Epistemic in/justice in patient participation. A discourse analysis of the Dutch ME/CFS Health Council advisory process

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Abstract

In healthcare settings, patient participation is increasingly adopted as a possible remedy to ill people suffering from ‘epistemic injustices’ – that is to their unfair harming as knowers. In exploring and interpreting patient participation discourses within the 2013–2018 Dutch Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) Health Council advisory process, this paper assesses the epistemological emancipatory value of this participatory practice. It reveals that in the analysed case, patient representatives predominantly offer biomedical knowledge about ME/CFS. They frame this condition as primarily somatic, and accordingly, perceive appropriate diagnostic criteria, research avenues and treatment options as quantifiable, objectifiable and explicitly non-psychogenic. This paper argues that such a dominant biomedical patient participatory practice is ambiguous in terms of its ability to correct epistemic injustices towards ill people. Biomedicalized patient participation may enhance people’s credibility and their ability to make sense of their illness, but it may also undermine their valid position within participatory practices as well as lead to (sustaining) biased and reductive ideas about who ill people are and what kind of

Abbreviations: CFS, chronic fatigue syndrome; ME, myalgic encephalomyelitis.
INTRODUCTION

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a highly contested condition. Its symptomatic appearance and cause, the evidence base for treatments, and even its existence is subject to fierce controversy for decades now (Brown et al., 2017; Lian & Bondevik, 2015). Consequently, people who experience symptoms of (or related to) ME/CFS report run into disbelief, stigmas, negative stereotyping and medical and financial disadvantage (Blease et al., 2017; Deale & Wessely, 2001). In order to deal with these people's marginalization, health politicians and policymakers increasingly opt for patient participation in setting policy agendas for research and care (Dieleman, 2015). This paper focuses on patient participation in ME/CFS policymaking.

In the literature, patient participation is generally appreciated for its emancipatory goals. This participatory practice aims to enable people to understand and express their subjective illness experiences and to institutionalize the integration of these experiences in deliberative settings that predominantly privilege the knowledge of clinicians, policymakers and researchers (Newbigging & Ridley, 2018). In doing so, patient participation may contribute to (better) fitting and (more) inclusive care and research endeavours for ill people (Abma, 2005; Beresford, 2003; Caron-Flinterman et al., 2007).

While many scholars debate how patient participation can be effectively implemented in healthcare policymaking (see a.o Caron Flinterman, 2005; Lewin et al., 2001; Malfait et al., 2018; Storm & Edwards, 2013; Bovenkamp et al., 2010), few studies assess the assumptions underlying patient participation. That is, this practice's emancipatory goals presume that ill people are indeed enabled to offer complementary and valuable experiential knowledge of illness within and through a formal, deliberative setting (Carel & Kidd, 2014; Goldberg, 2010; Irwin, 2006). By offering a systematic empirical examination of how people with ME/CFS actually participate in healthcare policymaking – and interpret why they do so – this paper provides an assessment of the emancipatory value of this participatory practice as well as briefly reflect on what may be done to improve patient participation in terms of genuine influence.

In order to do so, this paper uses discourse analysis to examine a critical case of ME/CFS patient participation: the most recent Dutch ME/CFS Health Council advisory process. In reaction to the 2013 citizen's initiative ‘Recognize ME’, the Dutch Health Council installed an advisory committee that would eventually deliver a report on diagnosing, researching and treating ME/CFS in 2018. While the Health Council usually bases their advices on scientific, evidence-based research, this Council's committee was the first with extensive patient engagement. In analysing discourses in this advisory process, Fricker’s (2007) concept of ‘epistemic injustice’ and, more broadly, social epistemological studies are used as heuristic tools. Fricker's conceptual framework not only helps to reveal that the marginalized positioning of people with ME/CFS may be traced back to their unfair knowledge they hold. The final section of this paper offers a brief reflection on how to navigate such biomedicalized participatory practices in order to attain more emancipatory ones.

KEYWORDS
chronic fatigue syndrome, discourse analysis, epistemic injustice, health council, myalgic encephalomyelitis, patient participation, social epistemology
harming as knowers, but also that discriminatory and emancipatory epistemic aspects influence and shape the ways in which patients participate in the ME/CFS Health Council advisory process. Social epistemological studies, moreover, help to understand how strategies and practices of patients within the advisory process contribute to establishing, sustaining or disregarding their epistemological positions about ME/CFS in relation to other participants in the advisory process (Anderson, 2012; Kidd & Carel, 2017; Maitra, 2010; Sherman, 2016).

BACKGROUND

Marginalization of ME/CFS patients

Within (social) media outlets and through patient organizations, people with ME/CFS report being misrecognized and stigmatized by healthcare professionals and by society in general (Blease et al., 2017; Grue, 2014). This marginalized position can be partly attributed to the fact that scientific debates still revolve around the diagnosis and etiology of ME/CFS. Central issues within these debates are whether ME/CFS is distinguishable from other diseases; what kind of symptoms are characteristic for this disease (Ware, 1992; Wessely et al., 1998); whether or not ME and CFS are separate diseases (Brown et al., 2017); and whether its cause is physical, psychological or both (Newbigging & Ridley, 2018). These discussions reveal the scientific uncertainty surrounding ME/CFS, which in turn fuels judgements about this illness as an invalid, self-inflicted or even imaginary condition (Newbigging & Ridley, 2018). Such preconceptions have real repercussions for whether and how people with ME/CFS have access to appropriate care (Anderson, 2012). Note that at the heart of this marginalized positioning of people with ME/CFS lie epistemic concerns about what knowledge is considered credible, who is integrated in spaces of knowledge production, and how such integration takes place.

