, p.20)

It is important to recognise that, even if this takes time, some with people with CFS/ME *do* re-establish such systems, and do eventually re-orientate themselves in a world in which various things appear salient, enticing, and worth doing. Chronic illness of all forms typically involves significant distress; however, some have suggested that there is a human disposition to adjust to changed circumstances (Haidt, 2006).

Carel writes that learning to live well with the facts of one's situation requires having an understanding of those facts. Developing this understanding, Carel writes, can lead to flourishing in unexpected ways (2016, p.142). Carel quotes from a Multiple Sclerosis patient who described previous abilities as "no longer within the sphere of possibility and are therefore not missed as though they were possible" (Schneider, 1998, p.71). Carel's reflection upon her own experience of illness is similar:

> Within a year my physical habits were entirely different. Whereas in the first months my body would attempt a brisk pace, hurrying up stairs, physical impatience, these movements have been erased from my bodily repertoire […] a new way of negotiating the world was incorporated into my physicality. (Carel, 2013, p.36)

Given time, some people with CFS/ME do adjust to a new world in which one can flourish. Consider the following EFQ response:

> Initially my world shrank enormously, but I found even in the early days that I was able to reinvent myself by discovering things I COULD do - specifically watercolour painting in which I became a pretty proficient amateur, selling prints & greeting cards as well as originals, several of those commissions. This became the "silver lining in the cloud" for me, just 2 years into the illness […] In the early days, it felt like the world had simply become an environment in which I couldn't cope. Increasingly, over the years, I have realised that, like the rest of the human race, I have my own abilities and limitations & need to apply these to living within systems & picking & choosing according to my abilities rather than my wishes. Having grand ambitions has been taken away from me. Appreciate the simple things in life. (#19)

This participant describes a process of, after having come to terms with their illness, adjusting to a new system of possibilities, commitments and projects. This involves the development of new expectations for the future: there is an acceptance that previously held "grand ambitions" are now no longer possible, but these previously held grand ambitions can be replaced with desires for other, "simpler" things.[56]

[56] Talking of sickness more generally, van den Berg describes a similar process of developing an interest in new, simpler projects once there has been acceptance that things will not be like they were before:

As I have mentioned throughout this chapter, it is important to recognise that the structure of one's experience does not always stably progress over time. In fact, it is plausible that any given token experience which involves significant upheaval will involve a chronic loss of access to types of possibilities required for the formation of any such replacing system, at least in its initial stages. It is also likely that in many cases, a felt violent restriction of one's world and identity will often precede the experience of being "between worlds" described earlier in this chapter, since experiencing a tension between worlds A and B is dependent upon having recognised B, which itself takes time and (often) help from others.[57]

Related to this, various external factors can influence whether and when somebody re-establishes a new system of values, goals, projects and possibilities. Some of these factors are particularly relevant for an experience of CFS/ME. I discussed the effect of experiencing unpredictable periods of post-exertional malaise and recurrent cycles of remission and relapse, as well as the epistemic predicament faced by people with CFS/ME who are exposed to conflicting views and pressures from others about which world they ought to be assimilating to.

"The patient who does not stubbornly cling to the memory of his healthy days discovers a new life of a surprising intensity. He becomes sensitive to little things. The healthy person is usually so much occupied by important matter of career, learning, esteem, and money that he is inclined to forget the little things." (van den Berg, 1966).

[57] One could even argue that such experience seems to appropriately reflect especially tragic circumstances, such as Deraniyagala's, and that in fact, smooth adjustment to a new world would be more indicative of pathology than the alternative. It might be, then, that experiencing such paralysis seems appropriate, at least in some cases.

8. Conclusion

In this chapter, I have sketched three under-appreciated types of structure that transformative experiences can take, illustrating the ways in which people with CFS/ME can experience each of these in turn. I first discussed "between worlds" cases, where one is stuck in limbo between two worlds and two identities, neither of which one currently feels at home in. I then discussed "resistance" cases in which one attempts to resist assimilation to a new world and identity in favour of preserving the original, despite the fact it is no longer sustainable. Third, I discussed "shrunken world" cases in which the old world and one's old identity is destroyed, leaving nothing left.

As well as CFS/ME, I have suggested that other experiences can involve similar existential shifts, such as depression, grief and trauma. It is highly likely that other experiences which I have not discussed here can take any of the structures I have outlined. It is plausible that interpersonal factors such as social support and subjection to stigma, are just as instrumental in affecting the trajectory of the existential shift as the experience itself. Indeed, Elizabeth Barnes claims that whether and how an experience is transformative is contingent on what sort of person you are, and on your social environment and circumstances, that is, "features external to the experience itself" (Barnes, 2015).

How difficult it is to adjust to the changes in one's bodily capacities will surely in part depend on external factors such as societal and interpersonal expectations, and the relationship with one's body, and the world, before the change. For instance, earlier I mentioned empirical work which found that of a sample of people with CFS/ME, those who engaged in "boom and bust" activity cycles were much younger. I suggested that this might,

in part, be a product of how young people experience their relationship with their bodies and the world as holding limitless possibilities for action.

Better understanding the various different forms that transformative experiences can take provides a framework for understanding the existential pressure that people with CFS/ME face. This is a significant philosophical contribution, but it also better equips us for creative engagement with therapeutic approaches to CFS/ME.

In what follows, I want to say more about how social and political dynamics can affect the experiences of people with CFS/ME. This brings me to Chapter 5, in which I take a closer look at how the testimony of people with CFS/ME is handled in the clinical encounter, and how this can affect patient experience.

Chapter Five: Epistemic Injustice[58]

1. Introduction

In this chapter, I show that tensions arise between attempts to protect against committing epistemic injustice in CFS/ME, and taking steps to understand the complexity of the patient's predicament. Accordingly, a balance must be struck between attributing appropriate degrees of respect and epistemic authority to both patients and medical professionals. Where this fails, it can undermine the epistemic status of the dominant group such that it restricts epistemic resources that may benefit patients. When attempting to address epistemic oppression, one need take care to avoid perpetuating it in the process (Dotson, 2012).

Therefore, I suggest that work on epistemic injustice in CFS/ME is at risk of obfuscating legitimate and potentially fruitful inquiry. As well as CFS/ME, I suggest that the key problems identified could apply to other cases within healthcare, such as Medically Unexplained Illnesses, Functional Neurological Disorders, Psychiatric Disorders and, as discussed in Chapter 6, the newly-emergent "Long Covid". Future work on epistemic injustice in healthcare must recognise and attend to this tension to protect against unsatisfactory attempts to correct epistemic injustice.

2. Epistemic Injustice in healthcare

Miranda Fricker's influential concept of epistemic injustice (2007) has seen application to many areas of philosophical interest including healthcare (Kidd et al, 2017). In what follows,

[58] An article closely based on this chapter has been published (see Byrne 2020).

I will focus on pathocentric epistemic injustices, that is, those that target ill persons (Kidd & Carel, 2018).

At its broadest, an epistemic injustice occurs when someone is harmed specifically in their capacity as a knower. Testimonial injustice, a particular form of epistemic injustice, occurs when a speaker is unfairly attributed a lower level of credibility than they reasonably deserve because of the speaker's membership of a certain negatively stereotyped group.[59] Here the speaker's testimony might be unfairly dismissed, excluded or seen as less valuable than it would otherwise be, on group membership grounds alone. As Fricker writes, "a speaker suffers testimonial injustice just if prejudice on the hearer's part causes him to give the speaker less credibility than he would otherwise have given" (Fricker, 2007).

Hermeneutic injustice, another form of epistemic injustice, is a structural problem that arises as a result of a collective shortfall in conceptual resources. In other words, hermeneutical injustice arises when a group of people struggle to understand their experience because of some inadequacy in the resources that are required to understand them. This conceptual deficiency results in the marginalisation of the group in question (Fricker, 2007, p. 153). A relevant example from a different context is the concept of marital rape. That the concept of marital rape was not formally recognised until the 1990s meant that the women who suffered it at the time were without resources to both privately understand their experience, but also to communicate it to others.

[59] Fricker later distinguished between *discriminatory* and *distributive* epistemic injustice (2013). David Coady has since compellingly argued that all forms of epistemic injustice can be understood and treated as *distributive injustice* (2017).

Such hermeneutic resources might be considered inadequate if they simply do not exist, if the resources do exist but are inaccessible to those who would benefit from them, and if the resources do exist and are accessible to the vulnerable group but lack uptake. Hermeneutic injustice does not only affect the marginalised group in question, but it also negatively affects the hermeneutically unjust group since this lack in resources results in a collective inadequacy of understanding.

Fricker has suggested that in such cases, both parties can be said to suffer from "cognitive disablement", but what is crucial for epistemic injustice, is that the victim is also cognitively *disadvantaged* because they are prevented from understanding their own experience (Fricker, 2007, p.151). Fricker has argued that this cognitive disablement prevents the victim of the injustice from understanding "a patch of experience which it is strongly in her interests to understand, for without that understanding she is left troubled, confused, and isolated" (ibid).

Kidd and Carel (2014) have suggested that Fricker's framework can help us to understand and articulate some of the epistemic harms experienced by ill persons. They argue that while the patient-clinician relationship is not inevitably unjust, it is structured in a way that makes certain pathocentric epistemic injustices likely to occur (p. 530). The authors cite such epistemic injustices as one probable cause for patient dissatisfaction, since a disregard of the patient's perspective on some matter relating to their own experience of illness is often detrimental to patient well-being, serving to undermine and deter further patient engagement with medical professionals (p.531).

Kidd and Carel argue that ill persons are especially vulnerable to testimonial injustice because there is often a presumptive attribution of certain characteristics to ill persons that negatively affects the perceived credibility of their testimony, such as cognitive unreliability and emotional instability. Accordingly, patient testimonies can be dismissed as irrelevant, confused, too emotional or too time-consuming (pp.529-30).

Where there is testimonial *justice* in healthcare, so they argue, patient testimonies would be recognised, actively sought out, and judged to be, at least in certain respects, epistemically authoritative (p.532). The authors state that medical professionals have epistemic authority over some matters, but that the same applies to patients, yet the various structures of medical institutions are such that the epistemic authority of the patients is often not accommodated. Kidd and Carel acknowledge occasions whereby the medical professional would be right to exercise epistemic authority, but maintain that in such cases, the clinician can often be overly dismissive (p.531). They also argue that ill persons are especially vulnerable to hermeneutic injustice because experiences of illness are often difficult to understand and communicate due to inadequately developed or respected hermeneutic resources (p.529).

Another feature of testimonial *justice* would be that the clinician would recognise that their failing to make sense of the patient's experience is not due to any fault of the patient. An appropriately just clinician, they suggest, might recognise "the fact that I don't understand you isn't your fault but mine […] I am untrained in the kind of articulacy you are using, and this hermeneutical context does not provide me with those resources" (p.532). Where there is hermeneutic *injustice*, then, testimony is not dismissed or disbelieved outright, but

the conceptual impoverishment of a particular institution, or in a particular context, prevents the patient's articulation of their illness-experience from being acknowledged and/or shaping clinical practice. Consequently, patients' attempts to articulate their experience are often not adequately recognised by medical professionals. In this respect, the two injustices are closely linked and work to sustain one another.

Kidd and Carel mention CFS/ME as a case in which an unfairly low degree of credibility is often attributed to patients. They write that many physicians do not recognise CFS/ME, and instead consider it a psychiatric, as opposed to a somatic, illness (p.532). Because of this contested nosological status, patient reports of distinctively bodily symptoms can be dismissed and explained away under different interpretations. Such an interpretation might be that the patient is suffering from a psychiatric disorder, or that in extreme cases where children are affected, that the children are suffering from abuse by their guardians. This has been documented as being traumatic for some when the interpretation of the medical professionals, the group with epistemic authority, is in tension with the considerably more vulnerable patient's own understanding of their illness.

Blease et al (2017) have since offered a complementary and fuller analysis of epistemic injustice in CFS/ME. The authors cash out both forms of epistemic injustice as follows, citing them as reasons for patient dissatisfaction. They write that when patients are victim to testimonial injustice, they experience implicit and explicit negative stereotyping leading to the downgrading of patient reports on their condition (p.551). A relevant negative stereotype about patients with CFS/ME might be an assumption that they have a particular

kind of personality. In such contexts, it is suggested or assumed that this type of personality is causally related to the manifestation of the illness.

In a study by Raine et al (2004), one GP described "a certain personality trait that is chronic fatigue waiting to happen", while another GP stated preference for treating patients with Irritable Bowel Syndrome over patients with CFS/ME because such patients are not as "heartsinky", which is a term used by GPs to describe patients who "exasperate, defeat and overwhelm their doctors by their behaviour" (O'Dowd, 1988). Another negative stereotype might be that patients who self-conceive as having CFS/ME are untrustworthy and therefore incredible. Patients can be denied credibility because of doubts about the legitimacy of CFS/ME, which easily bleed into doubts about the patient. As Blease et al write, "uncertainty about the condition translates into uncertainty about its sufferers" (2017, p. 550).

It is also argued by Blease et al (2017) that hermeneutic injustice affects CFS/ME patients because the conceptual impoverishment about CFS/ME is responsible for the lack of framework within which patients and medical professionals can make sense of the condition. Conceptual resources may be absent or contested, and consequently, the experiences of patients may not be recognised as pointing towards warranting a diagnosis of CFS/ME (p.553). Patients may present similarly to patients with depression, for example, and a lack of conceptual resources for distinguishing CFS/ME from depression might shift doctors towards interpreting the patient's experience in a particular way which may be at odds with the preferred interpretation of the patient.

Blease et al (2017) highlighted that testimonial injustice in CFS/ME is sustained and also accompanied by hermeneutic injustice, since healthcare professionals (the epistemically and practically authoritative group) fail to provide the appropriate training about CFS/ME to trainee physicians. This, they argue, facilitates 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" (p.555). Accordingly, the authors have highlighted a concerning degree of scepticism amongst some trainee medical professionals about the "reality" of CFS/ME (p.554).

Doubts about the reality of the condition can be understood as suspicions about whether or not what is understood as CFS/ME is deserving of a legitimate medical classification of its own, either supposing that the predicament of the patient is either better suited to another diagnosis, or not worthy of a diagnosis at all. Views of the former kind might be that the cluster of symptoms that is recognised as CFS/ME might be better attributed to other existing conditions which tend to be psychiatric, namely depression. On this view, CFS/ME represents no meaningful "kind" of its own, and supposed CFS/ME patients are already accounted for by existing recognised conditions.

