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Exploring the Experience of Healthcare-Related Epistemic Injustice among People with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

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Abstract

Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a chronic, disabling yet clinically “contested” condition, previously theorised through a lens of epistemic injustice. Phenomena conceptually close to epistemic injustice, including stigma, are known to have deleterious consequences on a person’s health and life-world. Yet, no known primary studies have explored how people with ME/CFS experience healthcare through a lens of epistemic injustice, whilst a dearth of research explicitly exploring healthcare-related injustice from a patient perspective has been noted. This qualitative study seeks to address this gap. Semi-structured interviews and interpretative phenomenological analysis (IPA) were used to explore the experiences of five people with ME/CFS in the UK, vis-à-vis healthcare-related epistemic injustice. One superordinate theme is presented, “Being de-centred in patient-centred care,” alongside two sub-themes: “Struggling for epistemic-existential validation” and “Negotiating socio-epistemic hierarchies, politics and ‘power’.” Findings suggest that healthcare-related epistemic injustice may differentially impact according to the patient’s social positionality (here, notably gender), and that a potential pathway of existential harm operates through threats to identity and personhood. Findings also indicate that cultural and political factors may further epistemic injustice in healthcare. Finally, epistemic injustice impacting as a chronic stressor cannot be ruled out and is worthy of further research. The experience of healthcare-related epistemic injustice can carry far-reaching yet varied consequences for patients. Future research should consider drawing upon more socio-demographically diverse samples and an intersectional approach is recommended. Further exploration of structural drivers of epistemic injustice may highlight a need for politically and socio-culturally cognisant clinical approaches.

Keywords

myalgic encephalomyelitis / chronic fatigue syndrome, epistemic injustice, healthcare experiences, healthcare policy, qualitative, interpretative phenomenological analysis

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Exploring the Experience of Healthcare-Related Epistemic Injustice among People with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

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Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a chronic, disabling yet clinically “contested” condition, previously theorised through a lens of epistemic injustice. Phenomena conceptually close to epistemic injustice, including stigma, are known to have deleterious consequences on a person’s health and life-world. Yet, no known primary studies have explored how people with ME/CFS experience healthcare through a lens of epistemic injustice, whilst a dearth of research explicitly exploring healthcare-related injustice from a patient perspective has been noted. This qualitative study seeks to address this gap. Semi-structured interviews and interpretative phenomenological analysis (IPA) were used to explore the experiences of five people with ME/CFS in the UK, vis-à-vis healthcare-related epistemic injustice. One superordinate theme is presented, “Being de-centred in patient-centred care,” alongside two sub-themes: “Struggling for epistemic-existential validation” and “Negotiating socio-epistemic hierarchies, politics and ‘power’.” Findings suggest that healthcare-related epistemic injustice may differentially impact according to the patient’s social positionality (here, notably gender), and that a potential pathway of existential harm operates through threats to identity and personhood. Findings also indicate that cultural and political factors may further epistemic injustice in healthcare. Finally, epistemic injustice impacting as a chronic stressor cannot be ruled out and is worthy of further research. The experience of healthcare-related epistemic injustice can carry far-reaching yet varied consequences for patients. Future research should consider drawing upon more socio-demographically diverse samples and an intersectional approach is recommended. Further exploration of structural drivers of epistemic injustice may highlight a need for politically and socio-culturally cognisant clinical approaches.

Keywords: myalgic encephalomyelitis / chronic fatigue syndrome, epistemic injustice, healthcare experiences, healthcare policy, qualitative, interpretative phenomenological analysis

Introduction

Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a chronic health condition characterised by post-exertional malaise, often accompanied by cognitive impairment, sleep disturbances, gastro-intestinal dysfunction, widespread pain and autonomic

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dysfunction (Carruthers & van de Sande, 2012). Despite high personal and societal costs of the illness, ME/CFS is aetiologically and nosologically contested, partly associated with lack of diagnostic biomarker, conflicting case definitions, debates over nomenclature and little space afforded to biomedical understanding of ME/CFS in medical curricula (Muirhead et al., 2021; Nacul et al., 2019). This contested status is associated with undue psychologisation, stigmatisation and marginalisation of people with ME/CFS within healthcare encounters (Anderson et al., 2012). For example, people with ME/CFS report questioning of moral character through being perceived by healthcare professionals as malingering, with some patients feeling coerced into taking psychotropic medication and reporting clinical reluctance to medically investigate symptoms (Dickson et al., 2007; Gilje et al., 2008). Patient experiences are supported by research capturing clinical stereotyping: ME/CFS has been framed as an inability to face existential challenges of life, a lack of work ethic and stoicism, and a burdensome, “heartsink” patient group (Chew-Graham et al., 2010; Raine et al., 2004). Such findings have been conceptualised through a framework of epistemic injustice (Blease et al., 2017; see also Carel & Kidd, 2014).