Epistemic injustice in ME/CFS

In theorizing the relationship between the marginalization of certain groups and their incapacity to create and share knowledge with others, Fricker (2007) coins the term ‘epistemic injustice’. This kind of injustice occurs when someone is unfairly harmed in her/his capacity as a knower. Fricker distinguishes two related kinds of epistemic injustice: testimonial and hermeneutic. Both injustices originate in a prejudice against certain knowers because of their social identity. Testimonial injustice occurs when someone is deprived of her/his credibility due to unfair identity prejudices (Fricker, 2007). Such unjust positioning amounts to, for example, groups of certain disdained genders or ethnicities, or – relevant to this paper – to ill people whose testimonies are dismissed or seen as less valuable by virtue of being negatively stereotyped as ill persons (Byrne, 2020). Hermeneutic injustice, moreover, renders someone unable to even articulate and give meaning to her/his experiences, much less communicate them to others (Fricker, 2007). People suffer from this kind of injustice when, as a result of structural identity prejudice, the interpretative sources available to them – such as shared stories, representations, concepts, etc. – are lacking or are too impoverished in order for them to understand their experiences (Anderson, 2012; Maitra, 2010).

Ill people are arguably particularly vulnerable to testimonial injustice because they are often attributed with certain characteristics that negatively affect their credibility, such as being emotionally unstable or irrational (Carel & Kidd, 2014). These people are also at risk for suffering from hermeneutic injustice. Since people who are ill are often reductively represented in public life – or not
represented at all –, they only have inadequately developed interpretative resources available in order to understand and make sense of their subjective illness experiences (Blease et al., 2017; Byrne, 2020; Carel & Kidd, 2014). In the case of ME/CFS, these two injustices seem closely linked and work to sustain each other. Blease et al. (2017) writes that the aetiological uncertainty about ME/CFS about the illness persists in stigmatizing and negatively stereotyping people afflicted with this condition and in insufficient conceptual resources for understanding and managing ME/CFS. As these people are stereotyped as imagining their symptoms, it may deflate their credibility through which they may have trouble accessing realms wherein knowledge is produced. This kind of exclusion in knowledge production settings may lead to a lack of appropriate shared resources about the illness and, consequently, to people finding it hard to understand and communicate their subjective ME/CFS experiences (Blease et al., 2017; Byrne, 2020). Then, when these hermeneutic gaps are interpreted as correlating with an in/capacity of ill people as knowers, it may, again, decrease their credibility and lead to testimonial injustice.

Un/just patient participation

One proposed remedy to epistemic injustices in healthcare settings is patient participation (Abma, 2005; Beresford, 2003; Caron-Flinterman et al., 2007). In the last two decades, healthcare politicians and policymakers have increasingly been experimenting with engaging ill people and patients in formal healthcare policymaking deliberations (Dieleman, 2015; Moes et al., 2020). This potential solution works under the assumption that these people's institutionalized place in deliberative settings as such enhances their credibility, but also that this institutionalization contributes to the enlargement of their ability to understand and reflect on their illness experiences, on their place in the world, and therefore, to find and share their ‘voice’. These people's voices, then, are presumed to utter a particular kind of knowledge: subjective illness experiences. This knowledge would provide insight into what it means to experience and deal with an illness from a first-hand, everyday perspective. As such, it is arguably intrinsically valuable to the development of healthcare policy agendas: aligning policy decisions with people's needs and wants regarding their illness would lead to more inclusive and better fitting care. This kind of experiential knowledge, moreover, is considered to be exclusively possessed by patients and ill people and as such, is complementary to those of the generally more dominant groups in healthcare deliberations: clinicians, policymakers and researchers. These latter groups would mainly offer biomedical knowledge that pertains to the physiological processes underlying the manifestations of a disease, something that is researched within various medical specializations such as biochemistry, microbiology and neurology (Abma, 2005; Beresford, 2003).

Many scholars underline the importance of patient participation as a correction to epistemic injustices and, as such, discuss its practical implementation (See a.o Caron Flinterman, 2005; Lewin et al., 2001; Malfait et al., 2018; Storm & Edwards, 2013; Bovenkamp et al., 2010). However, only few studies address foundational epistemological issues regarding this participatory practice, namely whether and how ill people are indeed enabled to offer complementary and valuable experiential knowledge of illness within patient participation – and if so, whether they are able to sustain and establish their knowledge as valid. Some scholars raise concerns about the ‘epistemological status’ that is accredited to ill people's knowledge (Irwin, 2006). These persons may not always have the capacities to effectively deal with the epistemic possibilities and difficulties of participating in formal decision-making procedures (Goldberg, 2010; Irwin, 2006) – something that could result in ‘symbolic patient participation’ (Peeters et al., 2014). In response to this risk, researchers in, for example, disability studies and mad studies encourage political and personal empowerment of ill people and strengthening peer
support (Beresford & Russo, 2016; LeBlanc & Kinsella, 2016; LeFrançois et al., 2013). Moreover, some scholars argue that negative identity preconceptions of clinicians and policymakers may still persist in institutionalized participatory settings, thereby contributing to (sustaining) unfair credibility judgements and inequalities in accessing knowledge sharing and production (Carel & Kidd, 2014; Irwin, 2006). In order to combat such persevering injustices, Carel and Kidd (2014) propose a phenomenological toolkit that would not only provide ill people with a framework for patient participation through which they may better understand and articulate their experiences, but that would also increase professionals’ epistemic humility and awareness of their prejudices in participatory practices.

Note that the common denominator within these critical approaches to patient participation is that they assume that with a focus on strategies and practices on the individual-interactional level – strengthening ill people's voices, increasing professional's epistemic humility, etc. –, ill people will (be able to) offer complementary, invaluable experiential knowledge. It is argued, however, that such approaches lack a sociological or social epistemological perspective that is pivotal in understanding and correcting epistemic injustice (Alcoff, 2010; Anderson, 2012; Maitra, 2010; Sherman, 2016). There are systemic sociocultural barriers at play that shape injustices on an individual epistemic level and that prevent ill people from understanding and sharing their experiences in participatory settings. Examples of such barriers are the deep cultural ingraining of ill persons’ negative stereotypes (Anderson, 2012) and the typical socialization of health professionals and policy workers of understanding dysfunctions in somatic, biomedical terms (Kidd & Carel, 2017; Wardrope, 2015).