Recall my discussion of Kusch's concept of "linguistic despair" in Chapter 1. Here, people with CFS/ME face the challenge of explaining their experience of fatigue (besides much else) in a way such that it can be understood and comprehended by others, but which is also sufficiently distanced from everyday uses of terms like "tired" and "fatigued" so that others do not under-appreciate the pervasiveness of the symptoms. A failure of others to understand that the experience of patients is drastically different from experiences of

everyday fatigue is common. There is an extent to which this problem is shared with a vast array of experiences of suffering (bodily or otherwise) when people attempt to describe their experiences. For example, the patient with endometriosis faces the challenge of describing her abdominal pain in such a way that can be understood, but which also distances her experience from "normal" cramping which afflicts the majority of females who menstruate.[60]

This failure to appreciate the illness experience in CFS/ME appears to be common to both lay-people *and* medical professionals. A study of student opinions by Stenhoff et al (2015) found that a significant number of trainee physicians expressed negative attitudes about CFS/ME, understanding it as mere "tiredness". Blease et al (2017) identified these attitudes as involving negative stereotyping of patients, and argued that this group are at a high risk of perpetuating testimonial injustices with their future patients, thus exacerbating hermeneutical gaps (p.555). This, they argue, highlights the need for medical training on CFS/ME and other medically unexplained conditions.

3. Appreciating conceptual impoverishment

I argue that there is a need for caution in attributing testimonial injustice to particular concerns expressed by medical professionals dealing with CFS/ME. Over-liberally explaining practitioners' behaviour in terms of negative stereotyping of patients, I suggest, risks failing

[60] People with endometriosis certainly can and do experience epistemic injustice both in wider society and in clinical contexts. It would be interesting to read a fuller analysis of the particular epistemic challenges it poses. Polycystic Ovarian Syndrome (PCOS) is a related condition which I discuss in Chapter 6. I would expect an analysis of these conditions to reveal some shared and some distinct features with related epistemic challenges.

to recognise the pervasiveness of the conceptual impoverishment of CFS/ME, thus potentially hermeneutically disabling patients. Ironically, such negative stereotyping of medical practitioners' behaviour would amount to a form of epistemic injustice directed at medical practitioners themselves. Chew-Graham et al (2010) surveyed GPs' attitudes towards making a diagnosis of CFS/ME, and the subsequent management of patients in primary care. Some GPs responded:

> Some people like a label, some people like to know what's causing their symptoms whether it's the truth or not and some people are looking for a label to attach to their symptoms. (GP17)
>
> Once you start labelling a patient if you're not careful you might have a self-fulfilling prophecy. (GP15)
>
> At a superficial level it's empowering because it gives them control over their life and their work, but at a deeper level it prevents them from engaging fully with the existential conditions of their life which is what they can't cope with. (GP18)
>
> I try to avoid it because once you give them the label you're actually setting them off on a track which will get them nowhere. (GP14)
>
> (Chew-Graham et al, 2010)

Blease et al (2017) reference the response from GP15 to demonstrate that some GPs believe that a diagnosis of CFS/ME is inherently problematic, and frame this to be indicative of negative stereotyping of patients and the related suspicions about the legitimacy of CFS/ME as a genuine illness classification. As well as documenting GPs' reluctance to diagnose CFS/ME, Blease et al (2017) also comment that the responses in the study show

that some GPs queried the value of referral as unnecessary or even harmful. Some GPs have indeed commented on the value of referral:

> Well, I don't think there is anyone to refer to. The specialist clinic is a waste of time; they just hold their hands up, "what can we do? Why, what are they sending this to us for?" (GP14)

Ultimately, these GP transcripts were taken to illustrate the prevalence of testimonial injustice insofar as they are indicative of patient testimonies not being acted on decisively as a result of disbelief about the condition, and so of the patient. I suggest, however, that it is not clear that this is the only plausible way to interpret these responses, nor is it clear that it is the best candidate explanation.

I suggest that to frame these responses as plain evidence of negative stereotyping is too quick, and demonstrates a failure to properly appreciate the complexities of CFS/ME. It is certainly true that people with CFS/ME *are* vulnerable to negative stereotyping, and that this can have a negative effect on how their testimony is assessed. However, at least some of the GP responses which have and may be continued to be identified as indicative of testimonial injustice, instead demonstrate sensitivity to legitimate and potentially fruitful paths of inquiry, and as such should not be conceived of as evidence of negative stereotyping. Recognising this highlights the need to acknowledge the complexity and heterogeneity of the condition. There exists a need to better scrutinise the conceptual problems surrounding the condition, and to better develop resources which accommodate, rather than ignore, these complexities.

Consider one particular claim of testimonial injustice, that is, that delays in diagnosis are indicative of a reluctance to take patient complaints seriously (Blease et al, 2017, p.553). This is a good example of a case in which to find a perpetrator of testimonial injustice in the doctor who is slow to diagnose CFS/ME may not be appropriate. Moreover, to make such claims of negative stereotyping here might function as an obstacle to acknowledging the extent of the relevant conceptual and epistemic problems with CFS/ME. Since there are not yet any consistently informative bio-markers for CFS/ME, the condition is diagnosed by exclusion (see Chapter 1). Generally, this means that the process of diagnosis will tend to take as long as it takes to rule out all possible alternative diagnoses which can present similarly. Patients can therefore often go through months, if not years, of testing and examination before a diagnosis of CFS/ME seems appropriate. This points to epistemic problems with CFS/ME which it would be a moral and professional failure to under-appreciate.

What about the related problem of reluctance to diagnose? In this case, it is not just that medical professionals are slow to identify CFS/ME as the appropriate diagnosis, but that they are in some sense resistant to offer it. Here, the argument can be made that doctors are reluctant to take complaints expressed by a patient as suggestive of CFS/ME due to scepticism about whether or not it is a legitimate illness category. Doctors may therefore adopt the view that the patient's complaints are better understood as belonging to some other diagnosis, or without one entirely.

To take this as plain evidence for negative stereotyping is to make a similarly problematic jump, since it is not obvious that reluctance to diagnose necessarily indicates negative

stereotyping. Reluctance to diagnose certainly *could* be a consequence of negative stereotyping. However, in this instance, the GP responses quoted by Chew-Graham et al (2010) are not sufficiently revealing to confirm that this is the most appropriate explanation. We ought to better recognise other legitimate reasons for GPs' reluctance to diagnose CFS/ME that need not have involved negative stereotyping. For instance, reluctance to diagnose CFS/ME, *and* reluctance to refer patients to a specialist centre, can also be explained by a lack of compelling evidence that such diagnosis and referral tends to be beneficial for the patient, considering the lack of effective treatment resources for patients and the controversy that surrounds existing labels and treatment options, as suggested above by GP14.

Reluctance to diagnose could also be indicative of fear of misdiagnosing, which arises from uncertainty about CFS/ME given its conceptual impoverishment, as another response from this study suggests:

> If someone else saw them who I felt was a good physician and also came to the same diagnosis as me then I would feel more confident that we were right. (GP15)

Being able to understand one's experience through the lens of a diagnostic label can bring patients great relief. John Berger in *A Fortunate Man* describes some of this relief nicely:

> Patients are inordinately relieved when doctors give their complaint a name. The name may mean very little to them; they may understand nothing of what is signifies; but because it has a name, it has an independent existence from them. They can now struggle or complain against it. To have a complaint recognised, that is to say defined, limited and depersonalised, is to be made stronger. (Berger, 1967)

Receiving a diagnosis of a chronic, poorly-understood condition, however, can also be a source of distress, confirming that one's situation is radically life-changing and with uncertain chance of effective treatment and full recovery. To this extent, making a diagnosis is a matter of weighing up the pros and cons of making that diagnosis for the life of the patient. Huibers and Wessely (2006) offered a narrative synthesis of the literature on the effects of diagnosis for patients with CFS.[61] They found that patients with a CFS diagnosis had a worse prognosis than patients without. They discuss numerous factors which can be influential here one way or another. In favour of diagnosis, they acknowledge that finding a label that fits one's symptoms can bring relief and a sense of legitimacy free of stigma which can "bring an end to the unbearable burden of uncertainty" (p.897).

On the other hand, they note that a transformation into the role as patient can be disempowering, catalysing an "illness identity" which can be especially harmful where one is surrounded by narratives of unlikely recovery. Moreover, in particular, they draw on evidence which suggests that patients who meet the criteria for diagnosis in an early stage of illness would in fact fare better if diagnosis were postponed, because the diagnosis itself can precipitate chronicity which may otherwise have been avoided (p.899). Suggesting something similar, Candy et al (2003) found that at six months post Infectious Mononucleosis infection, persistent fatigue was associated with negative illness perceptions, especially the beliefs about how long the fatigue would take to recover from (p.852).

[61] The literature they survey includes ME patients as well as CFS patients, but the authors' preferred term is "CFS".

Huibers and Wessely (2006) also suggest that what is important is not necessarily the act of diagnosis, but the sense of being believed and understood. This is suggestive of the idea that there might be a way to offer patients much of what is positive about receiving a diagnosis of CFS, without rushing to make the diagnosis where clinicians are not confident (see Chapter 6). Clinical strategies they suggest for dealing with fatigued patients include acknowledging suffering without encouraging maladaptive illness beliefs, and empowering patients to take an active role in recovery without inducing any blame or guilt (p.899). They write, "there is a world of trust and constructive cooperation to be gained".

The response given by GP15, taken by Blease et al (2017, p.553) to be indicative of reluctance to accept CFS/ME as a "real clinical syndrome", could just as plausibly demonstrate sensitivity to the types of considerations raised by Huibers and Wessely about how a diagnosis of CFS/ME can shape experience and influence self-interpretation and behaviour in patients.

There is a considerable body of literature dedicated to exploring such dynamics in many cases of illness and more broadly. Consider Hacking's discussion of looping effects, where he argues that various groups of people, once classified, develop not only individual but also collective new patterns of behaviour (1999, p.112). Mental disorders, for example, once assembled as meaningful objects of discourse and practice, can have causal influences upon the experience and behaviour of those classified within that group (Weinberg, 1997, p.217). It is not clear that being conscious that a diagnosis of CFS/ME may put patients at risk of a "self-fulfilling prophecy" is indicative of negative stereotyping. Rather, it is consistent with a

wealth of medical and philosophical literature that demonstrates the influence of diagnosis on experience.

The aforementioned concern of GP17, that some patients want to know what is causing their symptoms "whether it's the truth or not", may demonstrate that a doctor is aware of the relief and liberation that a diagnosis can bring to a patient, *but also,* that since CFS/ME has highly heterogeneous aetiology, symptomatology and phenomenology between patients, what is currently understood about CFS/ME does not offer a clear causal story. Some patients may desire a label, and benefit from it in some of the ways outlined above, despite the fact that receiving the label does not illuminate their condition's cause.[62]

Moreover, GP18, who expressed concerns about a diagnosis preventing patients from engaging in the "existential conditions" of their condition, may be demonstrating sensitivity to the fact that crudely dualistic understandings of illness remain present in society, not excluding some medical professionals (see Deary, 2005; Fuchs, 2005a; Kendler, 2005). If one understands illness in crude dualistic terms, a medical diagnosis of a "somatic" condition may be considered something that can and should be understood and treated biomedically.[63] Perhaps GP18 recognises that, in the context of a society where this perspective is common, a diagnosis of a somatic condition may act as an unhelpful obstacle. This diagnosis

[62] Huibers and Wessely acknowledge that some people will argue that the only question worth exploring in CFS is the question of its cause, and that "discussion about the meaning of diagnosis and its risks and benefits is at best meaningless and at worst an offensive distraction" (p.899). This reflects the perceived social power of a biomedical causal explanation. I discuss this more in the context of Long Covid in Chapter 6.

[63] See Hacking (1999, p.117) for a discussion of the difficulty of "bio/psycho choice", that is, the question of treatment. He writes: "Even though one may be firmly convinced that a disorder is biological in character, one may realise that the best way to treat it, at present, is psychologically".

might offer some relief, but where psychosocial factors like early-life trauma or psychiatric illness could be considered relevant to the development or maintenance of their condition, a CFS/ME diagnosis for a patient, either who has such a crude dualistic view or who exists in a context where such a view is ubiquitous, could prevent them from engaging with such aspects of their condition which it could be within their interests to engage with. Insufficiently critical dismissal of such concerns as cases of negative stereotyping and epistemic injustice is done at the risk of restricting potentially fruitful management and treatment options. It is important to accommodate cases whereby a practitioner's expression of such concerns is a demonstration of sensitivity to what might hermeneutically able and/or disable patients.

With this in mind, I suggest that at least some identifications of testimonial injustice in the GP responses listed are too quick. In many such cases, one can understand the responses as expressions of explicit or implicit sensitivity to a range of legitimate concerns that it is a medical professionals' duty to consider and factor into one's professional judgement considering the conceptual problems with CFS/ME. Taking these responses to be clear evidence of negative stereotyping is suggestive of the idea that the relevant injustices can be prevented by simply confronting and improving the attitudes of the medical professionals in question. It is problematic to attribute negative stereotyping to practitioners who may be expressing concerns that require action of a different kind, namely more work which is committed to trying to address the epistemic, conceptual and socio-political problems with CFS/ME.

4. Epistemic privilege

There are surely cases of testimonial injustice that remain; I do not wish to suggest that all accusations of epistemic injustice against people with CFS/ME can be "explained away". Obvious candidates for such injustices are cases where patients are met with accusations of laziness, malingering, seeking out a "sickness role" in order to receive compensation, or where the medical professional makes no attempt to recognise and understand the pervasiveness of the fatigue which is experienced, instead assuming it is phenomenologically alike regular, every day tiredness. Some EFQ respondents describes experiences along these lines:

> I had a doctor at university tell me that everybody gets "a bit tired" at university and that I wasn't feeling anything different to all the other students. (#9)

> For years, my GP told me I was just lazy and depressed, that I should just take up running. She refused to diagnose me because she said it would give me an 'excuse'. I still think about this a lot because I feel like that is how a lot of people view CFS. This only further contributes to my depression because I feel like my illness is my fault. (#17)

More complex injustices could include, for example, a medical professional's failure to show appreciation for the heterogeneity in aetiology and phenomenology of CFS/ME. Such a medical professional may outright disbelieve any patient testimony that diverges from that one preferred explanation, or even fail to recognise other plausible alternative explanations. The medical professional may therefore fail to properly respect, listen to or engage with

testimony offered by the patient, not considering it to have any relevance to the task of understanding a given patient's predicament.