Rooted in the work of British philosopher Miranda Fricker (2007), epistemic injustice encapsulates the wrongs done to an individual or group in their capacity as a “knower,” and can be further categorised as testimonial and hermeneutical injustice. Testimonial injustice occurs when a subject’s knowledge and experiences are discredited as a result of prejudice. Systematic testimonial injustice is said to “track the subject through different dimensions of social activity” (Fricker, 2007, p. 27) and is predicated upon what Fricker calls “negative identity prejudice.” This is defined as a form of prejudice “with a negative valence held against people *qua* social type” (Fricker, 2007, p. 35). In other words, negative identity prejudice, and ensuing testimonial injustice, are said to result from negative stereotyping based upon marginalised social identity or minority group membership. Whilst testimonial injustice operates on an individual (interpersonal or transactional) level, hermeneutical injustice can be conceptualised as a structural phenomenon. More specifically, hermeneutical injustice occurs when socio-culturally dominant explanatory or interpretative frameworks (tools we use to make sense of our world) fail to capture the knowledge, experiences and testimonies of a particular group, resulting in pockets of collective “conceptual impoverishment” (Fricker, 2007; see also Carel & Kidd, 2014). Hermeneutical injustice is defined as systematic when it gives rise to other forms of marginalisation, for example, when conceptual impoverishment surrounding a particular diagnosis prevents patients from accessing appropriate healthcare, creating a ripple effect across other social spheres. Hermeneutical and testimonial injustice are in practice interlinked (Blease et al., 2017; De Boer, 2021). When conceptual impoverishment that disproportionately and detrimentally impacts ill persons (hermeneutical injustice) is interpreted as an inherent incapacity of ill persons as “knowers,” this may result in negative identity prejudice toward that group, and subsequent downgrading of their knowledge contributions (testimonial injustice).

There are numerous gaps in our collective understanding of healthcare-related epistemic injustice, within the ME/CFS arena and more widely. For example, debate has arisen over the extent to which people with ME/CFS are subjected to epistemic injustice in healthcare fora, on what grounds and via what pathways (see Blease et al., 2017; Blease & Geraghty, 2018; Byrne, 2020; de Boer, 2021; Kidd & Carel, 2017). These gaps are compounded by a dearth of literature on how epistemic injustice is experienced from the patient perspective (see Young et al., 2019); to our best knowledge, there is no prior primary research on this topic within the ME/CFS arena. Indeed, a scarcity of articles investigating healthcare-related injustices and harm from the patient perspective has been reported (Geraghty & Blease, 2019). Nevertheless, phenomena that are conceptually close to epistemic injustice, such as stigma (see Buchman et al., 2017), have attracted more attention, with burgeoning literature demonstrating

the deleterious consequences of stigma within the ME/CFS arena and beyond (e.g. Åsbring & Närvänen, 2002; Dickson et al., 2007; Hatzenbuehler et al., 2013; Major & O'Brien, 2005). Taken together, these considerations indicate that the lived experience of healthcare-related injustice of an explicitly epistemic nature in the ME/CFS arena is worthy of investigation. The research presented here, using data from the first author's MSc dissertation on healthcare-related injustice, sought to address this research gap. Before presenting our research question, we demonstrate the rationale for this question by providing a more detailed account of current knowledge and debates vis-à-vis healthcare-related epistemic injustice in the field of ME/CFS.

Much of the current knowledge base and related debate in this field has arisen in association with particular healthcare models. On one hand, epistemic injustice in the ME/CFS healthcare arena has been partly related to the application of a biopsychosocial model in clinical practice (Blease et al., 2017; Geraghty & Blease, 2019; see also Maes & Twisk, 2010; Twisk & Maes, 2009). This model acknowledges psychological and social influences in health and illness, alongside biological influences, and was proposed to address the contended limitations of the biomedical model, a historically dominant healthcare framework that understands illness as an exclusively biological phenomenon (see Engel, 1977). Whilst the biomedical model was accordingly critiqued for biological reductionism (Engel, 1977), the biopsychosocial approach sought a more "holistic," person-in-context approach to healthcare. However, the biopsychosocial approach has in turn been criticised for lack of clarity over how biological, social and psychological influences interact and thus poor empirical testability, leading to the assertion that the model can be applied according to the biases of whomever applies it (Ghaemi, 2009; Shakespeare et al., 2017).

In conceptualising and managing ME/CFS, a particular variant of biopsychosocial model has been combined with cognitive-behavioural principles, with development of cognitive-behavioural "treatments," chiefly cognitive-behavioural therapy and graded exercise therapy (Deary et al., 2007; White et al., 2011). Whilst some people with diagnosed ME/CFS report benefits from these approaches (see MEA, 2015; Picariello et al., 2017; White et al., 2011), such findings and the manner in which the model has been applied has raised considerable criticisms (Geraghty & Blease, 2019; Maes & Twisk, 2010; Twisk & Maes, 2009). Chief among criticisms is that the biopsychosocial approach places undue emphasis on poorly evidenced psychosocial factors (for example, maladaptive illness beliefs, fear of exacerbating symptoms and ensuing activity avoidance), whilst neglecting biological factors, thereby unjustly framing ME/CFS as a psychosomatic or primarily psychogenic condition (Geraghty & Blease, 2019; Maes & Twisk, 2010; Twisk & Maes, 2009). Moreover, conflicting case definitions among other factors have clouded research findings (Nacul et al., 2019): biomedical proponents contend that cognitive-behavioural interventions offer negligible benefit for many people with ME/CFS, whilst having engendered harm in some cases (Geraghty & Blease, 2019; MEA, 2015; Twisk & Maes, 2009).