While these debates about patient participation offer valuable insights into this practice – and how it may (not) be emancipatory –, they are predominantly theoretical in nature and lack a systematic empirical examination of what patient participation entails in practice. This paper contends that we can only begin to understand patient participation and its in/capacity to correct epistemic injustices when we empirically investigate how ill people and patients actually epistemically participate in a concrete deliberative setting. Against the backdrop of abovementioned theoretical debates about epistemic injustice and the importance of adopting a social epistemological lens in understanding and fighting this injustice, this paper starts by asking what kind of knowledge people with ME/CFS provide in the participatory setting of drawing up the 2018 Dutch Health Council advisory report on ME/CFS.

Patient participation in Dutch ME/CFS healthcare policymaking

The Dutch Health Council advisory process on ME/CFS provides a critical exemplar of attempting to correct epistemic injustices through an extensive encounter between healthcare researchers, clinicians and patient representatives. This case of patient participation commences in the fall of 2013, when the ME-The Hague support group submitted its citizen's initiative ‘Recognize ME’ to the Dutch House of Representatives. In response, the Minister of Health asked the Health Council for advice on how to respond to this initiative. After consulting various scientists, health professionals and patient organizations, the Health Council installed a ME/CFS advisory committee in 2016. Two of the committee’s members were patient representatives: one was the representative of three cooperating patient organizations, and the other was affiliated to the ME-The Hague support group. The committee also took into account additional solicited advices from patient organizations, and from health professionals and researchers. The rationale behind including patient representatives and advices from patient organizations in the advisory process is explained in the 2018 advisory report of the committee:

The committee decided from the start that she would base her answers to the questions of the House of Representatives not only on the scientific state-of-the-art, but also – entirely
in the spirit of evidence-based medicine – on the knowledge, experiences and values of practitioners and patients, which are both represented in the committee.

(Health Council report 2018, 2)

The advisory report of the Health Council was signed by one of the committee’s patient representatives (i.e. the affiliate of the cooperating patient organizations) while the other representative formulated a minority view.

METHODOLOGY

In order to examine how people with ME/CFS and their representatives epistemically participate in the Dutch Health Council advisory process and whether this participation contributes to an emancipatory practice, this paper uses critical discourse analysis. That is, in delineating and interpreting discourses related to patient participation in the ME/CFS Health Council advisory process, this paper understands discourses as a social practice and examines the relationship between texts and power structures (Wodak, 2001). This means that it aims to understand the relation between, on the one hand, texts used in the ME/CFS advisory process that feature patient (representative) knowledge and, on the other hand, the constitutive significance of societal power relations, privileges, stigmas, inclusions and exclusions (Martínez-Ávila & Smiraglia, 2013). Through this approach, this paper attempts to establish the main themes related to knowledge sharing and production by people with ME/CFS in the contextualized advisory process, investigate the discursive strategies used, and analyse the implications of these themes and strategies for the practice of patient participation (Sandelowsky, 1995; ten Have, 1995; Wodak, 2009). In assessing these patient participation discourses, this paper builds on a corpus of literature that help to understand the analysed documents and their contextualization (o.a. Blease et al., 2017; Byrne, 2020; Fricker, 2007; Jutel, 2009; Persad, 2017; Sulik, 2011).

This discourse analysis includes texts that are drawn up in the ME/CFS Health Council advisory process and that feature patient (representative) knowledge, namely (1) documents received from the Dutch Health Council after submitting a ‘Freedom Of Information’ (FOI) –request, (2) the publicly accessible Dutch ME/CFS Health Council advisory report (Health Council 2018) and (3) the publicly accessible citizen’s initiative (ME-The Hague 2013). This means that the discourse analysis only includes texts that either have patient representatives as their author(s) or that refer to patient knowledge. See Table 1 for a detailed overview of the included documents in the discourse analysis.

The initial discourse analysis phase meant reading through the many pages of the included texts with an eye to featured knowledge of people with ME/CFS. With this focus, these documents were coded and, in turn, compared in order to identify broader themes and subthemes (ten Have, 1995). Examples of these initial codes were: ‘research: biomedical’; ‘treatment: psychological’; ‘recognition of being ill’. By consulting the literature on patient participation, epistemic injustice and social epistemology coherent patterns within and across these (sub-)themes were identified (Sandelowsky, 1995). As the analysis phase continued and the understanding of connections between different themes progressed, existing codes were re-coded if necessary. Eventually, this analysis identified four main themes and two subthemes related to knowledge sharing and production by people with ME/CFS (and their representatives) in the context of Dutch ME/CFS Health Council advisory process. The themes are:
TABLE 1  Overview of the analysed documents

| Document(s)                        | Contains                                                                 | Author(s)                           | Source                                                                 | Year  |
|------------------------------------|--------------------------------------------------------------------------|-------------------------------------|------------------------------------------------------------------------|-------|
| The citizen's initiative           | Petition ‘Recognize ME’                                                 | ME-The Hague group                  | Publicly accessible on: https://deziektcme.petities.nl/ (last retrieved 25-6-2020) | 2013  |
| Letters to/from the House of Representatives to/from the Dutch Health Council | Correspondence about the viability of the initiative                    | Minister of Health; director Dutch Health Council | FOI-request                                                        | 2013–2016 |
| Letters from the Health Council to ask patient organizations for advice | 5 Requests for advices to patient organizations prior to the committee's instalment | Director Health Council             | FOI-request                                                           | 2015  |
| Solicited advices from patient organizations | 3 documents with solicited advices from 5 patient organizations prior to the committee's instalment | ME-The Hague Group; 3 cooperating patient organizations; ME association | FOI-request                                                           | 2015  |
| Declarations of interest of the Health Council's committee members | 12 declaration of interests                                              | 12 installed committee members      | FOI-request                                                           | 2016  |
| Minutes from the committee's meetings | 8 min including attendance notes                                         | Secretary Health Council            | FOI-request                                                           | 2016–2018 |
| Written reactions on the draft report from patient organizations | 3 documents with reactions from 5 patient organizations on the final draft of the Health Council report | ME-The Hague Group; 3 cooperating patient organizations; ME association | FOI-request                                                           | 2017  |
| Health Council report on ME/CFS    | Report including the minority position                                  | Health Council                      | Publicly accessible on: https://www.gezondheidsraad.nl/documenten/adviezen/2018/03/19/me-cvs (last retrieved on: 25-6-2020) | 2018  |
a. Framing ME/CFS. This theme includes (referencing) knowledge about identifying and operationalizing ME/CFS as two distinct disorders (subtheme 1) and as (a) somatic condition(s) (subtheme 2).