Consider a case where a patient has previously experienced depression, and the physician's knowledge of this is then used to undermine and dismiss any testimony offered by the patient that indicates that they are not currently suffering from depression. This is a clear case of unfair and unwarranted negative stereotyping on the grounds that having previously experienced depression, at least in the eyes of the practitioner, is sufficient to consider the patient a member of a group of people who cannot make a meaningful epistemic contribution.

There is, however, reason to scrutinise whether the notion of testimonial injustice is the best notion to make sense of the kinds of problems that, prima facie, might seem like cases of epistemic injustice against patients with CFS/ME. Recall that to suffer testimonial injustice is to be wronged specifically in one's capacity as a knower. Fricker (2007) claims that to be a giver of knowledge is a fundamental part of what makes a human life valuable, and so not being taken seriously as such is to have one's human value undermined. In undermining one's capacity for reason, one's humanity is undermined:

> The capacity to give knowledge to others is one side of that many-sided capacity so significant in human beings: namely, the capacity for reason. We are long familiar with the idea, played out by the history of philosophy in many variations, that our rationality is what lends humanity its distinctive value […] In contexts of oppression the powerful will be sure to undermine the powerless in just that capacity, for it provides a direct route to undermining them in their very humanity. (Fricker, 2007, p.44)

This formulation of testimonial injustice, then, commits itself to the idea that to suffer testimonial injustice is to have one's rationality unfairly undermined. Indeed, the work on testimonial injustice in CFS/ME done by Blease et al (2017) largely functions as an attempt to highlight and protect against the negative stereotyping of CFS/ME patients as being irrational and thus undermined. However, there are cases in which this formulation of testimonial injustice cannot adequately capture what is unjust. Edward Harcourt has argued that this notion of epistemic injustice needs to be either rejected or refashioned so as to accommodate people with mental illness so that epistemic injustices can be said to have been committed against agents who are not fully rational:

> [If] every mental health service user is impaired with respect to their rationality, it might be thought to follow that they fail to meet the threshold—rationality—for being entitled to epistemic justice. If so, whatever people with mental health problems suffer at the hands of insensitive clinicians, it cannot be epistemic injustice. (Harcourt, 2021).

I think that Harcourt raises an important challenge here. Moreover, I think that illnesses like CFS/ME are especially epistemically challenging in a related way. Patients are certainly vulnerable to epistemic injustice principally because it is especially difficult to test the veracity of their epistemic contribution by way of medical testing. In the context of many other illnesses, biomedical tests can be highly informative. Consider hypothyroidism, typical symptoms of which include fatigue, muscle and joint pain, and depression. Patient testimony here may be difficult to navigate. However, with hypothyroidism and many other illnesses, blood tests can be done that are highly informative, broadly corroborating with and therefore serving to legitimate the testimony of the patient. The psychiatric predicament

associated with the somatic illness can then be framed in a way such that it is easily "understood" by others. In the absence of such validating tests for CFS/ME, the testimony of people with CFS/ME where they are also experiencing psychiatric symptoms is especially epistemically challenging, and thus, people with CFS/ME, where it involves psychiatric symptoms, are especially vulnerable to epistemic injustice.

As I have discussed earlier in this thesis, there is a large body of patient testimony and medical research which outlines the various ways in which psychiatric illness can be implicated in cases of CFS/ME. Some of this literature suggests that suffering from a distressing, stigmatised chronic illness like CFS/ME can simply cause depression (De Jean, 2013; Castro-Marrero, 2017). Some suggests that there are some cases of CFS/ME in which psychiatric illness, most notably depression, plays either an aetiological or constitutive role in their condition. As I discussed in Chapter 3, this suggests that the relationship between the CFS/ME and depression is at least more complicated than a straightforward case of reactive/secondary depression, in at least some cases (Goodwin, 2006; Steptoe, 2007; Harvey and Wessely, 2009).

In any of these cases the person suffering from severe depression, by virtue of being depressed, may suffer from a diminished or otherwise compromised capacity for decision-making, memory, and reasoning. So, in this sense, the rationality of the person with depression may be considered impaired (Ratcliffe, 2015, p.273). Research has shown that both patients with CFS/ME and depression performed worse on cognitive tests than healthy controls, although cognitive deficits were generally more subtle in those with CFS/ME (Lawrie, 2000). It is also not obvious that the cognitive deficits most strongly identified in

CFS/ME patients in this study, such as inhibited verbal fluency and recall/recognition, impair first-person insight. However, it is important to note that the study excluded participants with comorbid depression and CFS/ME, rates of which are high (Harvey, 2009). This is not uncommon, and as such, empirical data on cognitive impairments in "regular" primary depression are important to consider: it might be the case that what is found in such studies would also be found in the comorbid CFS/ME and depression group, were they examined.

Ratcliffe has pointed out that people with depression can lack insight into their condition while they are depressed. For example, one might only retrospectively gain insight into how isolated or lonely they felt when depressed once they have recovered (2015, p.36). Although one might expect this to be more common in depression or various other psychiatric illnesses, which by virtue of being "mental" illnesses affect the mental lives of patients, data suggests that patient testimony can be similarly unreliable in the context of many other more obviously somatic illnesses (Roberts, 2010). Ronald Pies has suggested that accordingly, patient narratives ought to be viewed with respect, but not uncritical credulity (2013, p.290). Respecting testimony requires that one assesses it sensitively and seriously, but there follows from this no requirement to believe that it is true. As Pies writes, in the context of depression in the bereaved:

> [T]he patient's own "theory of the case" may prove to be misleading or incomplete; eg, the patient may be unaware of, or ignoring, the presence of an underlying medical disorder; unresolved intrapsychic conflicts; or environmental stressors not related directly to recent bereavement. (p.289)

Consider also that children can and do also suffer from CFS/ME. Exact incidence rates are unclear, though research suggests that there are two age-groups with elevated prevalence of CFS/ME, one being children and adolescents aged 10–19, and the other being adults aged 30–39 (Bakken et al, 2014; Crawley 2018). Moreover, high rates of comorbidity with depression, with whatever causal explanation, are also strongly identified in this population, with research suggesting roughly one third of children affected can also be identified as depressed (Bould et al, 2011; Bould et al, 2013; Taylor et al, 2017).

On Fricker's formulation, testimonial injustice is an "epistemic insult" in that it involves the intellectual undermining of an epistemic agent (2007, p.49). As in the case of adults with depression, in the case of a child with CFS/ME, and possibly a child with CFS/ME *and* depression, recognition of the child's cognitive limits may be necessary to avoid bigger ethical and professional failures.[64] As Harcourt writes in the context of delusions in children and young people (CYP):

> Sometimes—as the CYP cases show—being listened to means being believed. But sometimes, as in some delusional episodes, being listened to precisely does not mean that. On pain of bargaining away service users' entitlement to being listened to, we need to make sure the entitlement to being listened to in psychiatric cases is not reduced to the entitlement to epistemic (testimonial) justice. (Harcourt, 2021)

It is implausible to maintain that the medical professional who acknowledges the potential severity and pervasiveness of a given patient's predicament, where they appear to be

[64] See Carel and Györffy (2014) for an interesting account of how epistemic injustice can affect children in medical contexts.

experiencing significant distress, "brain fog" and life-upheaval to the detriment of their cognitive clarity, commits an injustice by acting in accordance with their judgement to exercise caution with regards to assuming patient testimony to be authoritative and/or accurate about particular things, in particular cases.

It may be in the best interests of the patient with depression, whatever the causal mechanism (comorbid or otherwise), for the medical professional to be mindful of possible impairments to their rationality and first-person insight. Failing to do so and act accordingly can do a disservice to the patient in failing to understand the pervasive impact that CFS/ME can have on the *whole person* in a given society, not just the sensations in their contextless physical, object-like bodies. This raises concerns about claims of testimonial injustice being committed against a CFS/ME patient with depression, or against a child with CFS/ME, when the requirement for being victim to testimonial injustice is that one's rationality is undermined. I suggest there ought to be room for attentive and respectful listening *without* uncritical assumptions of credulity.

Blease et al (2017) recognise and accept the justified level of epistemic privilege that medical professionals have as a result of their training, but emphasise the need for recognition of different forms of epistemic contribution that patients can make, namely knowledge about the lived experience of their condition (p.552). I certainly agree that knowledge that can be gained by engaging with a patient's lived experience is certainly valuable; this is, after all, at the heart of a project in phenomenology. No matter how skilled and experienced the medical professional, and no matter how accurate their intuitions, fully appreciating the

predicament of any given patient requires engaging with the idiosyncrasies of that patient's circumstances.

However, it is not obviously true that the first-person perspective is reliably comprehensively privileged in any given group. A medical professional may have justified reasons to doubt that the child or depressed adult with CFS/ME can reliably understand and communicate the nature of their lived experience of their illness, some aspects of which are inextricably bound up with values, beliefs and interpretations. Similarly, an adult, rational CFS/ME patient is likely to have certain insights into their condition and their experience of it that the medical professional could not have grasped independently, however, the same patient may struggle to make sense of these experiences and convey them such that they can be understood by others, something which could be facilitated by the interpretative skill and relevant expertise of a medical professional.

Thus, claims that certain groups have epistemic privilege cannot easily be made even with respect to one particular epistemic domain, in this case, of lived experience: it does not seem to be the case that group x can claim epistemic privilege over matters p and q, whereas group y can claim epistemic privilege over matters r and s, and that both groups should take the other as epistemic authority on such matters. Rather, it seems that both groups x and y can contribute, sometimes independently and sometimes collaboratively, over p, q, r and s, and that accordingly, epistemic insight into CFS/ME ought to be a deeply collaborative exercise.

5. Participatory practice

Illness studies literature suggests a variety of approaches to patient participation, but generally assumes that a focus on strategy and practice on the individual-interaction level, such as giving patients the confidence and opportunity to assert their testimony and giving professionals the tools to cultivate epistemic humility, will mean that patients are able to offer invaluable experiential knowledge which will be complementary to the overwhelmingly biomedical perspective of clinicians and researchers who are not patients (de Boer, 2021, p.5). As Elizabeth Anderson has pointed out, however, approaches which focus only on testimonial injustices fail to challenge the structural and sociocultural barriers to epistemic empowerment (Anderson, 2012).

Marjolein de Boer has recently offered an analysis of an attempt to involve CFS/ME patients into an advisory process (2021). De Boer comments that existing attempts that have been made in healthcare to involve patients in such procedures are overly theoretical, and as such do not facilitate good understanding of whether and how patient participation can correct epistemic injustices. She comments that empirical investigation into how patients "actually epistemically participate in a concrete deliberative setting" is required (p.5). Accordingly, de Boer examines the epistemic contribution of patients by analysing a recent example: the creation of the 2018 Dutch Health Council advisory report on ME/CFS.

This participatory practice arose as a result of a support group who brought an initiative called "Recognize ME" to the Dutch House of Representatives. Following consultation with various Dutch bodies, the Dutch Health Council initiated an advisory committee for ME/CFS in 2016, some committee members of which were patient representatives. De

Boer developed an analysis of how patients participated in this advisory process by examining their epistemic contributions. The analysis offered four main themes related to knowledge-sharing and production by patients and their representatives (de Boer, 2021, p.8). Those themes were:

1. *The framing of the illness*. Concerns were identified about nosology, and patients made epistemic contributions about identifying and operationalising the condition, both as two distinct disorders (rather than CFS/ME or ME/CFS), and about the somatic nature of the condition.

2. *Diagnosing the illness*. Epistemic contributions were made about the biomedical diagnostic criteria which ought to be used to diagnose the condition.

3. *Researching the illness*. Epistemic contributions were made about the extent to which research into the condition ought to be biomedical in nature.

4. *Treating the illness*. Epistemic contributions were made about what kind of treatments are and are not appropriate, principally in relation to whether they are biomedical or non-biomedical.

De Boer notes that patients and their representatives offered various different types of knowledge that fits into these themes, and as such, they are largely recognised as credible knowers to the extent that they can discuss CFS/ME as a somatic disease with various biomedical criteria, research avenues and treatment options.

This seems like a good thing. Indeed, Dotson's work on *testimonial oppressions* helps to understand in what sense this constitutes an epistemic liberation. Dotson writes that

testimonial *quieting*, one form of testimonial oppression, takes place when an audience fails to identify a speaker as a knower (2011, p.242). Where CFS/ME patients are recognised as credible knowers over a relevant domain, they are epistemically empowered.

De Boer notes, however, that these four identified themes are problematically closely aligned with the existing uncertainties which constitute some of the epistemic struggles which patients face (p.8). That is, whether ME and CFS are in fact separate conditions; whether certain diagnostic criteria are reliable; whether an exclusive focus on biomedical research is appropriate; and whether resisting psychological therapies is appropriate. The worry here, then, is that the epistemic contribution patients offer is fraught with its own epistemic challenges. The question then becomes, to what extent will patients be empowered by the opportunity to offer this epistemic contribution?

De Boer acknowledges the stigma associated with psychiatric, and by extension, psychosomatic illnesses and cites this as a reason for preferring biomedical framing. De Boer comments that, on first glance, facilitating the framing of the illness as somatic might be seen to be a promising way of improving the epistemic position of people with CFS/ME, thus enabling them to have a recognised and credible illness. She is right, in my view, to argue against this, instead recognising that the consequences of this somatic framing may instead have negative epistemic consequences for patients (p.11).

De Boer also argues that the significant preference for a biomedical perspective appeared to inform selection of which patients are welcome to take part in the advisory process, and that more subjective, narrative illness experiences were lacking in the advisory process. She

notes that the Dutch Health Council's invitation letter to patient participants predominantly asked for input of and feedback on state-of-the-art scientific research (p.13).

In conclusion, De Boer offers explicit support for my claim that the rejection of non-biomedical, non-pharmacological treatment options risks restricting potentially fruitful inquiry into treatment options, as well as preventing patients from engaging reflectively with certain significant aspects of their condition.[65] Nonetheless, she acknowledges that the desire to fit one's experience into a bio-medical framework is an entirely understandable disposition given the stigmatisation patients are vulnerable to (see Chapter 6).

Like de Boer, I do not wish to suggest that bio-medical research into CFS/ME is not important. Rather, such research makes a vital contribution. One strong case for the continued support of such research is, as de Boer notes, that increased biomedical knowledge about the condition might allow patients to better understand aspects of the condition, such as its "symptomatic appearance". This can provide patients with increased hermeneutic resources for making sense of the subjective illness experiences of which bodily change is an important, constitutive part. Thus, the claims in this chapter are not intended to deflate the importance of this type of research, but rather, are intended to challenge the historic downgrading of other types.