Although health authorities in the UK and US have abandoned pre-existing recommendations for cognitive-behavioural treatments owing to lack of evidence base and patient testimony of harm (NICE, 2021; Reymeyer & Tuller, 2017), support for such treatments within a biopsychosocial paradigm persists (RCP, 2021; White et al., 2023). This on-going state of affairs has motivated discussions of epistemic injustice. Many reported detrimental aspects of ME/CFS healthcare, including delayed diagnosis, misdiagnosis, prescription of potentially inappropriate treatments, clinical reluctance to conduct biomedical investigations, and barriers to social support such as benefits (see Anderson et al., 2012; Gilje et al., 2008; Hale et al., 2020), have been associated with the biopsychosocial model (Geraghty & Blease, 2019; Twisk & Maes, 2009), with some aspects theorised through the lens of epistemic injustice (Blease et al., 2017).

On the other hand, it has been contended that the privileging of the biomedical model in healthcare may also facilitate healthcare-related epistemic injustice, since this biologically-focused model cannot accommodate the subjective (experiential and existential) aspects of illness (de Boer, 2021; Kidd & Carel, 2017). The lived experience of pain (a common symptom of ME/CFS) represents an exemplar of a health concern that cannot be fully understood by the biomedical model, and the experiences of patients with chronic pain has been duly theorised through a lens of epistemic injustice (Buchman et al., 2017). Furthermore, “structural and hierarchical features of the healthcare system” (Carel & Kidd, 2014, p. 535) have been identified as potentially contributing to epistemic injustice in the ME/CFS arena and beyond. Such features may include healthcare models but also extend to factors such as formality of healthcare discourse, time-pressured consultations, and task-based (rather than person-centred) consultations (Kidd & Carel, 2017). These points indicate a need to look beyond healthcare models when conceptualising and addressing epistemic injustice. Relatedly, it has been suggested that too readily interpreting tensions within ME/CFS healthcare encounters as clinical stereotyping or dismissal of patient testimony, and in turn too readily identifying this as testimonial injustice, risks overlooking the fact that clinicians (like patients) must navigate conceptual impoverishment (lack of adequate hermeneutical resources) arising from a nosologically uncertain condition (Byrne, 2020). Since hermeneutical injustice and related conceptual impoverishment represent structural phenomena, this again points toward the need for a deeper understanding of structural (“macro” level) facets of epistemic injustice, for example socio-cultural and political facets (see Anderson, 2012; Mladenov & Dimitrova, 2023).

Finally, whilst socio-cultural and political facets of healthcare-related epistemic injustice have been largely neglected in ME/CFS literature, interpersonal and intrapersonal (“micro” level) facets also warrant further research. For example, phenomena that are conceptually close to epistemic injustice, including stigma (see Buchman et al., 2017), have been contended to have an underestimated and detrimental impact on life chances, promoting marginalisation in terms of healthcare access, but also impacting upon education, income, social connectivity, physical and psychological health (see Hatzenbuehler et al., 2013; Link & Phelan, 2001). Stigma is also recognised as a source of stress in itself, potentially compounding pre-existing physical and psychological illness (Hatzenbuehler et al., 2013; Major & O’Brien, 2005). It is reasonable to speculate that epistemic injustice, in particular within healthcare, might impact in a similar fashion. Taken altogether, these points suggest a need to consider the “bigger picture” when conceptualising and addressing healthcare-related epistemic injustice. This, together with the afore-mentioned dearth of primary research engaging with the experience of epistemic injustice, led us to the following research question.

Firstly, we sought to explore the experiences and meaning-making of a small group of people with ME/CFS in the UK vis-à-vis healthcare-related epistemic injustice. Secondly, and relatedly, we sought to examine the perceived impact of such injustice upon the well-being of people with ME/CFS, where well-being is understood “holistically” as encompassing physical, psychological, social, financial, and occupational aspects.

Reflexive positioning

The first author is a chronically ill person diagnosed with ME/CFS (currently severely affected) with prior experience of working with people with ME/CFS in psychotherapy settings, including in the UK National Health Service (NHS). Personal and professional experience of epistemic injustice within this population has informed the research, and it should be noted that the first author does not subscribe to dominant biopsychosocial conceptualisations of ME/CFS. Additionally, the research was informed by years of informal exchanges with other

persons within the ME/CFS community. A focus within the study upon healthcare-related injustice and potential harms, naturally encompassing more negative healthcare experiences, was deemed necessary. This decision was supported by the afore-mentioned scarcity of literature on the subject matter, the first author's standpoint and her ascribing to the contention that, in arenas where injustice is normalised, an explicit focus on injustice is necessary (Fricker, 2007). The potential advantages and pitfalls of being part of the group under investigation (see Berger, 2015; Coyle, 2016) were acknowledged and discussed with co-authors throughout the research process. The first author drew upon reflective journaling, audit trail, supervisory guidance and triangulation from co-authors (Berger 2015; Shenton 2004; Yardley, 2015), alongside psychotherapy competencies (working with transference, countertransference and intersubjectivity), to reduce entanglement of personal experiences and beliefs with those of participants. Triangulation or consensus was undertaken with a view to enriching understanding, promoting researcher reflexivity and enhancing the study's trustworthiness, rather than seeking perspectival convergence (Yardley, 2015). Participants were previously unknown to the researchers and the first author made her diagnosis transparent in recruitment material, with a view to promoting trust and rapport (see Berger, 2015).