b. Diagnosing ME/CFS. This theme includes (referencing) knowledge about what kinds of biomedical diagnostic criteria regarding ME/CFS should be used.

c. Researching ME/CFS. This theme includes (referencing) knowledge about the extent to which ME/CFS research should be biomedical in nature.

d. Treating ME/CFS. This theme includes (referencing) knowledge about what kind of non-/biomedical treatments are (not) appropriate.

These themes are elaborated in different genres — ranging from formal and brief minutes of the Health Council committee meetings, to lengthy commentaries, to (summaries of) scientific papers in the solicited advices and to encyclopaedia-style sections in the advisory report. Across these different genre texts, people with ME/CFS and their representatives seem to be largely recognized as credible knowers in discussing ME/CFS as a somatic disease with various suitable biomedical — quantifiable, objectifiable and explicitly non-psychogenic — diagnostic criteria, research avenues and treatment options. However, the four identified themes describe the main sites of epistemic struggle for these patient representatives, namely whether ME is distinct from CFS (see: Section 4.1); whether the succinctness of the Health Council report's proposed diagnostic criteria is (not) defensible (see Section 4.2); what the repercussions are of patient representatives' exclusive focus on somatic, biomedical research (see: Section 4.3), and whether resisting psychogenic therapies is appropriate (see: Section 4.4).

RESULTS

Framing ME/CFS

The identification and operationalization of an illness as a condition with particular markers is significant to ill people. Such framing lets us decide what the illness entails, and thus who has it, when it appeared, when it has gone away, etcetera (Kukla, 2019). In doing so, framing an illness provides some kind of recognized order to a narrative of dysfunction and sorts out what is and is not perceived as real (Jutel, 2009). In this sense, framing is geared towards turning an illness into a stable epistemic object that provides a shared story about the illness, thereby enabling a credible position for ill people (Dumit, 2006). Unsurprisingly, then, the framing of ME/CFS is a dominant theme in the analysis of the ME/CFS Health Council participatory process.

Distinguishing ME and CFS

In the analysed documents, discussions about framing ME/CFS principally start with disputes about whether ME is distinct from CFS. Based on their argued different origin, most patient representatives involved in the advisory process explicitly hold that such a distinction should be made. That is, the citizen's initiative, the minority position and various solicited advices from patient organizations hold that ME is concretely defined in the scientific literature and in international diagnostic criteria as a disease that is located in the biological body — as a ‘disorder of the brain’ (Health Council report/minority position 2018), a ‘brain disease’ (Solicited advice ME association 2015), or a ‘neuro-immune disease’
(Citizen’s initiative ME-The Hague 2013; solicited advice ME-The Hague 2015). Such a locatable somatic place is argued to be largely absent in CFS – which is allegedly characterized by ‘inexplicable fatigue and malaise’ (solicited advice ME association 2015) or is ‘psychological’ (solicited advice Cooperating patient organizations 2015).

While patient representatives’ argue that the Health Council advice should merely or predominantly deal with ME as a condition, the eventual Health Council report states that ‘there is not enough scientific ground to distinguish ME and CFS’ (Health Council report 2018). The report therefore uses the combined term ‘ME/CFS’. Here, it seems that patient representatives’ input about distinguishing ME from CFS is deemed invalid, which may be suggestive for a case of epistemic testimonial injustice. That is, patient representatives are explicitly invited by the Health Council to evaluate and judge scientific research and operative diagnostic criteria, namely in the advisory invitation letter from the director of the Health Council:

What do you think of the […] report Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness from the American Institute of Medicine (IOM)? Do you know of scientific literature […] that the IOM missed […]? Do you know of scientific literature that is crucial in a good answering of the request for advice [to the Health Council]?5

Despite this invitation, however, it may be that ill people and their representatives – as laypersons – are nevertheless dismissed as un(der)qualified epistemic agents in the debate about the (lack of) scientific evidence for differentiating ME from CFS. Note that such testimonial injustice may impose a double injury on ill people (and their representatives) as it could instigate and intensify hermeneutical injustice. In being deemed un(der)qualified, patient representatives are excluded from (fully) engaging in knowledge sharing and producing settings, and such exclusion could impoverish – or at least be unhelpful to – people’s understanding and articulacy of their illness (Blease et al., 2017).

ME/CFS as a somatic condition

Whether it is called ME or ME/CFS, both the Health Council report and involved patient representatives operationalize the advertised condition as predominantly somatic – even though there seem to be different understandings about where the condition is exactly located in the physical body. That is, in line with contemporary trends to theorize the brain as a possible explanation for a variety of illnesses (Ortega & Zorzanelli, 2010), most texts by representatives (i.e. Citizen's initiative ME-The Hague 2013; Health Council report/Minority position 2018; solicited advices ME-The Hague 2015, ME association 2015) seem to understand this body part and its associated medical speciality (i.e. neurology) as the aetiological locus of ME. For instance, while the ME association (2015) speaks of ‘neurological dysfunctions’, the solicited advice from ME-The Hague Group (2015) explicitly points to a concrete biological process that causes ME: ‘an inflammation of the brain’. Moreover, the Health Council report (2018) and a solicited advice from the cooperating patient organizations (2015) also frame ME or ME/CFS as predominantly somatic. Rather than merely explaining ME with processes in the brain, they point to a plethora of bodily systems as being involved in ME/CFS. The cooperating patient organizations (2015) hold that:

ME is a serious, chronic, complex multisystem illness. […] There is enough evidence of a badly functioning immune system in ME. There is enough evidence that orthostatic
intolerance is often the case in ME. [...] In a series of studies [...] that are objective brain abnormalities found in ME/CFS patients.