One suggestion is that, though patient participatory practice ought to continue, a revision about what kind of epistemic contribution is sought is warranted. Perhaps more of an interest in the narrative, experiential, and phenomenological nature of patient experience

[65] De Boer is responding directly to the argument presented in Byrne (2020).

ought to be offered better uptake. Indeed, each of the chapters preceding this have attempted to show just how rich and informative this perspective on CFS/ME can be.

6. Conclusion

In this chapter, I have highlighted problems with how the concept of epistemic injustice has thus far been applied to CFS/ME. Epistemic injustice is a useful concept which has already aptly shown how CFS/ME patients are vulnerable to suffering from epistemic harm, however, I have resisted claims that identify testimonial injustices where the epistemic problem can be just as plausibly explained by the medical professional exercising appropriate medical sensitivity within the context of a vast conceptual impoverishment. I have also argued that there are multiple problems with the idea of the CFS/ME patient as entirely epistemically authoritative over their first-person lived experience. From this, I suggested that the process of gaining epistemic insight into CFS/ME ought to be deeply collaborative, as others have suggested is important in psychiatry and medicine more generally (Fulford et al, 2014, p.113).

There is certainly a need for careful research into what the epistemic contributions of patients can reveal about CFS/ME. There is also a need to carefully scrutinise dynamics that underpin attitudes about of what types of contributions are valuable. Illustrating this, I finished by offering a discussion of a recent an analysis of a case of CFS/ME patient participation (de Boer, 2021). This analysis showed that the types of epistemic contributions which are dominant, and considered valuable in such contexts, are themselves fraught with epistemic challenges. This offers another layer of support for my claim that fruitful lines of inquiry into CFS/ME risk being obfuscated by contemporary epistemic practices. In the

following chapter, I will look in more detail at some of the dynamics which underpin these issues, and show how they risk affecting not only research into CFS/ME, but also into "Long Covid".

Chapter Six: Long Covid, Nosology and Stigma[66]

1. Introduction

CFS/ME has been brought to the attention of the public, media, and research community since the Covid-19 pandemic became associated with a similarly-presenting condition most commonly referred to as "Long Covid".[67] Here, I will draw attention to some problems with the handling of this condition which are a familiar part of the history of CFS/ME. I suggest that a process of mutual-illumination is appropriate, thus proposing a way forward for research into both CFS/ME and Long Covid, as well as other associated conditions.

The recent debate around Long Covid has so far shown resistance to accept parallels between Long Covid and a set of existing conditions which have historically been subject to stigma, namely CFS/ME and psychiatric illness. This resistance, I argue, risks endorsing the stigma associated with such existing conditions, and as such, these dynamics of stigma ought to be dismantled in order to facilitate the development of effective clinical resources for all such implicated conditions.

As well as affecting proceedings at the structural level, I discuss how the aforementioned problems also risk affecting patients at the personal level by motivating the reconfiguration and restriction of patient illness narratives. The problems I identify therefore risk affecting both collective and individual understanding of Long Covid, CFS/ME, and psychiatric illness.

[66] An article closely based on this chapter has been published (Byrne 2022).
[67] Quotation marks are used to denote the term rather than its reference.

This chapter therefore contributes to the project of arguing for a conceptual revision of both conditions and the distinctions within which we attempt to understand them.

"Long Covid" refers to a period of illness after infection with SARS-CoV-2 which outruns the expected timeframe of the acute period of infection. Like CFS/ME, there is a marked lack of clarity around the condition and how it ought to be handled in clinical practice, which generates confusion for researchers, clinicians and patients. At its broadest, Long Covid encompasses a range of separate complaints, from viral persistence to post-intensive care syndrome (PICS) and organ damage, as well as all that is already captured by reference to post-viral *and* post-infectious fatigue syndromes (Mahase, 2020).

Given this, the case definition and symptom profile of Long Covid is not clearly established, and has been subject to frequent change. The UK National Health Service (NHS) has listed common Long Covid symptoms as follows: extreme tiredness (fatigue); shortness of breath; chest pain or tightness; problems with memory and concentration ("brain fog"); difficulty sleeping (insomnia); heart palpitations; dizziness; pins and needles; joint pain; depression and anxiety; tinnitus, earaches; feeling sick, diarrhoea, stomach aches, loss of appetite; a high temperature, cough, headaches, sore throat, changes to sense of smell or taste; and rashes (NHS, 2021a).

Extant literature increasingly discusses the need to clarify this and various other aspects of Long Covid, such as its aetiology, diagnostic criteria and treatment options. Epidemiological limitations, such as the absence of infection-free control groups in studies, inconsistent definitions of the condition, variable follow-up times, and heterogeneous inclusion criteria are amongst concerns which have been highlighted thus far (Carod-Artal, 2021).

For example, a recent bulletin from the Office for National Statistics (ONS, 2021) estimated that 1.1 million people in the UK reported experiencing Long Covid symptoms over the four-week period ending 6 March 2021. Unusual operational criteria were used here. The ONS criteria for having Long Covid symptoms, as opposed to acute SARS-CoV-2 symptoms, were satisfied if symptoms persisted for at least four weeks. Four weeks is not a long enough period of illness for diagnosis of any comparable post-viral syndrome, or CFS/ME, to be made: here, symptoms should have persisted for at least six months (Hickie et al, 2006; Wong & Weitzer, 2021). This is not an isolated example: strikingly, one systematic literature review has identified criteria for Long Covid as ranging from 14 to 110 days post-infection (Lopez-Leon, 2021).

Despite these methodological issues, there is interesting research being done into the disease mechanisms which give rise to the relevant symptoms. Immunological research has found several inflammatory markers which might be implicated in the condition (Oronsky, 2021; Salmon-Ceron, 2021). One of my aims here is to highlight ways in which the tasks of refining case definitions, aetiological and disease pathways for the relevant illnesses can be mobilised by reducing the interference of (largely implicit) stigma. Unpacking long-standing dynamics of stigma can support the recognition of shared features of Long Covid and other conditions, such as immunological features shared with CFS/ME, other post-viral syndromes and inflammatory depression.

Along with inconsistent case definitions for Long Covid, there is also some controversy around its name. This is partly a product of the aforementioned epidemiological problems, but the dynamics of stigma which I am interested in here are also implicated in this

imprecision. In October 2020, a blog for the *British Medical Journal* authored by medical professionals, academics and patients who have suffered from Long Covid, was published online. This blog post encourages medical professionals to continue to embrace the patient-made term "Long Covid", as opposed to alternative proposed labels like "Post-Covid Syndrome", on the grounds that it is better able to navigate socio-political as well as clinical challenges posed by the condition. Amongst other reasons, the authors argue that terms which associate the condition with other delegitimised conditions should be avoided:

> Crucially, Long Covid side-steps "post," "chronic," and "syndrome." These can end up delegitimizing people's suffering, making it harder to access care—especially when a syndrome or chronicity becomes associated with women and/or minoritized people. (Perego et al, 2020)

This is an interesting claim. There is certainly evidence that conditions with "post", "chronic", and "syndrome" in their names are stigmatised (Blease et al, 2017; McManimen et al, 2018). "Long Covid" has linguistic distance from existing labels like post-infectious fatigue syndrome. Moreover, though there was at a time significant interest in "chronic Epstein-Barr", it has never been referred to as "Long Epstein-Barr". "Long Covid" therefore distances itself from conditions with which we are already familiar.

It seems plausible, then, that the term "Long Covid" avoids such stigmatisation where "Post-Covid Syndrome" does not. However, the language of "side-stepping" calls for further scrutiny here. The concern raised here is that words "post", "chronic" and "syndrome" delegitimise suffering as a consequence of being associated with stigmatised groups. Yet, it is

left implicit (a) which groups have historically had their suffering delegitimised and (b) what is delegitimising about the terms.

2. Post-infectious fatigue syndromes

The most obvious candidate for (a) here is CFS/ME. What we know so far of the clinical presentation and symptomatology for Long Covid is that it is strikingly similar to that typically recognised in CFS/ME, despite the fact that case definitions for both are unclear (Wong & Weitzer, 2021). As with lack of clarity about the case definition of Long Covid, mixed views are found about whether, for instance, CFS/ME captures post-viral fatigue syndrome, and indeed whether this captures post-infectious fatigue syndrome without viral agent (David et al, 1988).

There is, of course, long-standing lack of clarity about how CFS/ME ought to be handled in clinical practice. As a striking recent example, proposed revisions to the NICE guidelines for CFS/ME, originally published in 2007, were withdrawn last minute: medical professionals expressed concern that the only existing, though controversial, treatment options for CFS/ME, Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) were no longer supported in the new guidelines. The withdrawal of the revised guidelines, and the various responses to this decision, highlight the salience of the issues raised in this and the preceding chapter, namely that dynamics of stigma are heavily implicated in attempts to make medical progress with such conditions.[68]

[68] For more information on the reasons behind the withdrawal, and the subsequent upset, see Grover (2021).

Despite lack of clarity over a case definition for CFS/ME, similarly-presenting post-infectious complications are clearly identifiable throughout history. Striking parallels in clinical description can be found with neurasthenia, a "hot potato" of 19th century medicine (Wessely, 1991). Of the various familiar post-infectious syndromes identified through history, some have been epidemic, such as the Spanish flu, the "benign Myalgic encephalomyelitis" of the Royal Free Hospital in 1955, and Severe Acute Respiratory Syndrome (SARS) (Islam et al, 2020). They have also been sporadic: the particularly strongly implicated Epstein-Barr Virus (White, 2007; Katz et al, 2009; Pedersen et al, 2018); tick-borne encephalitis (Haglund & Günther, 2003); Q-fever (Helbig, et al 2003) and Giardia, for example (Litleskare et al, 2018). Infection is of course not sufficient for post-acute sequalae: there are many people who fall ill with various viral and bacterial infections whom avoid such complications. The sufficient conditions for CFS/ME, namely what additional causal factors trigger the final causal pathway, are unclear.

As well as the role of infectious agents, recall that there is evidence for the view that there are cases of CFS/ME in which depression and psychological stressors appear to be aetiologically relevant (Goodwin, 2006; Steptoe, 2007; Harvey & Wessely, 2009; Borsini et al, 2014). Some people with CFS/ME cannot and do not cite an infectious trigger, and moreover, some who suspect one such trigger cannot always have their suspicions corroborated by tests. Patients for whom no organic cause can be found can find themselves vulnerable to doubts about the organic nature of their disease, especially where evidence supports the aetiological power of psychological stressors. We have seen this historically. For instance, doubtful of organic disease, McEvedy and Beard famously

dismissed the epidemic at the Royal Free as girls' hysteria (1970). These dynamics persist to this day, and delegitimising attitudes are still frequently documented (Raine et al, 2004; Stenhoff et al, 2015).

In an attempt to dismantle delegitimising attitudes, hypotheses for the organic causes of CFS/ME have been pursued, though they subsequently failed (van Kuppeveld & van der Meer, 2011; Panelli et al, 2017). Lack of clear data here of course comes as a disappointment to both researchers and members of the patient community. This is a medical problem in so far as it is an obstacle to the development of effective treatments for CFS/ME. This is a social problem in so far as inconclusive biomedical data delegitimises, sustaining scepticism about whether or not there is "really anything wrong" with the patients, such that the complaints must instead be "imaginary" or "all in one's head".

In the 1980s, David et al challenged the "sterile" argument over whether post-viral fatigue syndrome is better explained as "hysteria" or "organic disease". Various others have also highlighted the problems with such distinctions, mapping it on to the related functional/organic distinction (David et al, 1988; Bell et al, 2020). Not excluding the types of phenomenological critiques of an unhelpful division between illnesses of mind and body which I discussed in Chapter 1, what all such critiques tend to have in common is their frustration with Descartes, or more charitably, the caricatured picture of mind-body dualism associated with Cartesian thought. Kendler demonstrates such gripes in the context of discussing the role of "difference-makers", i.e. causal factors, in a pluralistic view of causation in psychiatry:

> Empirically based pluralism can help place in perspective claims like 'panic disorder is a brain disorder' that have become increasingly common in the last several decades. […] It might be seen as true in the sense that brain- and biology-related difference-makers contribute to risk for panic disorder and false in the sense that it claims that panic is a 'hardware only' kind of disorder. Although such claims reflect an appropriate need for medical and social legitimacy for psychiatric disorders, they are neither entirely true nor terribly helpful in the context of empirically based pluralism. The view that only by being 'biological' does a psychiatric disorder become 'real' is a symptom of the Cartesian error. (Kendler, 2012)

Or as Peter White writes specifically in the context of CFS/ME in his "philosophical epilogue" to a recent paper on nosology:

> Western medicine is still the bedevilled by Cartesian dualism, which determines that phenomena are either physical or mental, whereas the reality is more complex and compelling. So the question as to whether CFS/ME is a neurological or mental illness is clearly meaningless, since it has features of both, and cannot be classified convincingly as one or the other. (White, 2019)[69]

Recent immunological research also serves to support the idea that it is not possible to identify some "privileged level that can unambiguously be used as the basis for developing a nosologic system" (ibid) which is assumed under the functional/organic distinction. Rather, acknowledging the complexity of the relevant causal landscape is important. What is also

[69] See also a similar sentiment in Ware (1993): "Patients resist a psychiatric diagnosis because […] psychological disorder is stigmatised. The origins of stigma lie in the implication of responsibility in psychiatric illness and in the naturalist paradigm devaluing of afflictions of the mind as imaginary. These hidden values reveal the moral dimension of diagnosis, naturalism and the dualistic metaphysics in which both are embedded."

important is reliably distinguishing between aetiology at different levels across contexts, something else which uncritical use of the functional/organic fails to do (Bell et al, 2020).[70]

Some recent immunological research suggests that increased release of inflammatory cytokines is shown to be implicated in the pathogenesis of some though not all cases of CFS/ME (Strawbridge et al, 2019; Yang et al, 2019). Similarly, a fast-growing body of evidence suggests similar inflammation can play an important role in at least some potential subtypes of mood disorders such as depression, such as in development and resistance to treatment (Steptoe, 2007; Harrison et al, 2009; Pariante 2017; Strawbridge et al, 2020; van Eeden et al, 2020). Evidence also supports the hypothesis that environmental stressors can exacerbate inflammation (O'Callaghan et al, 2019). As I suggested in Chapter 1, phenomenological work which illustrates the striking similarities between the lived experience of some instances of depression and inflammatory somatic illnesses like influenza also corroborate the hypothesis that there might be at least a subtype of depression in which inflammatory sickness response is strongly implicated: "The category 'depression' does accommodate 'no difference' [with the phenomenology of somatic illness] cases, but it accommodates various other cases too" (Ratcliffe, Broome, Smith & Bowden, 2013). This is therefore suggestive of a more complex picture in which illnesses do not permit to separation between categories like functional/organic and psychiatric/somatic.