Materials and methods

Design

Interpretative phenomenological analysis (IPA) was chosen as methodology and analytical method, combined with semi-structured interviews as data collection method. IPA can be understood as underpinned by three main theoretical influences (Smith et al., 2009). Firstly, IPA's primary epistemological position, phenomenology, emphasises how people experience the world; the correspondent inductive approach and focus on personal meaning-making was considered appropriate for the research questions, especially given that ME/CFS represents an epistemically marginalised patient group. Secondly, IPA is influenced by idiography which privileges the particular over the general (Smith et al., 2009); an in-depth analysis of how particular people (persons living with ME/CFS) experience a particular phenomenon (epistemic injustice) within a particular context (the healthcare arena) was deemed apposite given the scarcity of primary research on the study's subject matter. Thirdly, the hermeneutics-inspired (interpretative) aspect of IPA acknowledges that individual capacity to "know" is contingent upon sociocultural context; a double hermeneutic is created as the researcher seeks to make sense of participants' meaning-making (Smith & Osborn, 2015). Semi-structured interviews, facilitating collaboration and co-construction of knowledge whilst allowing participants to take the lead within the boundaries of the phenomenon under investigation, were thus considered consonant with the theoretical underpinnings and ethos of IPA (see Smith & Osborn, 2015). The hermeneutics-inspired underpinning of IPA foregrounds the impact of the researcher(s) upon the research, demanding attention to reflexivity (see Berger, 2015).

Interview schedule

The interview schedule (see Figure 1) was informed through extant literature as outlined in the introduction, together with consideration of the research questions, desire to maximise trust and rapport with participants, and intention to avoid closed and leading questions (see Smith et al., 2009).

Figure 1*Interview schedule*

1. How do you prefer to refer to ME/CFS?
2. Tell me about how you came to be diagnosed with ME/CFS?
3. What does having ME/CFS mean to you?
4. Tell me about the kind of healthcare encounters you have had, as somebody diagnosed with ME/CFS?

Prompt: Primary care; Secondary care / specialist care services

5. How did these experiences make you feel?
6. How involved did you feel in these encounters?

Prompt: To what extent did you feel that your ideas about and understanding of your illness were taken on board?

Prompt: To what extent did you feel able to ask questions and / or raise concerns?

7. To what extent were the reasons underpinning any treatment options explained to you?
8. To what extent were potential advantages and potential drawbacks of treatments explained to you?
9. To what extent, if any, do you feel that these encounters have impacted your health and your life more generally?

Prompt: In what way?

Prompt: Physical, psychological, financial, social, occupational

10. How do you make sense of what you have told me?
11. Is there anything else you would like to add to what we have talked about today?

Initial questions (*How do you prefer to refer to ME/CFS? Tell me about how you came to be diagnosed with ME/CFS?*) were more general and sought to ease participants into taking the lead, whilst adding context to the subsequent data. The interview schedule then turned toward addressing the research questions (for example, *Tell me about the kind of healthcare experiences you have had?*), including aspects of epistemic injustice (for example, *How involved did you feel in these encounters?*). The closing question (*Is there anything else you would like to add to what we have talked about today?*) sought to ensure that participants had opportunity to address anything that the interviewer might have overlooked. In this regard, since cognitive dysfunction is a common feature of ME/CFS, the topic guide was sent to participants in advance of interviews, allowing them to familiarise themselves with the subject matter. Consistent with the ethos of IPA, both the topic guide and interview style were sufficiently flexible to allow participants to introduce unanticipated aspects of the phenomenon under investigation (see Smith & Osborn, 2015). For example, other than the closing question, the order of questioning and precise questions asked varied according to the unique flow of each interview.

Table 1
Participant Demographic Data

Participant (pseudonym)	Age	Ethnicity	Gender	Education level	Employment status	Years since diagnosis* (reported in January 2020)	Severity of ME/CFS (self- rated)**
Ivor	65+	white	man	Bachelor's degree	Retired on ill- health grounds	17 years	moderate
Marie	25-34	white	woman	A-levels	Unable to work due to ill-health	2 years 3 months	moderate
Elizabeth	45-54	white	woman	Bachelor's degree	Unable to work due to ill-health	20 years (Note: 24 years since symptom onset)	very severe
Jane	55-64	white	woman	HND	Unable to work due to ill-health	6 years 5 months	moderate
Art	45-54	white	man	Master's degree	Unable to work / retired on ill-health grounds	3 years 9 months	moderate- severe

* Period between symptom onset and diagnosis ranged from months to years; exact data were not collected

** Severity assessed using the ME Association Disability Rating Scale (MEA, 2016)
Mean age = 52 years Mean years since diagnosis = 9 years 11 months

Participants

A volunteer sample of five participants (see Table 1) was recruited via the ME Association, a UK-based ME/CFS patient organisation. IPA requires small samples to generate rich and nuanced data at both individual and collective levels; a sample size of five was considered amenable to achieving such an analysis whilst managing time constraints (see Smith et al., 2009). Inclusion criteria comprised adults living in the UK, fluent in English, with a self-reported medical diagnosis of ME/CFS, for whom ME/CFS was the primary health issue. Exclusion criteria included current diagnosed psychological or psychiatric comorbidities and vulnerable adults, with a view to protecting participants and reducing biases arising from differential diagnosis or misdiagnosis (see Newton et al., 2010). A diagnosis of fibromyalgia also excluded participants; although ME/CFS and fibromyalgia are frequently co-morbid, levels of clinical stereotyping may differ according to diagnosis (Åsbring & Närvänen, 2003). Relatively homogeneous samples are preferred in IPA, to retain the idiographic emphasis whilst allowing analysis of converging and diverging data patterns across individuals' life-worlds (Smith et al., 2009). In our study, the extent of homogeneity in the sample was determined by participants having an interest in the research question, together with the parameters set by inclusion and exclusion criteria; particular sub-groups of the ME/CFS

population (according to severity or intersected social identity) were not specified owing to the dearth of literature on the study's subject matter, alongside pragmatics of recruitment and timeframe considerations.