The Health Council report (2018) also uses the term ‘multisystem illness’ and cautiously refers to even more bodily systems in describing ME/CFS:

various bodily systems could be involved [in ME/CFS], such as the immune system, the metabolic system, the cardiovascular system, the central nervous system, the neuroendocrine system, the microbiome and the genome.

(Health Council report, 2)

With this dominant somatic framing, it is unsurprising that patient representatives’ and the Health Council report both explicitly state that ME or ME/CFS is not a psychogenic condition. Based on a solicited advice of the cooperating patient organizations, the Health Council report even presents psychogenic explanations of ME/CFS as ‘prejudices’ of health professionals. The report reads:

The Dutch multidisciplinary guideline from 2013 gave an overview of the international literature about the ways in which patients with ME/CFS are treated. Many doctors turn out to have prejudices with respect to the illness ME/CFS, its causes and the patients that suffer from it. The illness would be ‘psychosomatic’, caused by ‘psychic’ or ‘psychosocial’ factors and would correlate with the personality of the patient. ME/CFS Foundation Netherlands, ME/cfs association and Support group ME and Work incapacitation write in a joint letter to the Health Council that doctors and other healthcare workers in The Netherlands are no exception to this international pattern. The committee [of the Health Council] subscribes this observation from its own experience.

(Health Council advice, 30)

The report continues:

The committee [of the Health Council] is convinced that the care for patients with ME/CFS in The Netherlands, here and now, could and should be better. A first requirement is that prejudices and ignorance that currently trouble too many healthcare workers in their contacts with patients with ME/CFS, are taken away. Education and in-service training [of health professionals] play an important part in this.

(Health Council report 2018, 37)

This explicit somatic and non-psychogenic framing is indicative for the persevering hierarchical dualism between psychogenic and somatic realities. In our contemporary culture, we tend to think of physical realities as more objective and thus more real, whereas psychogenic realities are deemed subjective and even imaginary. This dualism is embedded in the relationship between, on the one hand, disorders ascribed to the psyche and, on the other hand, non-reason allied with an assumption of personality failure and inferiority. Consequently, people with supposed psychogenic conditions tend to be perceived as incomprehensible and deviant, and their disorder as less real, even imagined (Newbigging & Ridley, 2018; Porter, 1987; Sharpe & Greco, 2019). As stigma associated to framing a disorder as psychogenic is thus deeply discrediting, and as physical realities are perceived as more real, it is understandable that ME/CFS patient representatives seem to avoid markers of stigma by framing ME/CFS as primarily somatic (Brown et al., 2017). In this sense, it seems that not (merely) framing as such is pivotal in establishing
ME/CFS as a ‘real’ disorder (Dumit, 2006; Jutel, 2009), but more the particulars of this illness’ framing: that ME/CFS is a somatic and non-psychogenic illness. The resonance between the Health Council report and documents by patient representatives about this dualist somatic/non-psychogenic framing thus seems promising, at least at first glance, for improving the epistemic position of people with ME/CFS – enabling them to have a recognized and credible illness story and, by extension, possibly a more just testimonial positioning. However, as we will see in the next section, the consequences of such a somatic framing – namely that this condition is/should be predominantly approached within and through biomedicine – may hold various negative epistemic concerns for people with ME/CFS (and their representatives).

**Diagnosing ME/CFS**

The way in which an illness is framed has, of course, great implications for how an illness is approached – for how and by whom it is diagnosed, but also whether and how we can learn more about it, and, ultimately, whether and how we can make it go away. The unanimous framing of, in this case, ME/CFS as a somatic disorder in the Health Council advisory process closely relates to highlighting the importance to diagnose this condition with and through a biomedical lens, as well as to the promoted centrality of biomedical research about and treatment of ME/CFS. Even though both the Health Council report and patient representatives advocate such a biomedical approach, there seem to be several sites of epistemic struggle for people with ME/CFS and their representatives within this biomedical promotion: the succinctness of the proposed diagnostic criteria (discussed in this section), the strong emphasis on biomedical research (discussed in Section 4.3), and whether psychogenic therapies should also be presented as legitimate treatment options (discussed in Section 4.4).

Both patient representatives and the Health Council report argue that an appropriate ME/CFS diagnosis is based upon the illness’ symptomatic appearance. These symptoms are quantifiable and mainly refer to the biological body – typically to neurological mechanisms, but also to immunological, cardiovascular, pulmonary, gastrointestinal, and/or genitourinary bodily aspects. Within the advisory process, however, there appears to be some disagreement about the exact list of legitimate diagnostic symptoms. That is, in their solicited advices to the Health Council committee, the cooperating patient organizations (2015, 2017) are ambiguous towards the committee's proposed diagnostic set of symptoms, a set that is based on the report of the American Institute of Medicine (IOM) ‘Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness’. It seems that this ambivalence may be traced back to the possible epistemological consequences of using these diagnostic symptoms for ill people. The cooperating patient organizations argue in their 2015 solicited advice that:

> The diagnostic criteria of the IOM are simplistic in nature and possibly a good fit for doctors to handle. We hope that it will make diagnosis easier and quicker.

In following up on this statement in their reaction to the final draft of the Health Council report, the cooperating patient organizations (2017) state that

> With a diagnosis, illness symptoms are taken seriously and possible to treat. Although we prefer the ICC-criteria [The International Consensus Criteria, 2011), we think that the recommendation to use the IOM criteria for the clinical practice is important progress.

These quotes show that the cooperating patient organizations seem to hesitantly celebrate the proposed set of diagnostic symptoms because they would potentially improve the position of people with ME/CFS.
as credible knowers because their ‘illness symptoms are taken seriously’ (Cooperating patient organizations 2017). Note that this quote makes clear that the biomedical knowledge offered by people with ME/CFS in the advisory process should not (necessarily) be conceived as opposite to their first-hand experiences of the condition. 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.