[70] Bell et al (2020) write: "Indeed, the extent to which it can reliably distinguish between types of causes for particular signs, symptoms and syndromes seems to differ depending on the signs, symptoms and syndromes being assessed. […] Rather than a general distinction, it is more akin to various local distinctions, each defined and limited by context (p7).

2.1. Resisting parallels

Is Long Covid to be understood as another type of post-infectious fatigue syndrome, then? Perego et al (2020) comment that the term "Long Covid" is appropriately non-specific in that it does not imply any one given pathogenesis or aetiology. This seems like a virtue, since research into Long Covid is fast-evolving, and there remain many unknowns. One might think, however, that "long" implies viral persistence as does "chronic" in previously discussed conditions, namely chronic Epstein-Barr Virus. This might be misleading, since there are insufficient grounds to think that this is typically true of the phenomenon. One might therefore think that "Post-Covid Syndrome" is more permissive, since it implies only lasting complications of an infection with SARS-CoV-2. "Post-viral fatigue syndrome" is even less committal, since it implies no such role from any one virus in particular, and furthermore, "CFS/ME" does not necessitate that it is post-viral at all (something else the authors suggest that "Long Covid" uniquely achieves).

In a similar vein to the *British Medical Journal* blog piece by Perego et al (2020), a recent comment piece in the *Lancet* criticises the recent NICE guidelines for Long Covid on the grounds that the guidelines do not go far enough to distance Long Covid from post-viral fatigue:

> In the guideline there are implicit assumptions about the nature of long COVID, which could result in some likening it to post-viral fatigue and may lead to providers over-emphasising a psychological component. (Gorna et al, 2020)

This makes clear a sense of urgency to separate Long Covid from similar existing conditions, stemming from a desire to avoid the mistreatment that patients with post-viral fatigue

syndrome have been victim to. The authors' worry about over-emphasising a psychological component can be interpreted in two ways. Either (i) the authors think that post-viral fatigue syndrome has a psychological component which Long Covid does not, and that this should be recognised or (ii) the authors think that the suffering of patients with PVFS has historically been harmfully psychologised, and the same mistake should be avoided here. To defend (i) would require substantial medical insight into both conditions which we do not yet have. To defend (ii) demonstrates a failed opportunity to challenge the poor treatment of those with PVFS. On both interpretations, the sentiment is concerning.

Despite rapidly emerging parallels between Long Covid and CFS/ME, the motivations for resisting associations between Long Covid and conditions such as CFS/ME now become clearer. To resist terms like "post", "chronic" and "syndrome" is, at its foundation, to resist the stigma associated with them. In resisting the association of Long Covid with such stigmatised conditions, one perpetuates the stigma associated with such conditions. Not only is this harmful to patients who are already suffering from such contested illnesses, it also produces a high-stakes environment whereby accepting parallels between Long Covid and CFS/ME risks delegitimising the suffering of the millions of people who are thought to be suffering from Long Covid.

Despite significant overlaps in clinical presentation, it will remain unclear to some why the fact that infection with SARS-CoV-2 is a necessary condition for Long Covid is not sufficient to disarm the threat of the parallel with CFS/ME. Though it is of course not a sufficient condition, the necessary implication of a viral trigger is already more than we have ever been able to say about CFS/ME. However, there are a number of reasons why this is not

sufficiently protective against inherited stigmatisation. First, matters are complicated by insufficient resources for reliable testing. As is current practice, there is good reason not to exclude those without a positive SARS-CoV-2 test from diagnosis and treatment of Long Covid due to the large numbers of people who were not able to access a test, as well as significant concerns about the sensitivity of tests, especially the rate of false negative results in lateral flow tests taken at home (Crozier et al, 2021). To employ such exclusion criteria would be to risk excluding a significant number of people who have in fact been infected. Accordingly, treatment can be sought based on clinical presentation alone when there is a reasonable assumption that the patient has had SARS-CoV-2 (NHS, 2020).

However, without this aetiological confidence, there is little to no way of knowing whether or to what extent infection with SARS-CoV-2 was implicated in the final causal pathway of the subsequent illness. We can see, then, that there is very little by which to separate Long Covid, at least in some of its forms, from CFS/ME.

3. Psychiatric illnesses and monocausality

It is now clear (a) which groups have historically had their suffering delegitimised. This section addresses (b) what is delegitimising about the terms resisted. Pejorative descriptions of ill-health predicaments such as CFS/ME, where they are reduced to predicaments "all in one's head", are pejorative as a result of their association with yet another set of stigmatised illnesses: psychiatric, or mental, illnesses. The stigmatisation of psychiatric illness has a long and complex history. Here I will discuss only a small aspect of it: available causal explanation.

Kendler has recently argued that the so-called "ghost" of monocausal psychiatric disorders "lurks in our memory", describing a late 19th century love-affair with monocausal theories. Kendler claims that the "doctrine of specific aetiology" continues to influence psychiatric practice, and by extension, wider social attitudes (2019). Kendler identified this motivation for pursuing monocausal explanations in psychiatry as having been fuelled by the successful discovery of a clear aetiology for a wide-spread encephalitis termed "general paresis of the insane" (GPI). Following this revelation, the task for psychiatry became, rather than description of signs and symptoms, to define disorder in relation to its specific underlying cause.

Consequently, conditions which did not appear amenable to such causal explanation were resigned to a lower status, considered "syndromes" as opposed to proper diagnoses. Thus, the condition for legitimacy was amenability to monocausal, biological explanation. In more recent times, hypotheses which have since been shown to be false are good examples of failed attempts to legitimise an illness by appealing to a particular type of causal explanation, such as depression's serotonin hypothesis and schizophrenia's dopamine hypothesis:

> Although the original articles proposing these theories were couched in qualifications, as a psychiatry resident in the late 1970s, I was taught these theories as monocausal explanations. Schizophrenia was caused by excess dopamine transmission. Decades later, I would commonly see patients who would say some version of "my psychiatrist said I have a chemical imbalance in my brain" and then proceed to summarize one or more of these theories. (Kendler, 2019, p.1088)

Related to this disposition towards seeking a particular type of causal explanation in medical practice is the distinction between illness-integrating and illness-alienating dispositions in patients. For example, consider a comment from a patient after receipt of a diagnosis of bipolar disorder: "people suddenly realised I wasn't doing things for attention [...] It was because I have a brain disorder" (quoted in Hassall, 2020). This response is clearly *illness-alienating*, giving connotations of disease as a "foreign invader" parasitic on oneself, like a virus. In this particular case, having a brain disorder clears one of all accusations of self-constitutive flaws, such as blame-worthy personality traits and behaviours such as attention-seeking and manipulation.

Behaviours which may have otherwise *appeared* self-constitutive are then provided with an illness-alienating explanation, that is, explanation at the biological level. The background assumption in such descriptions is that the reality of having a brain disorder exposes psychological-level explanations to have been false, rather than allowing that both are true at different levels of explanation. As Hacking writes in the context of schizophrenia, "the medications make it easier for someone who is afflicted by such a mental illness to think of it as something "other", a thing, almost an agent that acts upon one. One's stupid, or gross, unfeeling or simply crazy actions can then be blamed on the illness which has become an evil agent" (1999, p.113).

The relationship between self and symptoms is a complex one, and patients undoubtedly experience this relationship in a multitude of different ways. Throughout history, illness narratives have featured various different hypothesised origins, namely the devil, aliens, or other sources entirely outside of the self. Conversely, some experience their symptoms as

an integral part of their identity, and identify with the symptoms of their illness as much as they do with other states, dispositions, attitudes, beliefs and so on. In the context of mental illnesses, Jennifer Radden has argued that in different periods throughout history, various ways of framing one's illness narrative have been more or less salient, and subject to reconfiguration in particular ways as an effect of stigmatisation (Radden, 2008, p.171-2). Today, she suggests, attitudes are less obviously moralistic yet remain stigmatising, encouraging reductionist, highly "medicalised" framing:

> […] memoirs from our present era introduce new elements, such as the reductionistic assumptions of modern biological psychiatry where symptoms are dismissed as the meaningless causal products of a disordered brain. These assumptions are almost inescapable, given the ubiquity, authority, and influence of medical psychiatry today. (Radden, 2008, p.173)

The availability of a monocausal biological explanation for mental illness is somewhat protective of stigma, offering patients a sense of relative protection from blame. Where amenability of one's predicament to monocausal biological causal explanation is the route to relieving stigmatisation, problems follow. The problem here is that it is a quick-fix solution which promises what it cannot always deliver. For one, it places potentially unreachable conditions for being absolved upon a group of people who are often already relevantly vulnerable.

As I have discussed, clinical resources for diagnosing, classifying and treating Long Covid are yet to be established and developed, and the development of such clinical resources would surely lessen the burden on patients. If one takes familiar conditions from throughout

history to be informative here, however, one will recognise that establishing these clinical resources will not be straightforward. That patients are vulnerable to stigmatisation in lieu of such resources exposes more than a medical problem: an important set of the problems that arises for patients without these resources does so because of the stigmatisation of associated conditions, namely psychiatric illness. Thus, these conditions of legitimacy ought to be dismantled in tandem with the task of establishing clear clinical resources. Kendler makes this point nicely:

> […] both clinicians and their patients would feel more secure if a large indisputable cause were found for their disorders. This, however, is a social and not a scientific problem […] [T]he legitimacy of the discipline of psychiatry does not rest on our ability to find single major causes of our disorders. (Kendler, 2019)

Kendler points out that in contemporary medicine, multicausality is increasingly embraced, and that this does not pose a threat to the legitimacy of somatic conditions (ibid). Rather, the problem of legitimacy being conditional on monocausality persists for illnesses which historically have been subject to reduced legitimacy, that is, those associated with mental illness. Unfortunately, the lingering stigmatisation of psychiatric illnesses carries over into the stigmatisation of contested conditions such as CFS/ME, and now by extension, should the parallel be accepted, Long Covid. We are not in a position to claim that CFS/ME is a psychiatric condition, to reiterate Wessely's words, "whatever that means, though it is rarely something good" (Holgate & Komaroff, 2011). Rather, it is true that such contested illnesses have historically been associated with psychiatric illness, and we still lack consensus over how to classify them.

4. Problems for patients

This section makes clear how the aforementioned dynamics risk affecting patients with Long Covid symptoms. The challenges I have mentioned so far predominantly affect structural-level decision-making about naming and classification. In what follows, I also suggest how the identified dynamics also risk influencing patients at the personal level.

Radden's observation that the illness narratives of patients with mental illnesses can be subject to reconfiguration as an effect of stigmatisation is incredibly salient here. People presenting with symptoms which are equally compatible with CFS/ME and Long Covid are also vulnerable to this, with some uniquely concerning consequences for diagnosis, treatment and self-understanding. In what follows, I make clear what might motivate such a reconfiguration and what its effects might be, by detailing contexts in which tensions arise between two grounds for seeking a Long Covid diagnosis over a CFS/ME diagnosis: social grounds (the avoidance of stigma), and medical grounds. So long as the stigmatisation of psychiatric illnesses persists, the social grounds risk superseding medical grounds.

There are various different factors at play here which might motivate people to reconfigure their illness narratives in a certain way, all of which illustrate the comparative availability and desirability of a Long Covid diagnosis. The combination of lack of fully informative biomarkers and similar clinical presentation means that, with some exceptions, there will be a substantial number of patients who are equally eligible for both diagnoses. CFS/ME is (a) highly common but (b) under-recognised and (c) highly stigmatised. It is (b) and (c) which affect the configuration of a patient narrative, and (a) which makes this especially problematic.

4.1. Why the diagnosis matters

If it is unclear whether or not the patient in question has had SARS-COV-2, and their symptoms are sufficiently broad, there are good medical grounds to favour a diagnostic label which is open-minded to other pathogeneses, such as CFS/ME. However, the associated stigma means that such diagnoses make patients considerably more vulnerable in both clinical and social contexts. This is not to say that Long Covid patients are not vulnerable to such dynamics at all, rather, they have *comparative protection*. There are, unfortunately, a significant number of reports of patients with suspected Long Covid reporting being dismissed and ignored by GPs and employers (Lancet, 2020). Some of the reasons for this will be similar to reasons behind negative experiences of patients with existing contested illnesses (Blease et al, 2017; Byrne, 2020). Nonetheless, it appears to be the case that Long Covid "has avoided the earlier obscure fate of ME/CFS with an outpouring of public and expert acknowledgement for its status as a medical illness and its significant long-term health impact" (Wong & Weitzer, 2021).

The emergence of Long Covid since the beginning of the pandemic has, of course, been newsworthy in a way that CFS/ME has never been. Long Covid is thus in the public consciousness in a way that CFS/ME is not, or has ever been. Likewise, investment into support and treatment of people with Long Covid has been comparatively vast: NHS England alone have invested more than £100 million into Long Covid care (NHS, 2020; NHS, 2021b). In contrast, a review by the ME Association found reported that little more than £49 million had been spent on CFS/ME research 2006-2015 across the USA, UK, Europe and Canada (ME Association, 2016). Admittance to specialist Long Covid clinics is

dependent on patients having had either an official diagnosis, *or* a reasonable basis for believing they had SARS-CoV-2. As I have discussed in Section 2.2., there are good reasons for admitting patients who only satisfy the second disjunct here: testing has been difficult to access, and is not completely reliable.

However, criteria for satisfying the second disjunct are not clear either. Case rates in the UK have been at times incredibly high, so it is not clear what constitutes a reasonable basis for believing one has in fact had SARS-CoV-2. Given case numbers, a reasonable basis might be just recollection of a period of acute illness in the last 18 months followed by lasting effects for more than 4 weeks. This is incredibly permissive. Cases of similarly-presenting illnesses, such as CFS/ME, will continue as does the circulation of other viruses that appear to be implicated in them and often go undiagnosed, such as Epstein-Barr Virus.