Procedure

Participants were recruited through the UK ME Association's website and social media. Interested parties responding to the advertisement were sent further study information, alongside a consent form and demographics questionnaire to complete pre-interview. All participants provided verbal and written consent both to participate and to have anonymised quotes from audio recordings published and chose a pseudonym to be used to accompany citations in the findings. Interviews were conducted by the first author, with no others present, via Skype ($n=3$), telephone ($n=1$) and face-to-face ($n=1$) according to participant location and preference (see Figure 1, for interview schedule). Participants were given the opportunity to complete the interview over more than one meeting, take breaks during interview and encouraged to stop when necessary, according to their health needs. A post-interview debrief provided details of information and support services. Four participants had one interview lasting an average of 70 minutes. One participant (pseudonym Elizabeth) had two interviews lasting 109 minutes in total. Consonant with semi-structured interviewing, participants were encouraged to lead within the framework of the topic guide, whilst the interviewer had opportunity to pursue salient points (Smith & Osborn, 2015). Interviews, which took place over the first quarter of 2020, were digitally audio-recorded and transcribed verbatim. Data saturation (Saunders et al., 2018) was deemed inconsistent with IPA's iterative approach; rather, the scope of data collection was guided by balancing analytical depth and breadth within time constraints (Smith et al., 2009). The study gained ethical approval from the University of Derby Research Ethics Committee (ETH1920-4052 21-01-2020). Findings were shared in summary form with participants and with ME/CFS patient organisations.

Analysis

Transcripts were analysed manually using IPA and analysis proceeded via steps outlined in Smith and Osborn (2015), broadly delineated as (1) looking for themes, (2) connecting themes and (3) continuing the analysis with other cases. (1) The first author read the first transcript several times before proceeding to annotation (associations, questions, summaries, preliminary interpretations) in the left-hand margin. *Example: no explanation from clinicians, fobbed off, having to "fit a script."* The right-hand margin was used to develop candidate emergent themes, moving from annotation to a higher level of abstraction, making theoretical connections, whilst ensuring themes were grounded in raw data. *Example: testimonial dismissal, biased hermeneutical resources, quest for epistemic validation, conceptual rigidity in healthcare.* (2) Connections were sought between emergent themes, resulting in clustering and collapsing of themes alongside development of superordinate themes. *Example: where is the patient in patient-centred care?* This stage was facilitated by listing all emergent themes for that case onto a piece of paper in chronological order, and then "eyeballing" the list to imagine and explore different configurations (see Smith et al., 2009). A table of themes was then produced for the first case, listing superordinate themes and subordinate themes, data extracts supporting these themes and location of extracts in the transcript. (3) In continuing the analysis, the first author took each transcript afresh with an attempt to bracket off previous analytical insights (Smith & Osborn, 2015), producing a separate tables of themes for each case. When all five transcripts had been analysed, a final (group-level) table of superordinate and subordinate themes was constructed by comparing and

contrasting tables of themes for each individual case and accounting for convergences and divergences across and within cases, resulting in relabelling and reconfiguring of themes. This was facilitated by colour coding, printing out and cutting up each participant's table of themes (including accompanying data extracts), arranging the resultant pieces of paper on a large, flat surface and then moving the pieces around to explore different configurations, seeking best fit and overall coherency relative to the research questions (see Smith et al, 2009). For example, the final (group-level) superordinate theme presented here (*Being de-centred in patient-centred care*) was generated through comparing and contrasting individual-level tables of themes, including individual-level superordinate themes (Examples: *Where is the patient in patient-centred care?* and *Negotiating paradoxes in healthcare*), whilst also moving back and forth between the wider data picture and individual data extracts. This iterative process is consistent with the "hermeneutic circle," the dynamic relationship between the whole and its parts (see Smith et al., 2009).

Early stages of analysis were thus fully data-driven, reflecting IPA's phenomenological underpinning; later stages of analysis became more interpretative, as concepts associated with the framework of epistemic injustice (Fricker, 2007) were applied to make sense of participants' accounts, whilst ensuring that interpretations were grounded in raw data. Consensus was sought through co-authors repeatedly reviewing transcripts and tables of themes throughout the process, ensuring that themes were grounded in raw data.

Findings

One superordinate theme ("Being de-centred in patient-centred care") and accompanying sub-themes are presented and discussed. Participant quotes are identified by pseudonyms (see Table 1).

Being de-centred in patient-centred care

In apparent contradiction with the concept of patient-centred care, participants variously experienced psychological explanatory frameworks, perceived prejudice among healthcare professionals (in turn, associated with the label "chronic fatigue syndrome"), epistemic hierarchies and political agendas as being positioned at the centre of their healthcare encounters. Additionally, invalidating encounters were emphasised within the social security (benefits) system. Combined with a perceived lack of care and patient-practitioner partnership, such experiences impacted upon the wellbeing of participants. In some cases, this "de-centring" of the patient coincided with perceived threats to identity or personhood. In contrast, rarer reports of positive healthcare encounters appeared to engender a stronger sense of personhood. These accounts are explored through the following subordinate themes: "Struggling for epistemic-existential validation" and "Negotiating socio-epistemic hierarchies, politics and 'power'."