However, when it comes to the proposed diagnostic symptoms, the cooperating patient organizations also ‘foresee serious pitfalls’ (Cooperating patient organizations, 2015):

> The International Consensus Criteria, the ICC (2011), [in comparison with the IOM criteria], give a more extensive set of criteria. The ICC does more justice to the many and wide-ranging complaints and symptoms of patients that inhibit patients in their daily lives. The ICC also emphasize the mutual coherence between the symptoms more than the IOM criteria do. [In using the IOM criteria, then,] this complex [symptomatic] mechanism [inherent in ME/CFS] can easily be wrongly understood and trivialized.

(Cooperating patient organizations, 2015)

In order to avoid this risk of trivializing ME/CFS and harming the epistemic position of people with ME/CFS, the cooperating patient organizations argue for acquiring ‘thorough, specialist knowledge’ about the coherence of the disease’s symptoms (Cooperating patient organizations 2015). Note that whereas this preventive approach is understandable in the light of patient representatives’ quest to gain recognition for ME/CFS as a ‘complex’ and ‘multisystem’ disease – and arguably for the existence of the disease to begin with –, it may be argued that it is rather difficult to accomplish. In our current biomedicalized world, specialized knowledge about diseases’ symptoms largely depend on complex, scientific data and technologies, such as cell failure algorithms and MRI scans (Sulik, 2011). These data sets and technologies are predominantly only accessible and interpretable by certain professional specialists – like neurologists, cardiologists or immunologists. As such, it is (very) difficult for medical specialists to acquire knowledge about the coherence between ME/CFS symptoms that are assigned to various particular medical specialities and their specialist data and technologies (Callahan, 2009; Hunter & Cohen, 2006).

**Researching ME/CFS**

The plea for specialized, quantifiable and highly technological research to ME/CFS’ symptoms is echoed in the more general call for extensive biomedical research made by various patient representatives and within the Health Council report (Crabu, 2016). While understandings of appropriate biomedical research differ across the analysed documents, most texts refer to ‘biomarkers’ and the production of ‘biobanks’ as a promising route for finding a cause and a cure for ME/CFS – and by implication, for being recognized as having to deal with a real disease on a daily basis (Health Council report 2018; solicited advices ME-The Hague 2015, cooperating patient organizations 2015). As molecular devices, biomarkers are designed to stratify people according to a particular biological profile. By using large datasets on human biological characteristics, which are collected in so-called ‘biobanks’, biomarkers may help to predict an person’s response to a certain therapeutic treatment, for example to a specific drug (Kohli-Laven et al., 2011). In their solicited advice, ME-The Hague Group (2015) recommends to prioritize funding of ‘innovative biomedical research with a focus on biomarkers and diagnostic tests. [And] to provide Dutch researchers with access to existing biobanks’. The Health Council
report, then, seems to endorse this recommendation by stating that ‘scientific research […] to storing bodily tissue in biobanks’ could be funded through a new national scientific programme to ME/CFS.

This united emphasis on the importance of biomedical – highly specialized, technological and quantifiable – research, and particularly on biomarkers, may not only be indicative of that the knowledge of people with ME/CFS is reflected in the Health Council report. It may indeed suggest an instance of epistemic justice, namely that patient representatives are recognized as credible knowers in defining appropriate research paths to ME/CFS, but may also implicate aspects of epistemic injustice. That is, several medical sociologists argue that biomarker research and its categorization of human subjects in certain biological characteristics may invite biased thinking and discriminatory practices (Clarke et al., 2009; Fitzgerald, 2014; Kahn, 2010; Persad, 2017). Such mechanisms, then, do not only result in a low(er) epistemic reliability of the conclusions drawn in biomarker research, but also in enhancing prejudices about these groups which may, in turn, lead to (sustaining or increasing) testimonial and hermeneutic injustices (Persad, 2017).

Moreover, one could argue that, in general, the strong emphasis on biomedical approaches in researching (and also in diagnosing) ME/CFS may already involve aspects of epistemic injustice. Even though people's everyday experiential knowledge about ME/CFS seem to fuel the predominant biomedical framing of and approach to this illness, within the advisory process only (or mainly) biomedical knowledge – that is objective, quantitative data about various aspects of the biological body – seems to be counted as valid for assessing the possible cause and cure for ME/CFS (Lock & Nguyen, 2018). Indeed, while the Health Council report and various patient organizations explicitly underscore the importance of experiential knowledge in researching and diagnosing ME/CFS, such data is barely brought to fore as evidence within the advisory process. In the few instances where experiential knowledge is presented in the analysed documents, they either take the form of an enumeration of illness symptoms, or of quantified outcomes of patient questionnaires. An example of this latter kind of experiential knowledge is:

According to a recent questionnaire amongst the following of the ME/cfs Association, 80% of the patients received their diagnosis after more than a year, for 40% of the patient it even took four years or longer.

(Health Council report, 2018, p. 15)

People's non-quantifiable, non-objectifiable but systematically researched everyday illness experiences and dealings are largely lacking in the advisory process.

Note that this absence of lived, experiential knowledge at the expense of offering biomedical knowledge may be perceived as a strategy of people with ME/CFS (or their representatives’) to participate in the Health Council Advisory process as valid knowers. That is, even though the Health Council underscores the importance of experiential knowledge, their invitation letter to patient organizations to provide an advice predominantly asks for input of and feedback on state-of-the-art scientific knowledge (see Section 4.1 for details on this letter).

Fricker (2007), however, calls this favouring and dominance of objective, in this case biomedical information – and, by implication, rejecting non-objective experiential information – ‘epistemic objectification’ and discusses it as a kind of epistemic injustice. That is, in stressing the importance of objective evidence – even though ill people themselves may also do this – ill people are not fully regarded as ‘epistemic agents who convey information’ but instead mainly as ‘states of affairs from which the inquirer may be in a position to glean information’ (Fricker, 2007, 132). In doing so, one may fail to sufficiently attend to people's experiential illness testimonies, which in turn, may lead not
only lead to testimonial injustice but also to insufficient shared illness understandings and thus to hermeneutical injustice (Persad, 2017).