Though there are reasonable grounds for this permissiveness, it can have problematic consequences. For instance, patients with identical clinical presentation can be offered different standards of treatment *only* because of their diagnostic label, even though they might pick out the same kind. In some counterfactual situation without the Covid-19 pandemic, then, some patients who would have received CFS/ME diagnoses, receive Long Covid diagnoses instead. It also means that people who had already received CFS/ME diagnoses before the pandemic are unfairly and arbitrarily denied social support and treatment which might be equally appropriate for them. There are only social grounds making it the case that some people, i.e., those with Long Covid diagnoses, are offered better social support and treatment options than those with CFS/ME diagnoses. This

disadvantages patients, and is exacerbated by resistance to the parallel between Long Covid and CFS/ME (Tuller & Lubet, 2020; Trueland, 2021).

4.2. Seeking a diagnosis

People who are yet to be diagnosed (where their clinical presentation is equally compatible with either diagnosis) are importantly affected in being made vulnerable to particular pressures to reconfigure their illness narrative in various different ways. The problem this presents is that, as I have discussed, one's diagnosis gate-keeps access to comparative privileges, and moreover, which diagnosis is received can be contingent upon, *or* perceived as contingent upon, as little as presenting with an illness narrative that satisfies the aforementioned existing conditions for legitimacy.

It is important to clarify where I am setting the scope of "narrative" here. Here I am interested in patient narrative only to the extent that it involves a patient's "theory of the case", i.e., what caused their illness, and what their illness consists in (Pies, 2013). Though a patient's "theory of the case" can be tightly bound up with other features of illness narratives, such as the patient's emotional life, and their relationships with others, these features are not important to my claim here.

Patient narrative can be affected in the process of seeking a diagnosis because of the comparative salience and availability of certain narratives. Because of the resources that are available to them, patients can internalise a sense of what qualities their narrative ought to involve and thus be pragmatically disposed towards constructing a narrative which has those qualities. We can distinguish between various different types of narratives, such as narratives

that are private, narratives that are shared with chosen others, or narratives that are offered publicly (Ratcliffe & Byrne, forthcoming). The interactions between these types of narratives are intricate and complex. Here, I am focusing on how private narratives are influenced, as well as how private narratives interact with narratives which are shared with some, or all, others.

Here, one factor which might dispose people towards a Long Covid narrative is implicit trust in what is perceived as legitimate in the eyes of the medical establishment. Ratcliffe has argued that it is partly through trusted others that one constructs a narrative, and that the literature that one is exposed to and endorses partially depends on who is trusted (Ratcliffe, 2018, p.19). Where the medical establishment is trusted (tacitly or otherwise), and legitimacy through the eyes of the medical establishment appears to require a theory of the case which has certain features, motivation for pursuing a particular type of illness narrative over another arises.

It is important to recognise cases in which the weight of doubt from others does lead to some patients doubting that their condition is in fact legitimate. Such patients seem to express a distressing tug-of-war type experience, flitting between conviction that their condition is legitimate, and "giving in" to the doubtful voices resulting in an internalised sense that they are malingering or that it is "all in their head". Generally, however, patients feel sure of the reality of their illness and the symptoms that are part of it.

Patients may therefore assume that their symptoms ought to be explainable by the presence of a disease entity worthy of medical interest. Consider a patient who is of firm conviction that the extreme fatigue and pain in their chest is real, that they are not "making

it up", nor is it "all in their head". With the necessary implication of a viral trigger (though without knowledge of sufficient conditions for the illness), a Long Covid narrative appears to better meet the perceived requirements for legitimacy than a CFS/ME illness narrative which is comparatively "mysterious": saturated with associations with blame, poor prognosis, poor life quality and lack of social and medical support, receiving a CFS/ME diagnosis can be harmful and burdensome to the detriment of patient recovery (Huibers & Wessely, 2006). One's illness more easily fits within an illness-alienating framework if one is "contaminated" with something from the outside, external to oneself, which is widely recognised by others as a very real threat to all. One might therefore be disposed towards a Long Covid narrative despite the lack of any medical grounds suggesting that one's symptoms are the result of infection with SARS-CoV-2 rather than any other infectious agent, or something else altogether.

As well as this, it might also be the case that it is the diagnosis that the patient is most aware of, or even the only diagnosis the patient is aware of, since CFS/ME is not a diagnosis with which people are generally familiar. As I have mentioned in Section 4.1, given at times exceptionally high case rates, it is unclear what constitutes reasonable grounds for thinking one has been infected with SARS-CoV-2 are: one might plausibly consider living and working in a host of given countries throughout the pandemic sufficient grounds for assuming one has at some point been infected, and is therefore suffering from Long Covid if the appropriate symptoms emerge (especially if one is not aware of alternative, similarly-presenting illnesses).

One might identify further testimonial injustices here. In Chapter 5, I discussed Dotson's work on testimonial oppression and discussed how patient participation on a CFS/ME advisory committee in the Netherlands appears to constitute an epistemic liberation insofar as patients were recognised as knowers, thus overcoming *testimonial silencing.* The second of the two forms of testimonial oppression highlighted by Dotson makes clear why this solution does not go deep enough. *Testimonial smothering,* another form of testimonial oppression, is understood as "the truncating of one's own testimony in order to ensure that the testimony contains only content for which one's audience demonstrates testimonial competence" (Dotson, 2011, p.244). Or, as is put by Jack Warman in the context of Domestic Violence and Abuse (DVA): somebody is victim to testimonial smothering when they know that p, but nevertheless withhold testimony which expresses p because they reasonably believe that their testimony will be refused outright or misunderstood in a way that leads the hearer to hold harmful beliefs (Warman, forthcoming).

Dotson notes that testimonial smothering takes place in contexts which are charged with "complex social and epistemic concerns" (ibid). This is certainly one such context. I suggest that de Boer (2021) picked up on something like this in the context of patient participation in CFS/ME discussed in the preceding chapter. She discusses patient "strategies" in the context of their vulnerable epistemic position:

> Rather, their promotion of using biomedical diagnostic criteria could be conceived as a strategy to bring in an alternative agenda that is based on their first-person experiences of dealing with a highly stigmatized condition; the criteria bear the promise of being acknowledged and recognized in their day-to-day suffering. […] Besides from understanding

> their biomedicalized framings and approaches as a contributing to potentially finding a cause and a cure for ME/CFS, it may also be understood as a strategy to fit into and thrive within an advisory process that has a predominant scientific, biomedical character.

I suggest that something like this might plausibly take place in the context of Long Covid. Here, a patient may be presenting with symptoms equally compatible with both diagnoses, yet privately judge that a CFS/ME diagnosis is more appropriate than a Long Covid diagnosis. A patient might, for instance, be more confident in another trigger (another viral infection or trauma), or not be able to identify any acute trigger at all (perhaps noticing gradual onset over a long period of time). Yet with a lack of clear clinical guidance on CFS/ME, and a reasonable basis to believe that the social and medical support on offer would be poorer with a CFS/ME diagnosis, patients might be disposed towards pursuing a Long Covid diagnosis in order to be more likely to receive fuller investment, support and care.

Some patients, of course, have positive experiences with others (family, employers, medical professionals) such that they do not feel disposed towards particular types of narrative to protect themselves from harm. As a form of epistemic injustice, the concept of testimonial smothering is informative here in clarifying that this dynamic affects vulnerable groups: it is indicative of social privilege to be free of the suspicion that your theory of the case will end up denying you the receipt of adequate respect. In what follows, I further illustrate this by explicating ways in which structural dynamics can contribute to the complexity of a patient's predicament going under-recognised.

4.3. Appreciating complexity

An additional relevant feature of the types of narratives that are encouraged is that they do not sufficiently accommodate complex causality. In consequence, the aforementioned social dynamics risk *restricting* patient narratives. As I detailed earlier in this chapter, the type of causal explanation associated with legitimacy is typically biomedical, and not inclusive of psychological-level factors. Such causal explanations do not therefore equally accommodate causal factors which are neither necessary nor sufficient. These factors are medically important, since removing causal factors which are neither necessary nor sufficient can still play a role in preventing disease: indeed, though most identified causes are neither necessary nor sufficient to produce disease, a cause need not be either necessary or sufficient for its removal to result in substantial disease prevention (Rothman & Greenland, 2005).

We can see how this resistance to accommodate such elements of a causal explanation plays out in wider medical contexts if we consider a relevant example from endocrinology. Polycystic Ovarian Syndrome (PCOS), since it is safely classified as an endocrine disorder, is not stigmatised in the same way as contested illnesses, though its aetiology is still poorly understood, has unclear diagnostic criteria, and often takes a long time to be diagnosed: the causal explanation for PCOS is generally described as either "unknown", with a suggestion that genetic features are likely instructive. PCOS is still significantly stigmatised, however, in part because it affects only women.

Research into PCOS does suggest that there are causal factors at play which are neither necessary nor sufficient, however. Research shows that both psychological stress and insulin

resistance are causal factors which can influence the development of the condition (Franks et al, 2006; Crespo et al, 2018). However, they are clearly neither necessary nor sufficient: there are women who have been exposed to significant levels of psychological stressors who do not have PCOS, and there are women who have PCOS who have not been exposed to significant levels of psychological stressors. The same is true of insulin resistance. However, eliminating psychological stressors, or preventing insulin resistance, has potential to prevent the condition.

Even where such causal factors are recognised in medical literature, however, they are selectively embraced depending on the context, namely the nosological status of a given condition. A related issue is that how illnesses are classified depends upon the extent to which diagnostic technology can detect biomarkers, rather than being informed by our best available science on causation (Bell et al, 2020). Bell et al offer an example of damage to the nervous system to illustrate this point. Clinical diagnostics are rarely able to measure the presence of damage to the nervous system, and as such, the relevant syndromes associated with damage to the nervous system are rarely considered organic (p.6). There is, however, considerable scientific evidence that women who are subject to intimate partner violence see a brain injury prevalence of between 19-75%, but generally in the form of mild traumatic brain injury where diagnostic neuroimaging cannot detect changes (rather they have been detected in studies which examine damages to cognition and functional connectivity) (ibid). Despite this strong scientific evidence, the authors point out that discussions of the mental

health consequences of intimate partner violence are almost always framed in terms of social and emotional (or psycho-social) causation, without reference to injury to the brain.[71]

In the context of PCOS, attending to one of the two aforementioned causal factors, psychological stressors rather than insulin resistance, makes patients vulnerable to stigmatisation by virtue of being associated with the supposed unreality of "psychiatric" or "functional" illness. Featuring psychological stress at the forefront of a PCOS patient's theory of the case makes her vulnerable to the appraisal of her condition as less medically important than it might otherwise be, which might have consequences for her diagnosis and/or treatment.[72] Similarly, for a medical professional to pursue sensitivity to psychological stress in a clinical encounter with the patient might be considered uncharitable, delegitimising, or psychologising, in a way that pursuing insulin resistance would not.[73]

Here one must be careful not to underappreciate the negative effects of "psychologising" medical complaints, which can be vast. Indeed, PCOS is still significantly stigmatised, however, in part because it affects only women.[74] Psychologising, crucially, involves the psychological components of an illness being harmfully *over*-emphasised. People with poorly

[71] Interestingly, one recent paper found an increased prevalence in the development of Fibromyalgia and Chronic Fatigue Syndrome in female survivors of intimate partner violence (Chandan et al, 2019). They found that they were almost twice as likely to develop the conditions than women who had not been exposed to intimate partner violence.

[72] Bell et al (2020) also report that clinicians accommodate the functional/organic distinction in their practice as to strategically navigate healthcare systems in order to provide effective care for patients.

[73] At least in the UK under the NHS, it is actually somewhat optimistic to think that a case of PCOS might warrant this much medical attention in a typical clinical encounter given the financial and temporal constraints doctors currently face. It is therefore more likely that (i) diagnosis will be missed in favour of prescription of hormonal birth control (HBC) thus disguising symptoms and delaying further investigation, usually until the patient faces fertility challenges or that (ii) a diagnosis will constitute an end to the involvement of the doctor in the management of the condition.

[74] This is possibly the kind of thing that Perego et al had in mind in their BMJ blog when they described how being associated with women delegitimises a condition.

understood conditions are especially vulnerable to this because lack of understanding about the aetiology of a condition is often exploited, leaving room for neither necessary nor sufficient causal factors to be improperly weighted such that they are mistaken for causal factors which are. Hence, psychological-level causal factors can be over-weighted such that it turns a blind eye to the complexity of the condition. There is an important, though under-recognised, distinction between over-emphasising and recognising the psychological components of a given condition. That the latter is easily misconstrued as the former risks restricting both individual and collective attempts to understand Long Covid.

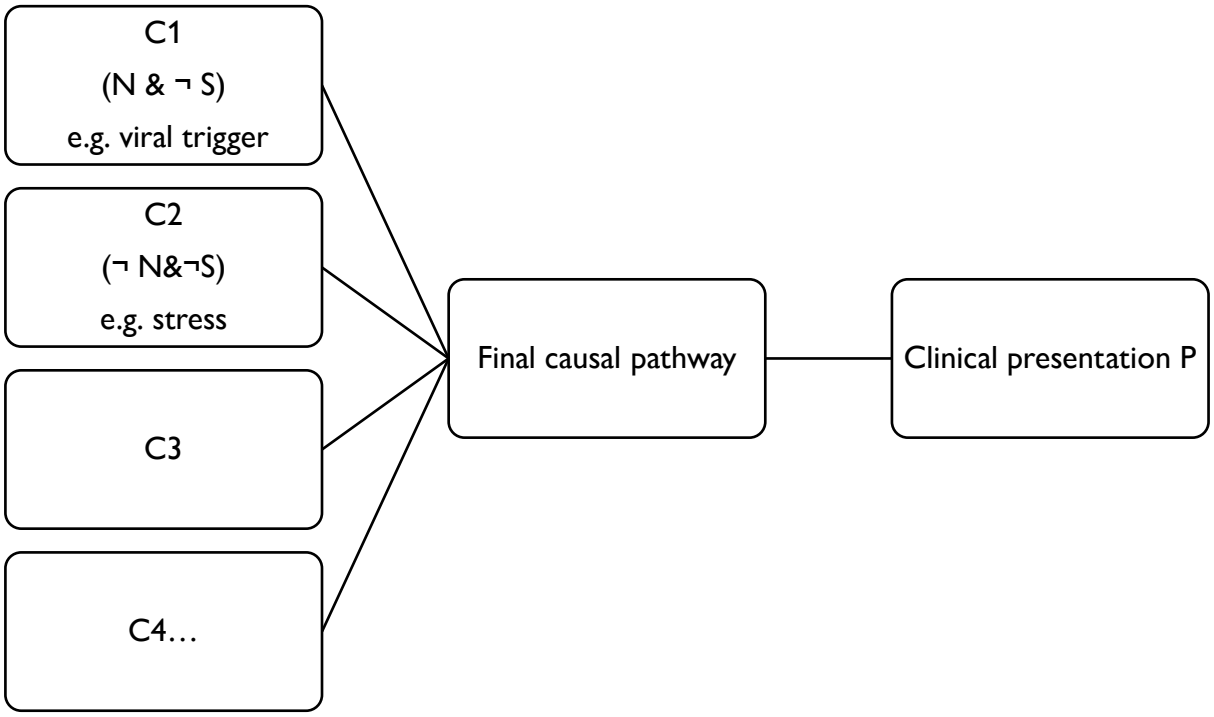

Fig.1. Causal factors. A causal factor C can either be necessary, N, but not sufficient, S (N&¬ S), or neither necessary nor sufficient (¬ N&¬S). E.g. C(N) in the context of Long Covid might be infection with SARS-CoV-2. Whichever causal factors trigger the final causal pathway are jointly sufficient. Recognising all causal factors at play is important for

> understanding the final causal pathway, just as blocking one causal factor can prevent the realisation of the final causal pathway.