Struggling for epistemic-existential validation

Participants recounted invalidating encounters in primary and secondary (ME/CFS specialist) NHS care. The motif of invalidation was especially marked in Elizabeth's account, who perceived her moral character to be under question: "You're attention-seeking, you're dramatic, you're just making it up, you're a liar, you're a malingerer – I've been called all of these things" (Elizabeth). Elizabeth reported instances of such negative stereotyping arising as soon as she entered the consulting room; in these cases, the concept of negative identity

prejudice is supported. Elizabeth partially ascribed such prejudice to the nomenclature “chronic fatigue syndrome.”

I believe I would be taken more seriously by GPs etc. if I did not have a “CFS” diagnosis. I can be so ill sometimes, extreme difficulty breathing, chest pains, tremors, mini blackouts, falling over etc. and they do not entertain the thought of referring me to a specialist. Someone else presenting with these symptoms would be given some examination at least. (Elizabeth)

Here, the lived experience of ME/CFS, predominated by multiple, debilitating physical symptoms, is starkly juxtaposed with a diagnostic label (CFS) that reveals nothing beyond “chronic fatigue.” Whilst this article makes no claims regarding the suitability of the term ME, it could be contended that epistemic (hermeneutical) injustice in ME/CFS healthcare can be discerned in the commonly used diagnostic label CFS, reflecting and reinforcing conceptual impoverishment around the condition. Such conceptual impoverishment, which has the effect of distorting (minimising) the experience of living with ME/CFS, may then lead to inadvertent testimonial injustice among clinicians when patients’ health-related testimony (evaluated against clinical understanding of the diagnosis) appears to be “dramatic,” “attention-seeking,” or “making it up,” and the moral character of the patient is then brought into question.

Participants particularly struggled with the experience of ME/CFS being conceptualised by healthcare professionals through a psychological lens (a lens not shared by participants), with recommendations of psychosocial interventions and/or psychotropic medication. For example, Ivor recounted how repeated psychologisation of his concerns by clinicians had delayed diagnosis: “For five years I was treated by medical professionals as somebody who had depression and anxiety, they kept fobbing me off with stronger and stronger anti-depressants and suggested talking therapies.” Whilst such instances might be construed as a difference in opinion rather than epistemic injustice, it is important to note that Ivor found anti-depressants unhelpful and had communicated this to his GP, suggesting clinical privileging of a dominant (psychological) framework over patient first-hand experience. The impact of this “fobbing off” was striking: “I just felt as if I wasn’t being treated as a human being” (Ivor). Here, there is a suggestion that epistemic and existential harms may be interlinked.

The entwining of epistemic and existential harms figured in the experiences of other participants. The most powerful example was identified in Elizabeth’s meaning-making of her epistemically invalidating healthcare encounters: “They are just trying to kill you off - that’s what it feels like - trying to kill you off.” Elizabeth thus appears to experience epistemic injustice as existential erasure. Additionally, Jane recounted the impact of a (perceived psychologising and invalidating) benefits assessment and subsequent tribunal on her sense of self:

The whole DWP experience was quite traumatic with not being believed because of the medical condition [...] You just feel as if you are not as worthy as somebody else ... that you’re being made out to be a scrounger. I have had several conversations with two or three very close friends afterwards, almost asking their opinion of what they think about it ... I was trying to see what they thought of me. Did they feel I was a scrounger because I was asking for a benefit because I was unable to work. It was almost like I needed reassurance that I wasn’t a scrounger [...] I’m not myself because of having to fight my corner and it puts all this extra pressure on me that I really can’t cope with. (Jane)

Considered collectively, there is strong implication among participants of threats to identity and even to personhood: of being considered undeserving, morally lacking and feeling “not myself” (Jane), of perceived physical erasure (Elizabeth) and of not being acknowledged as a fully-fledged human being (Ivor). The use of “just” in both Ivor’s and Jane’s account, alongside use of third person “you” (“you are not as worthy...”), suggests a need to minimise or create psychological distance from the emotional pain of feeling less worthy or less human. A similar dynamic can be observed in Elizabeth’s reporting of clinical stereotyping as previously discussed (“you’re a liar, you’re a malingerer”). Jane’s need to seek reassurance from friends underlines the power of healthcare discourse in infiltrating her self-concept, and the extent to which her perception of other people’s disbelief and dismissal produced self-doubt. Additionally, the potential for relationships to promote or mitigate epistemic harms, and to bolster or undermine one’s sense of personhood, can be inferred. This last suggestion can be further probed through analysis of data divergence, that is, more positive experiences of healthcare.

Diverging from the strong motif of disconfirming encounters, Art described being “fortunate” in that he had almost always felt believed (though not necessarily understood) by clinicians: “I feel that I have been very fortunate, in that I was at a workplace that had its own doctors - they knew of the condition and were very aware of it” (Art). One instance of NHS healthcare experiences (of a specialist ME/CFS clinic group course) as recounted by Ivor stood out owing to its positive valence:

She [ME/CFS specialist clinic practitioner] came along to one of the sessions and she said, “I’m going to tell you how I think you can cope, but this isn’t gospel, it’s all sorts of emerging ideas ...please give me your feedback and if you have negative feedback I’d love to hear that, positive feedback I’d love to hear it.” You know, she was willing to learn and that was brilliant. [...] It made me feel so much more confident - and I wasn’t the only one feeling that because in the tea breaks when we were chatting amongst ourselves, everybody said how much more positive they felt. Someone understood and was willing to, you know, do the legwork. (Ivor)

Whilst the importance Ivor attaches to being valued as a contributing epistemic agent in his healthcare is demonstrated by his description of this encounter as “brilliant,” perhaps more remarkable is that this also impacted him psychologically, leaving him feeling “positive” and “confident.” In particular, Ivor’s account of his new-found confidence indicates a stronger sense of self or personhood (quite literally, self-assured) emerging as a result of a perceived epistemically just and equitable interaction. Thus, true care partnership, founded upon the principles of epistemic justice, may be therapeutic in itself.