**Treating ME/CFS**

In line with the above sections about diagnosis and research, the analysed texts about treatment mainly emphasize **biomedical** approaches in relieving ME/CFS symptoms, for example through medication (Solicited advices ME-The Hague 2015; ME association 2015; Cooperating patient organizations, 2015/2017; Health Council/Minority position 2018; Health Council report 2018). In documents from patient representatives, this biomedical approach generally goes together with a strong resistance to psychogenic or psycho-behavioural therapies, specifically to ‘cognitive behavioural therapy’ (CBT) and ‘graded exercise therapy’ (GET). These therapies aim to progressively engage people with ME/CFS in physical activities by helping to alter their thoughts and behaviour (Smith et al., 2014). In their solicited advice, the cooperating patient organizations (2015) state that the ‘effectiveness [of these therapies] is not proven and can even cause harm to the patients’ wellbeing’. This statement is reiterated and underscored in the advisory report:

> A 2008 questionnaire research amongst the following of the ME/CFS patient organizations shows that the percentage of patients that had the impression that CBT led to improvements (30,4%) was approximately as high as the percentage that said that they have deteriorated (27%).

(Health Council report 2018, p. 25)

In line with these standpoints, the two patient representatives in the Health Council committee resist using CBT as a treatment for ME/CVS. The Health Council report writes that:

> they [the patient representatives in the committee] point out that many patients with ME/CFS have negative experiences with this therapy and they object to practicing the kind of CBT that is primarily used in The Netherlands.

In his minority position (2018), one of the patient representatives even holds that ‘no [psycho-behavioural] therapies should be offered to patients’. However, the Health Council report (2018) also states that the majority of the committee agrees that ‘CBT is a treatment worth considering’. The report elaborates:

> The image that emerges from many studies, [that are] summarized in various overview studies, is that the effectivity of CBT is complicated. Depending on the chosen inclusion criteria and analysis methods, the overview studies that have been incorporate more and less positive statements about the effectivity of CBT with adults with ME/CFS.

Within this discrepancy between the strong resistance by patient representatives and the report's relative openness to psycho-behavioural therapies, both testimonial and hermeneutic injustice may be at play – albeit in contradictive ways. That is, the two patient representative committee members hold that the report's openness ‘does not do justice to the negative experiences of many ME/CFS patients’ (Health Council report 2018). The report's openness, then, may indeed be suggestive of negative credibility judgements of testimonies by people with ME/CFS (and their representatives’) – and thus of testimonial injustice. Yet
in following the report’s argument that there is an inconclusive, ‘complicated’ evidence base for these therapies and that, therefore, openness to psycho-behavioural therapies may be legitimate, patients representatives’ call to treat ME/CFS solely through biomedical treatments may increase the risk of epistemic injustice. That is, the primary focus on biomedical therapies and the rejection of psycho-behavioural ones would not only run the risk of restricting potentially fruitful inquiries of treatment options, but may also prevent people from engaging reflectively with certain significant aspects of their condition, such as their behaviour and emotions. As these aspects may arguably help people to (better) understand and make sense of their condition (Byrne, 2020), not reflecting on them could lead to (or leave intact) hermeneutical gaps about their illness that could have been filled with an openness to psycho-behavioural treatment options.

**DISCUSSION AND CONCLUSION**

**Biomedicalization as epistemic injustice?**

Contrary to the assumptions in the literature on patient participation (Abma, 2005; Beresford, 2003), this paper reveals that people with ME/CFS and their representatives in the context of the Dutch ME/CFS Health Council advisory process do not explicitly tend to voice subjective illness experiences. Instead, they predominantly offer biomedically oriented knowledge. That is, by referring to biomedical, scientific texts and diagnostic criteria, patient representatives mainly frame ME/CFS as a condition that is diagnosed through physical and quantifiable symptoms. Accordingly, appropriate research to and treatment of ME/CFS is understood as biomedical: as objectifiable investigations to the biological body and as relieving symptoms through medication therapies. This emphasis on somatic framings and biomedical approaches to ME/CFS often goes hand in hand with representatives' strongly rejecting psychogenic understandings and treatments of the illness, and with an absence of non-quantifiable evidence in their advices on suitable diagnostic strategies and research avenues.

These patient representatives’ emphasis on ME/CFS as a somatic and biomedical condition is, of course, very understandable. 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. Moreover, the ascribed importance to biomedical knowledge by people with ME/CFS could be understood against the backdrop of people's first-hand knowledge of living with ME/CFS. People with a somatic, biomedicalized illness seem to suffer less from stigma and negative prejudices then they would when their illness is psychologically framed and approached (Porter, 1987; Sharpe & Greco, 2019). In this sense, then, promoting a biomedical framing of and approach to ME/CFS captures the hope of not having to deal with the stigma surrounding ME/CFS on an everyday basis – and by extension, receive better and more care. One could argue, furthermore, that biomedical knowledge about ME/CFS may also contribute to people understanding certain aspects of their condition – for example its physical causes or symptomatic appearance – thereby potentially providing them with increased hermeneutic resources for making sense of their subjective illness experiences (Wardrope, 2015). Thus, as this paper shows that ME/CFS patient representatives' strong biomedically oriented knowledge is largely recognized and reflected within the eventual Health Council report, the analysed case of ME/CFS patient participation appears, at first glance, indicative of a rather emancipatory participatory practice.