As research suggests to be the case with CFS/ME, there might be various causal factors at play in Long Covid which are neither necessary nor sufficient, but for which intervention might be effective (see Figure 1). However, where these factors implicate the psychological life of the patient, they are not embraced, despite some good scientific grounds to embrace them. Indeed, this was illustrated by responses to Carmine Pariante's recent piece in *The Guardian*. Pariante commented that stressful life events can precipitate illness (mental and physical) and that conversely, psychological therapies can help patients with all manner of somatic diseases, CFS/ME and now Long Covid included (Pariante, 2021).

Some critics claimed that Pariante's approach is guilty of psychologising the relevant conditions at the expense of securing investment to fund biological-level treatment. Comments on the piece suggest that Pariante is perceived to be exploiting aetiological uncertainty by over-emphasising psychological-level causal factors, and thus undermining patients. This is an example of the conflation of recognising and over-emphasising psychological-level causal factors, such that merely acknowledging these causal factors seems to make oneself vulnerable to them being inflated by the hearer.

This dynamic can foster restrictive patient narratives in the ways I outlined earlier in this chapter, where structural dynamics give patients a framework by which to understand their own experience. Patients may be disposed towards constructing a particular illness narrative which meets the conditions associated with legitimacy, and by virtue of knowing that their suffering is real, patients might believe that psychological-level causal factors have no place

in their illness narrative. This is problematic where reasons for these dispositions are solely social, and survive upon the stigmatisation of other conditions.

These dynamics can be reinforced by the way that mental health challenges associated with Long Covid are discussed. A recent piece in *Science* notes that anxiety is an important feature of Long Covid experiences for some (Alwan, 2021). Alwan discusses causes of *secondary* anxiety such as being denied adequate support and recognition, writing "anxiety may be secondary to not recovering rather than being the primary manifestation of the illness". There seems to be a worry here that if anxiety were understood to be part of the primary dysfunction, this could delegitimise it: perhaps it would invite speculation about psychogenic causal mechanisms which would threaten the condition's classification as "organic". What is under-appreciated here, is the possibility that anxiety might be part of the primary dysfunction, yet an object of blame for the presence of such anxiety is not required. Where scientific evidence does not rule out cases of either primary or secondary anxiety in Long Covid and related conditions, dismissing the former risks restricting how some patients understand their own experiences of anxiety.

Indeed, the distinction between "primary" and "secondary" psychiatric dysfunction comes from a similar place to the functional/organic distinction and thus can also be called into question (see Chapter 3). Bell et al have made a nice observation about this:

> More recent diagnostic manuals have attempted to de-emphasise the functional-organic distinction although the changes are mostly cosmetic – by altering the terminology used to refer to 'organic' and changing how diagnoses are grouped. Psychiatric syndromes are now more commonly labelled as "secondary" to "disorders or diseases classified elsewhere" or

> "due to another medical condition" rather than 'organic' in both the DSM-5 and ICD although the implications are virtually identical. (2020, p.3)

One might also expect dynamics of testimonial smothering to apply here too. Some patients who are relevantly vulnerable may find themselves under pressure to reconfigure their illness narrative in order to protect themselves from stigma. Here, patients may restrict their illness narratives because they either assume or know that if they engage with potential psychological-level causal factors, this risks them being either undermined by the hearer, receiving worse standards of care, or both.

In a clinical context, if a patient explains that they are experiencing significant anxiety, this makes them vulnerable to having their predicament dismissed as less medically important than it would otherwise be if their complaints appeared more exclusively bodily. Whether a set of complaints are taken to be indicative of a functional/organic or psychiatric/somatic dysfunction implies "very different things about the patient's autonomy, responsibility and deservedness" (Bell et al, 2020, p.5). If it is true that the distinctions in question are not as convincing as the ubiquity of their use suggests, their influence in determining what types and standards of care are available to patients constitutes a gross failure. Challenging the deeply-entrenched hierarchy of illness and the distinctions which survive upon it is essential to make good progress with all of the relevant conditions such as CFS/ME, Long Covid, psychiatric illness and all other such conditions which uncomfortably sit somewhere in a rather grey in-between.

5. Conclusion

Given these considerations, the picture that emerges is that implicit social factors risk influencing patients to reconfigure and restrict their illness narratives in order to satisfy the conditions associated with legitimacy. These social factors survive on deeply entrenched, long-standing dynamics of stigmatisation against other sets of illnesses, namely psychiatric illnesses and contested illnesses like post-infectious fatigue syndromes which are delegitimised by association. As well as disadvantaging patients with CFS/ME, this obfuscates various aspects of scientific inquiry into "new" related conditions as they emerge, namely Long Covid. These dynamics ought to be challenged if we are to make social and scientific progress in both individual and collective understanding of all such implicated conditions.

Future Directions

I have shown in this thesis that philosophical, as well as scientific, work has a key role to play in developing a nuanced understanding of CFS/ME (and related conditions such as Long Covid). The philosophical analysis I have offered has highlighted the need for a revision of various commonplace distinctions and categories inside and outside of medicine. Principally, my analysis shows that one cannot understand CFS/ME within the confines of the distinction between psychiatric and somatic illness, functional and organic illness, and primary and secondary psychiatric dysfunction.

A key contribution of my analysis was to show that attempts to understand the relationship between CFS/ME and depression will continue to fall short so long as these distinctions keep their grip. As well as this, I have also shown that attempts to understand the relationship between CFS/ME and depression have so far been limited by failing to recognise the role of grief in CFS/ME. Recognising the presence and importance of grief here significantly contributes to the development of a sophisticated understanding of CFS/ME experience.

My analysis has brought to light a number of further questions which warrant careful investigation. Moreover, the phenomenological approach that I have applied here can be utilised in an ongoing philosophical research programme to further investigate additional aspects of CFS/ME experience which have been made salient by my account.

My phenomenological analysis of CFS/ME has brought to light various themes which appear to be salient in some cases, such as trust, loneliness, trauma and shame. In Chapter 6, I

touched on the fact that there is an important relationship between trust in certain people and certain institutions, and the development of certain illness narratives in CFS/ME and Long Covid. This raises the further question of whether and how experiences of trust and distrust can shape people's wider experiences of CFS/ME. An analysis of people's pre-morbid networks of trust could illuminate some of the currently under-appreciated social risk factors for the development of certain comorbid psychopathologies in CFS/ME which are currently lacking. In Chapter 3, I discussed how different styles of relationships are made more or less vulnerable by the particular CFS/ME symptoms faced. This raises the question of whether different relationships involve different types of trust. Further research into whether the *types* of trust one has in certain people or objects in advance of becoming ill shapes the phenomenology of the illness experience itself could offer significant insight here. Exploring the ways in which trust is compromised or lost in individual cases of CFS/ME supports the development of a better understanding of individual patients' distress; having the conceptual tools to understand the unique features of a given patients' experience supports the development of well-targeted therapeutic treatment.

The relevance of trauma in CFS/ME was acknowledged in the discussion of pathological grief (Chapter 2). I mentioned Therese Rando's (1997) claim that anticipatory grief often meets the criteria for post-traumatic stress. From this, I noted that the three respondents to my questionnaire study who mentioned trauma did so each time in the context of a discussion of loss. This observation raises the important question of whether there are experiences of trauma in CFS/ME which go under-recognised. If so, this would complicate matters in that the messiness of trauma will be introduced into existing discussions of the messiness of

depression and grief. A rich phenomenological investigation of trauma in CFS/ME and related conditions could illuminate things here. Better understanding how the destruction of one's previously taken for granted world can face radical upheaval, and why, how and whether this shift can be experienced as traumatic, could also have significant therapeutic benefit for patients; even just giving patients the tools to understand their experience in these terms might prove ameliorative.

This is importantly related to experiences of loneliness. In her work on trauma, Lillian Wilde builds on Gerda Walther's notion of "habitual unification" which is purported to constitute a background feeling of belonging in a shared world that characterises everyday experience. This sense of unification with others involves experiencing others as being similar in a significant way, as sharing the same "basic attitude" (Wilde, 2021). Trauma strips the person of this, shattering a once habitual sense of being unified with others. On Wilde's view, trauma challenges one's fundamental assumptions about the world, assumptions which were key to establishing meaningful connections with other people (p.8). Something like this is described by one of the EFQ participants:

> One further loss that I would mention is the ability to be on the same wavelength or level of understanding as other people. You are suddenly in a different world altogether and your needs and restrictions are completely alien to other people and often very tiresome to them. You can no longer understand or identify with their confidence in themselves and their worlds because you can see everything that is missing from their viewpoint and that they have recklessly failed to take account of. This creates a very jarring state in almost every exchange of conversation and it's felt as a kind of loss of innocence but also the gain

> of a kind of wisdom that is replete with grief and suffering and a terrifying kind of foresight' (#25)

This participant describes their predicament in the language of loss: innocence, wisdom, shared understanding. One is no longer on a shared wavelength with others, but is instead extradited from a shared world and thrust into a new, unfamiliar and lonely world. This raises the issue of whether experiences of loneliness are commonplace in CFS/ME. A number of additional research questions become pressing. Are there distinctive types of loneliness which people with CFS/ME are vulnerable to? What makes a person more vulnerable to more pervasive types of loneliness? How can loneliness be overcome here in order to restore what was lost?

Answering these questions will provide important insights into how the condition is experienced, as well as how the interpersonal dimension is implicated in its phenomenology. Better understanding the ways in which connections with others have been short-circuited has therapeutic potential in that it can illuminate not yet recognised ways of restoring connections with other people under exceptionally challenging circumstances.

My analysis of the impact of stigma in CFS/ME also raises interesting research questions about the experience of shame, since one might expect shame in medical contexts to be intricately related to stigma. For instance, where one is the recipient of a stigmatised diagnosis, one might be vulnerable to feeling shame in particular contexts where this diagnosis is disclosed to others. Plausibly, one can also experience shame over the loss of one's abilities such as bodily or cognitive capacity. Only one EFQ participant explicitly mentioned feelings of shame:

> It took a huge amount of pushing to be taken seriously by my GP. The lack of research, perhaps, can be to blame for this, but I did feel ashamed going to my GP, who was so keen to diagnose me with depression and move on. (#31)

This response is suggestive of an experience of shame attached to an experience of CFS/ME in so far as CFS/ME is associated with depression. It is plausible that the threat of being diagnosed with a psychiatric illness, with all that this brings, can exacerbate and add an additional dimension to the already shameful experience of being made physically, cognitively and emotionally vulnerable by illness. Closely studying experiences of shame in CFS/ME has potential to demonstrate the impact of such stigma on patient experience.

It is important to acknowledge that experiences of shame in medical contexts are not only relevant to patients but also to healthcare professionals who are also vulnerable to shame where they are also vulnerable to human error. As Lyons, Gibson and Dolezal (2018) write:

> Despite the importance of transparency about medical error and initiatives to ensure patient safety, there remains a culture of blame and shame in health care. […] That doctors are willing to write about the emotional aspects of practice is important. Stories about shame inform us of how debilitating it can be, how it can impact upon relationships with colleagues and patients, how it may undermine personal and patient welfare, and how we might develop strategies to prevent or manage its more invidious manifestations.

An important research topic here is the perspective of the relevant medical professionals dealing with people presenting with CFS/ME. As I discussed in Chapter 5, medical professionals can be criticised for failing to listen to patients as well as failing to take appropriate action to ensure the correct diagnosis and treatment for them. I discussed

studies which looked into GP attitudes to CFS/ME which found considerable uncertainty about what the condition is, and how it is best handled in primary care. I drew attention to how conceptual and epistemic issues around CFS/ME can exacerbate this. My contribution here shows the need to carefully investigate the burdens of being the epistemic authority for such a challenging illness for which there is no clear course of action. It is not so much medical error that is relevant here, but rather the feeling of not being able to do *anything*. It is therefore important to investigate feelings of failure and powerlessness amongst practitioners here. Establishing whether and to what extent practitioners experience shame here could highlight opportunities for training and/or support. Offering a different perspective, this work would also add nuance to existing literature on GP attitudes to CFS/ME, creating a more comprehensive picture which reflects the experiences of all relevant stakeholder groups.

Interdisciplinary work

As well as considering how phenomenological research can help to shape and inform scientific practice, it is also important to nurture mutually-illuminating interactions between philosophy and other disciplines such as social sciences and psychology, as well as branches of medical science like psychiatry, endocrinology and immunology. It is by challenging the firmly-entrenched distinctions between psychiatric and somatic illness, and functional and organic illness, that new avenues for interdisciplinary research become possible.