Negotiating socio-epistemic hierarchies, politics and “power”

Participants expressed an awareness of the relative social and epistemic (socio-epistemic) authority of clinicians over patients: formal qualifications, social status and “power” were cited as markers. Whilst such markers are not inherently positively or negatively valenced, a notable finding was that social and epistemic hierarchies appeared to carry negative connotations for Elizabeth (to a lesser extent, also Marie and Jane) and neutral, occasionally positive (productive) connotations for Ivor and Art. These connotations broadly coincided with the nature of reported healthcare experiences: Ivor and Art reported mixed experiences, Marie and Jane reported very largely negative experiences, and Elizabeth reported exclusively and highly negative experiences. Marie, for example, recounted repeated struggles to have her

health-related testimony taken seriously within the context of a ME/CFS specialist clinic group course:

I would ask questions, I couldn't understand how to pace [a self-management method for energy-limiting health conditions] for *my* life but that was always just brushed aside, it was very much a script they [clinicians at the ME/CFS clinic] were reading from ... there was no chance to ask questions and when you did you were just told that might come up later ... and if it didn't, your question wasn't answered. [...] if you don't fit their script, you're stuck. (Marie)

Marie's experience appears far removed from the concept of patient-centred care. Marie actively sought clinical advice for her particular circumstances, yet her account suggests that the dominant hermeneutical framework ("script") was so tightly held by clinicians that any perceived threats to the framework (here, from Marie's experience) were ignored or "brushed aside." This dynamic was again discernible when Marie informed the clinic staff that travelling to and from sessions was negatively impacting her health, to which the clinic responded by discharging her: "I don't think there's any other illness you can have and get discharged because you're too ill" (Marie). The paradox inherent in Marie's testimony (being discharged for being too ill) is also evident in Marie's meaning-making of such encounters: "I've never felt that someone has wanted to help me" (Marie). In both cases, perceived lack of care appears to be the lasting memory of a healthcare encounter. In both cases, socio-epistemic hierarchies within healthcare appear to displace the patient from the centre of the encounter. The most powerful example of this in Marie's account was when a clinician, overriding Marie's testimony to the contrary, ascribed the development of new symptoms to ME/CFS, without further investigation. Marie was later admitted to hospital, requiring treatment for a non-ME/CFS medical issue.

Jane described how she was reduced to tears over not feeling heard by her primary care providers, and made meaning out of such encounters in part through collective struggles with "the powers that be," noting that many healthcare-related structures were "too big for us to be able to influence" (Jane). Amplifying this, Elizabeth's testimony represented the most striking account of "power" and extra-clinical influences. In addition to being very clear in her position that clinicians held "too much power," Elizabeth foregrounded her perception of an overarching political agenda prioritised over patient testimony:

I don't think it is possible to understand how people with CFS/ME are regarded unless you are aware of the influence insurance companies and benefit agencies have had. I could write a book about that, along with another on being screwed over by the DWP [UK Department of Work and Pensions] and its disability analysts. The objective is to increase the length of a window of time in which we are functional so that we can go back to work... and providing CBT/GET therapies which are claimed to have a high improvement rate so it's the patient's fault if it doesn't work. [...] Other countries have taken this model, not because it's true but because there's a political agenda, particularly insurance companies not wanting to pay out. (Elizabeth)

For Elizabeth, politics fills a space created by the perceived absence of a solid empirical justification for her care. Elizabeth's meaning-making raises the possibility that hermeneutical and testimonial injustice in ME/CFS healthcare may be driven to some degree by structural (here, political) influences beyond the control, and perhaps awareness, of both patients and

healthcare professionals. Elizabeth's suggestion of extra-clinical influences was re-iterated in the context of her experience of "activity management" (which Elizabeth believed to be graded exercise therapy under another name), where Elizabeth described being coerced into undertaking exercise, with deleterious consequences:

It was a case of "I want objective measures that you're improving – you have to do this or the course ends." And I told him [physiotherapist] this is going to make me really ill [...] I was actually having seizures it was that bad – the relapse from that. And if I refused to do what he was asking, I was obstructive and uncooperative (Elizabeth).

Elizabeth partially ascribed her experience to an underlying treatment narrative: "with physiotherapy you go into their department and on the wall it says, 'you get out what you put in.' So that implies it's your fault it didn't work" (Elizabeth). This narrative, as will be picked up in the discussion, is one with socio-political and cultural implications. The contrast between Elizabeth's perception of ME/CFS healthcare (coercive, harmful) and its expected ethos of beneficence appeared to be associated with loss of trust in clinicians: "I have no trust in them whatsoever" (Elizabeth). This sentiment was echoed by Marie: "Unless I'm dying I just won't go [to see the GP] now because I know I'll be told it's 'just the ME'."