This paper, however, also demonstrates that such a biomedicalized practice of patient participation may instigate and maintain various instances of epistemic injustice. That is, it shows that in patient representatives’ promulgating biomedical knowledge, this knowledge of laypersons, especially in
comparison to expert participators such as clinicians and researchers, may be deemed invalid and unreliable. These patient representatives may then run the risk of being excluded from policy documents, whereby they arguably suffer from testimonial injustice. Moreover, even when these patient representatives’ biomedical knowledge is acknowledged and recognized in participatory practices, this paper reveals that such practices may still incorporate epistemically unjust aspects. That is, a strong focus on the importance of biomedical evidence in diagnosing, researching and treating ME/CFS may lead to (sustained) reductive, even discriminatory thinking about who ill people are and to biased ideas about what kind of relevant knowledge these people hold. These prejudiced views, in turn, may lead to a (continual) dismissal of the validity these people's illness testimonies and to (maintaining) hermeneutic gaps that inhibit these people from making sense of their illness.

At this point, it may be concluded that the analysed case of ME/CFS biomedicalized patient participation is ambiguous in terms of its emancipatory value. It is indicative of epistemic injustice but may also resolve or prevent such injustice. How, then, should we navigate such a biomedicalized participatory practice in order to attain a more epistemically just one? The final section of this paper offers a tentative answer to this question.

Towards epistemic justice in patient participation

Against the background of this paper’s empirical findings of ME/CFS patient participation, an emancipatory participatory practice would arguably entail acknowledging, on the one hand, the value of biomedicalized framings and approaches of ME/CFS for enhancing the credibility of people with ME/CFS and their ability to make sense of parts of their illness experiences. On the other hand, in avoiding biased and reductive thinking about ME/CFS, such an emancipatory practice would resist the idea that biomedicalized understandings of ME/CFS is an all-encompassing conceptual framework for this condition. In doing so, this practice may consider the idea of actively integrating other relevant, non-biomedicalized voices of people suffering from ME/CFS – for example of people that narrate lived illness experiences. With such an integration of non-quantifiable, non-objectifiable experiences of their everyday lives, people with ME/CFS are incidentally also provided with an evident epistemically complementary and valid position in participatory settings. In other words, an emancipatory participatory setting would recognize the value of (focusing on) ill people's/patient representatives' (and others') biomedicalized knowledge about ME/CFS, but would not take such biomedicalized understandings as complete and exclusive descriptions of this condition.

In thinking along with Fricker (2007) and her successors (Beresford & Russo, 2016; Carel & Kidd, 2014; Irwin, 2006), designing such a balanced participatory practice would predominantly take place on the individual-interactional level. It would involve, for example, empowering people to voice their lived illness experiences (Beresford & Russo, 2016) or increasing the epistemic humility of biomedicalized voices in participatory settings (Carel & Kidd, 2014). Such nourishment of experiential knowledge about dealings with and making sense of illnesses, and altering the ascribed importance to biomedical knowledge is valuable. However, it primarily targets individual instances of testimonial injustice or mitigates the effects of particular hermeneutical injustices (Wardrope, 2015). It does not engage with the sociocultural roots of epistemic injustices that may arise in overly dominant biomedicalized patient participatory settings (Anderson, 2012). After all, a strong focus on biomedicalized understandings of ME/CFS is not solely the result of concrete individuals proclaiming the value of this particular way of understanding this condition, but also originates in a widely shared biomedical conceptualization of health and illness (Wardrope, 2015). As such, countering unjust tendencies in dominant biomedicalized patient participation settings would also involve the reshaping of
collective sociocultural understandings of health and illness in public life. In other words, combating epistemic injustice in patient participation requires an explicit sociological or social epistemological perspective. In line with Anderson (2012), this reshaping may take the form of encouraging, perhaps even enforcing epistemic humility in relevant social institutions, for instance, in Health Councils. Such humility needs to involve an institutional attentiveness to the epistemic boundaries of biomedicalized voices in patient participation and the value of actively seeking out and fostering explicit non-biomedical, lived experiential perspectives on illness. Furthermore, the reshaping of collective sociocultural understanding of health and illness may also transcend the strict realm of health policy-making, and involve the (re)construction of public representations of illness and health that emphasize the value of non-biomedical perspectives in describing and understanding illnesses – for example, of describing everyday illness experiences in news reports, educational material for health professionals, or in documentaries.

Note that this particular conceptualization of an emancipatory patient participation practice gives rise to a fundamental discussion about patient participation. That is, it raises the issue whether certain aspects of epistemic injustice, namely the deliberate muting or exclusion of biomedicalized patient (representative) voices and the privileging of experiential illness voices, may be justifiably incorporated in patient participatory settings. In the light of this papers’ conclusion that serious epistemic concerns may arise from ill people mainly emphasizing (the importance of) their biomedical knowledge, this paper would like to open a discussion about that a careful (pre-)selection and training of voices of ill people on both an individual-interactional and institutional level may be necessary in establishing a more emancipatory patient participation practice, and furthermore, about the question how such training and selection of illness voices should take shape in practice.

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Marjolein Lotte de Boer: Conceptualization (lead); Data curation (lead); Formal analysis (lead); Investigation (lead); Methodology (lead); Writing—original draft (lead); Writing—review & editing (lead).

DATA AVAILABILITY STATEMENT
Original data collected through the Freedom of Information-request at the Dutch Health Council will not be shared with third parties.

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ENDNOTES
1 As I will elaborate on in this paper, both of the names ‘ME’ and ‘CFS’, as well as their relation, are controversial. For clarity purposes, however, I mostly refer to the illness as ‘Myalgic Encephalomyelitis/Chronic Fatigue Syndrome’, or ‘ME/CFS’ in brief.
2 In being true to the post-modern method of discourse analysis, this paper refrains from the belief in the possibility of an objective reality about ME/CFS and testimonies thereof. In doing so, it abstains from making any claims about the truth or falsity of the described knowledge, and instead offers a systematic discourse analysis into the epistemic ways people with ME/CFS and their representatives participate in health care policy-making.
‘Freedom of information’ (FOI) refers to the right to access information held by public bodies. Accessing this information is included in the Universal Declaration of Human Rights (art. 19) as a fundamental right of freedom of expression. Dutch citizens can submit a FOI-request to public bodies in order get access to documents that hold relevant information for them.

4 Quotes from the analyzed documents are translated from Dutch by the author.

5 Italics added by the author.

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