Nosology

As I defended in the Introduction to this thesis, I have worked with a broad notion of CFS/ME here. Peter White has recently written in favour of this view from a strategic point of view. He argues that from a broad starting point, subsequent research can identify relevant clusters and sub-groups which could serve as a spring-board for better understanding how the condition, or particular sub-categories of it, relate to particular viruses or infections as well as other recognised conditions such as depression. As White writes:

> Subgroups can then be sought by screening for different factors, depending on the hypothesized aetiological factors being studied. Type of onset could be a subgrouping phenomenon, such as the illness being triggered by a specific infection. Alternatively, categorization could be by comorbid disorders, such as mood disorders or other functional somatic syndromes. Behaviour could be used to classify classes by physical actigraphy and/or sleep architecture. Biological categorization could include hormonal assays such as the hypothalamic-pituitary-adrenal axis, or these could be the hypothesized pathophysiology to be tested in classes defined indifferent ways. Psychosocial associations could be studied by looking at life events and difficulties and their psychiatric and physiological consequences. (White, 2019)

These hypothesised categories might delineate groups for further philosophical study. From this, the subsequent phenomenological work can contribute to the refinement of the hypothesised categories. Detailed phenomenological analysis, as I have shown, can provide nuanced ways of distinguishing between experiences which might seem superficially similar under certain frameworks, such as typical depression screenings which do not consider the possibility that the patient is experiencing grief. This work can point towards ways of

establishing better validity for a variety of other hypothesised sub-groups, some of which are categorised based on prevalence of mood disorder (see Chapter 1).

Some psychiatrists are working on better understanding the genetic bases of CFS/ME and other related "boundary" conditions. For instance, Kenneth Kendler is currently working on the genetic bases for CFS/ME, Fibromyalgia and Irritable Bowel Syndrome.[75] Better understanding these conditions on a genetic level has potential to lessen the burden of distinctive types of stigma against patients, namely, stigma against conditions whose biological-level basis is "mysterious". There are other branches of psychiatry committed to "closing the gap" between psychiatric and somatic illness. This has potential to advance the understanding of boundary conditions like CFS/ME which, under current frameworks, sit in an uncomfortable "no man's land". For instance, in a defence of the discipline of immunopsychiatry, Pariante writes:

> [T]his new theoretical approach facilitates the identification of biological mechanisms and therapeutic interventions with well-defined, hypothesis-based immune mechanisms and pharmacological targets. This, together with the introduction of the notion of psychiatric disorders as disorders with biological changes that are outside the brain and measurable in the blood, could close the gap between psychiatry and the rest of medicine, potentially reducing the stigma associated with mental health problems. (Pariante, 2015)

Though I have raised issues with approaches to tackling stigma which rely upon biological-level breakthroughs, it is important to acknowledge the instrumental value that research at this level could have. Supporting biomedical research into CFS/ME is compatible with

[75] Personal correspondence.

philosophical argument for the view that biological-level understanding should not be the condition for the illness having medical legitimacy. Research of this type is not seeking a mystery-busting biomedical breakthrough discovery for CFS/ME, which (a) has historically been difficult and (b) demands something which is likely unachievable. Rather, doing this work has great potential for challenging and dismantling the distinction between bodily and psychiatric illness while leaving room to accommodate heterogeneity in presentation and aetiology.

Patient support

The detailed and informative responses I received in the EFQ shows this to be a useful method for further study into CFS/ME and related conditions. Another study, similar in structure to the EFQ with a revised set of follow-up questions, could be conducted in order to explore in greater detail some aspects of experience which came to light in the original data set. In Chapter 3, I discussed how engagement with support groups and patient networks can be an exception to a general state of feeling misunderstood and cut off from others in CFS/ME. Somebody with CFS/ME might, for example, have lost trust in people in general but be able to sustain a sense of connectedness to other people with similar experiences of CFS/ME, that is, people that understand. Getting at something like this, one questionnaire respondent wrote: "The relief when I walked into my first meeting [at] the [redacted] Fatigue Group was huge. Suddenly there was a group of people who "got it"." (#20)

Existing empirical work suggests, however, that there is a balance to be struck here between finding other people with CFS/ME with whom one can be "on the same

wavelength", and being adversely affected by types of engagement with the relevant support groups. These adverse effects relate to the impact that patient support groups can have on illness perceptions, and the effect that illness perceptions can have on outcome in turn (Friedberg et al, 2005; van Houdenhove & Luyten, 2008). Huibers and Wessely describe some of these effects:

> Ultimately, a pessimistic illness perception can become a self-fulfilling prophecy of nonrecovery. This group of CFS patients tends to view their symptoms as part of an overwhelming, mysterious, unexplainable disease that struck them out of the blue and from which they most likely will never recover. These illness expectations are often fuelled by the media, support groups (not least because support groups have an inherent bias towards those who have not recovered) and other sufferers (Huibers & Wessely, 2006).

In my view, more empirical work is needed here to clearly calculate the advantages and disadvantages of involvement with patient support groups. A phenomenological stance would be useful in such empirical work. Outcomes of phenomenological work into the type of interpersonal connectedness that support groups offer can provide an important contribution to a study into the balance which needs to be struck between patient support groups offering support for and recognition of the many challenges faced by patients, but also remaining recovery-orientated.

Prevention and treatment

Thinking beyond the current constraints on the current UK National Health Service (Buck, 2018), there is a wealth of outstanding scientific research into CFS/ME and related conditions which is important for developing preventative and ameliorative measures which

can be employed before the "final causal pathway" is triggered. Thinking preventatively, some social and political change is required: extant research is suggestive of a number of social determinants for the development of CFS/ME, for instance Chandan et al (2019) showed that exposure to intimate partner violence increases risk of developing CFS/ME and related condition Fibromyalgia. Thinking amelioratively, there is some interesting research on the anti-inflammatory effects of Vagus Nerve Stimulation (VNS) on a variety of conditions including related condition Fibromyalgia (Johnson & Wilson, 2018).

Some scientific work on ameliorative measures such as these can be supplemented by phenomenological work. Collaboration with interdisciplinary centres and researchers who have looked at the efficacy of embodied movement therapies are especially promising here. As reported by Koch et al (2013), work in philosophical phenomenology has given rise to theories of body memory which has inspired the development of the subsequent embodied therapies which can be used in a variety of contexts such as in trauma or post-natal depression. Koch et al (2019) suggest that dance interventions can assist emotion regulation, writing that it "may be mediated, for example, by authentic expression, experienced agency, body–mind integration, and physiological changes". Physiological changes following dance and movement therapies have been documented, such as in relieving hypertension (Conceição et al, 2016).

The theoretical work here is in its early stages. There are a variety of ways in which further philosophical research could contribute to its development. My account of the variety of ways in which CFS/ME can impede emotion regulation opens up possibilities for research into how (i) embodied therapies which facilitate emotion regulation might be identified as a

therapeutic target for CFS/ME and (ii) further phenomenological work into emotion regulation can provide a useful framework for thinking about barriers to emotion regulation in a variety of other contexts. Outcomes from such interventions can be used in turn to refine the theoretical foundation. For instance, it might become clearer how one can distinguish between primary and/or comorbid depression, grief and trauma with reference to bodily phenomenology by monitoring differential treatment responsiveness to certain embodied therapies.

There is a wealth of possible future research directions for the interdisciplinary study of CFS/ME and related conditions. I have provided a valuable starting point here by showing how a philosophical perspective provides novel and unique insights into the complexities of the experience of CFS/ME, complexities which have so far gone under-appreciated. I have shown how operating within the confines of the distinctions between psychiatric and somatic illness, functional and organic illness, and primary and secondary psychiatric dysfunction restricts the development of a rich understanding of CFS/ME which is sensitive to its pervasiveness, heterogeneity and intrapersonal dynamism. The perspective I have offered here allows CFS/ME to be understood in all of its awkward detail.

Appendix 1: Notes on methodology

Study design

Objectives

This objective of this questionnaire study was to investigate aspects of the experience of the condition, which is currently lacking.

Questions

Participants were asked twelve questions, listed below. Excluding these twelve, participants had to tick a mandatory "informed consent" box, and select whether or not they were happy to be asked follow-up questions. All 31 participants answered "yes" here, but no follow-up questions were issued. The twelve questions asked were as follows:

1. How does CF/CFS/ME make your body feel?
2. How does CF/CFS/ME affect your emotions and moods?
3. How, if at all, has CF/CFS/ME affected your sense of self?
4. In what ways, if at all, does your experience of CF/CFS/ME make the world seem different to you?
5. Has your experience of CF/CFS/ME involved any sense of loss?
6. How do you feel about the future?
7. How, if at all, has CF/CFS/ME affected the way you think?
8. Is your experience of CF/CFS/ME constant, or does it change over time? If so, how?
9. How, if at all, have the views and advice of others impacted your experience?
10. Do you feel as though there is a 'right' way to respond to having CF/CFS/ME?
11. How, if at all, has CF/CFS/ME affected your relationships?

12. Please add anything else you would like the investigator to note about your experience of CF/CFS/ME. You may be asked follow-up questions on points of interest.

Informed consent

Consent was sought by embedding a mandatory tick-box onto the online questionnaire. Participants were required to tick the box which stated they had read and understood the Information Sheet, for which there was a link to the document held on Google Drive.

Recruitment and sampling

Participants were eligible to participate only if they experience or experienced CF/CFS/ME, either self-defined or officially diagnosed; were an adult, were English speaking; and had given Informed Consent.

An invitation to participate in this study was disseminated to various groups. I targeted a number of local and national patient groups such as the well-known ME Association and local branches associated with it. Cognisant of the potential for bias here given the fact that preference for the term "ME" over "CFS" is socially and politically loaded, I was careful to address this. I also disseminated the invitation to participate to staff (academic and non-academic) and students at the University. I anticipated that this would attract a broader range of participants, some of whom will not have had formal diagnoses, thus capturing "hidden cases" as well. The questionnaire was also publicly advertised on a number of online fora, including a "Long Covid" Facebook group. Data was collected online via a questionnaire hosted by Google Forms. There was a final sample size of 31.

Limitations and risks

One limitation of the sample here is that the most severely ill patients were automatically excluded by virtue of not being well enough to navigate a computer. A consequence of this

is that my data fails to accommodate the experience of a particular *type* of person with CFS/ME.

Given the subject matter, there was a risk of participant distress in reciting personal and often upsetting life experiences. This was mitigated by the reminder to participants that they had complete control over how much detail was offered in their responses, and that no question was mandatory. Safety measures for sign-posting were in place for any participant that disclosed information which required further action.

Data storage and analysis

Data was obtained and stored on a secure University drive in accordance with the proposal approved by the University of York Arts & Humanities Ethics Committee. Data was anonymised two weeks from reception to give participants the opportunity to make edits to their submission. I used a linking code, also stored on a secure University drive, to link participant email addresses to the anonymised participant number.

I carried out a thematic analysis on the data obtained, in line with recent research on thematic analysis within a qualitative paradigm (see Clarke & Braun, 2017). The themes were largely pre-delineated by the questions asked (e.g. loss; sense of self), however, each transcript was analysed line by line to identify key themes which were not explicitly accommodated by the original set of questions (e.g. emotion regulation).

Appendix 2: Information sheet

A Questionnaire on Chronic Fatigue/Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

Information Sheet

Background

The University of York would like to invite you to take part in the following research project: A Questionnaire on Chronic Fatigue/Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CF/CFS/ME). Before completing the questionnaire, please read the following carefully.

The Principal Investigator (PI) Eleanor Byrne, is a PhD candidate in the Department of Philosophy, University of York. The PI's questionnaire design, to be integrated into the PI's doctoral thesis, has passed a thorough ethical review from the University of York's Arts and Humanities Ethics Committee.

Questionnaire outline

This questionnaire aims to explore some aspects of the experience of CF/CFS/ME. A detailed and sophisticated understanding of the lived experience of CF/CFS/ME is currently lacking. This research aims to develop such understandings, developing an account of the lived experience of CF/CFS/ME in contrast with analyses of other illnesses and adverse life events.

Participants will be sent, through email, a link to a questionnaire which is to be completed and returned online within two weeks. Depending on the responses given, participants may be sent a further set of follow-up questions. These are to be completed and returned within a further two weeks. No questions are compulsory, and the length of the responses is entirely up to the participant. Participants are also welcomed to respond to the questions as formally or informally as they wish.

You can edit your responses once you have submitted the form, if you wish to come back to it later. All edits will be accommodated until two weeks after the form was sent.

Participants may find writing about their experience of CF/CFS/ME difficult. Participants should note that it is entirely up to them how much/little they disclose. Participants should also welcome the opportunity to share their experience and contribute to knowledge in an area that is critically ill-understood.

Why have I been invited to take part?

You have been invited to take part because you have identified as suffering from, or having suffered from, CF/CFS/ME.

Do I have to take part?

No, participation is optional. If you change your mind at any point during the study (i.e. the two weeks given to respond to a set of questions), you will be able to withdraw your participation without having to provide a reason. Should you wish to do so, please contact the PI.

Data processing

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR:

Processing is necessary for the performance of a task carried out in the public interest

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data.

In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the GDPR.

Data will be processed for the purposes outlined in this notice.

Will you share my data with 3rd parties?

Anonymised full transcripts may be made available to the PI's academic supervisors, Professor Matthew Ratcliffe (matthew.ratcliffe@york.ac.uk), Stephen Holland (stephen.holland@york.ac.uk) and potentially thesis examiners (currently unknown).

Anonymised direct quotes in research outputs may be reused by the PI or other third parties for secondary research purposes. Participants will have access to the research output once the Researcher's doctoral thesis is published on the White Rose eTheses online repository.

How will you keep my data secure?

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data. For the purposes of this project, we will keep data on a secure University drive.

Information will be treated confidentiality and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project. In addition, we will anonymise or pseudonymise data wherever possible.

Will you transfer my data internationally?

No. The University's cloud storage solution is provided by Google which means that data can be located at any of Google's globally spread data centres, however, the University has data protection complaint arrangements in place with this provider. For further information see, https://www.york.ac.uk/it-services/google/policy/privacy/.

Will I be identified in any research outputs?

No. All data included in research outputs will be anonymised by the Researcher.

How long will you keep my data?

Data will be retained in line with legal requirements or where there is a business need. Retention timeframes will be determined in line with the University's Records Retention Schedule.

What rights do I have in relation to my data?

Under the GDPR, you have a general right of access to your data, a right to rectification, erasure, restriction, objection or portability. You also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see https://www.york.ac.uk/records-management/generaldataprotectionregulation/individualsrights/.

Questions or concerns

In the first instance, for all questions relating to the research project, please contact the PI, Eleanor Byrne (eleanor.byrne@york.ac.uk).

If you have any questions about this participant Information Sheet or concerns about how your data is being processed, please contact Keith Allen, Chair of the Arts and Humanities Ethics Committee (keith.allen@york.ac.uk). If you are still dissatisfied, please contact the University's Acting Data Protection Officer (dataprotection@york.ac.uk.)

Right to complain

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.

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