In contrast to the above accounts, whilst Ivor and Art recounted both negative and positive experiences, their attitudes toward clinicians and the healthcare system generally appeared more optimistic. For example, Ivor recounted how the "confident" opinion of a physiotherapist vis-à-vis the alleged benefits of graded exercise therapy persuaded him to comply with the therapy, and how he was then positioned as uncooperative by the therapist when his health deteriorated as a result. Nevertheless, Ivor described a general respect toward clinicians and, as detailed in the previous sub-theme, wanted to share positive experiences during interview. In a similar vein, Art noted lack of understanding among clinicians, and appeared to blame himself for his lack of progress in "graded activity": "I think I've proved so many times that I'm not very good at this yet – I keep crashing" (Art). Nevertheless, the following, final account from Art represented a notable divergence in data patterns.

Whilst Art noted the power differential within healthcare encounters with consultant physicians - "you were very much presenting yourself to the person, the great man or great woman, for them to deign to look at your case" - he reported finding most encounters with GPs "positive." Here, it is notable that Art was able to draw on GP services through his work, and also described how he would actively avoid any GP who was perceived as dismissive, whilst planning for what he wanted to say in a consultation: "I would write it down and literally tick it off if I had managed to understand it or if I'd managed to ask the question." In making sense of his healthcare encounters, Art also noted that his social positionality may have impacted:

For the consultant, I can only imagine what it would be like for somebody much younger than me, who didn't perhaps have that background [Art's profession], who didn't have the language skills, or the education, or whose first language wasn't English ... I wonder what they would have got from those conversations. I didn't feel any problem asking because I felt it was important to understand my condition and what the prognoses were and all the rest of it. I didn't always understand the answers especially with the endocrinologist because there was a lot of jargon involved. But if there was jargon I would get them to spell out the words and I would write them down so I could look them up. (Art)

Here, Art indicates a form of social hierarchy (based upon socio-cultural identity markers such as education level and language proficiency) as being relevant to his ability to navigate healthcare encounters; the term “conversations” suggests a two-way process where Art experienced a valorising of his epistemic contributions. In other words, social hierarchies and epistemic hierarchies are interlinked. Art’s account also suggests that a degree of epistemic labour and strategizing was undertaken (preparing for consultations, avoiding dismissive clinicians, writing things down in the consultation), to mitigate epistemically unjust encounters. It may be asked what impact such labour has on a person’s well-being, and what happens if that person does not have the physical or social resources to strategize in this way. A possible answer to this can be found in the case of Elizabeth, who lived with very severe ME/CFS (see Table 1). In her late 40s, having been diagnosed with ME/CFS in her early twenties and lacking social support, Elizabeth had never been able to work, had no partner or children, and was living hand-to-mouth under constant fear of loss of benefits which was her only income. Having attempted to “educate” her healthcare providers numerous times, she now appeared to have given up hope of positive change. Elizabeth described her life as “eroded.”

Discussion

Findings suggest that epistemic injustice in healthcare fora – which for participants notably included the social security arena – carried detrimental but varied consequences for participants that may be conceptualised through a variety of pathways. The potential of epistemic injustice to cause harm via inappropriate healthcare interventions, psychological distress, delayed diagnosis, loss of patient trust, and barriers to accessing appropriate medical care and social accommodations, has been noted in extant literature (Blease et al., 2017; Geraghty & Blease, 2019) and is evident in this study’s findings. Whilst some such harms have been associated with the application of a biopsychosocial model (Geraghty & Blease, 2019), our findings suggest that other “structural and hierarchical” factors within healthcare (Carel & Kidd, 2014) are involved. Certainly, Ivor’s experience of specialist clinics was very different to Marie’s experience; since specialist clinics typically draw from the same (biopsychosocial) framework, other factors must be assumed to impact. In this regard, the strong theme of politics and “power” within Elizabeth’s account suggests that influences outside of the patient-practitioner relationship, and outside of the health system, may impact on epistemic injustice within healthcare, indicating a need to look beyond healthcare models. Moreover, this study’s findings additionally suggest that healthcare-related epistemic injustice may impact detrimentally on identity and personhood and that social positionality (notably gender) may influence how epistemic injustice is experienced. These issues will now be considered further.

It has been argued that it is “an essential attribute of personhood to be able to participate in the spread of knowledge by testimony and to enjoy the respect enshrined in the proper relations of trust that are its prerequisite” (Fricker, 2007, p. 58). It therefore follows that to exclude an individual or group from contributing to knowledge generation and sharing is to deny that individual or group personhood (Guenther, 2017). Thus, epistemic agency, identity and ontological security may be entwined, suggesting potential existential harms of epistemic injustice (Guenther, 2017; see also Fricker, 2007). This suggestion is most strongly supported by Elizabeth’s account, who experienced systematic epistemic marginalisation by clinicians and benefits assessors as a form of existential erasure. This account is consistent with Fricker’s argument that, in cases of systematic epistemic injustice, “a person may be, quite literally, prevented from becoming who they are” (Fricker 2007, p. 5). Likewise, our findings support Fricker’s contention that epistemic injustice can “cut deep,” harming subjects not only in their capacity as knowers, but also “undermining them in their very humanity” (Fricker, 2007, p. 44). In this respect, it is notable that some research demonstrates perceived assaults to identity

among people with ME/CFS (Åsbring, 2001; Dickson et al., 2008). In Jane's case, the desire for reassurance from others regarding her true identity may represent a way of coping with perceived identity threats posed by epistemic injustice. Whilst identity disruption has in some cases been associated with the consequences of applying a biopsychosocial model in clinical practice (see Geraghty & Blease, 2019), our findings highlight overarching structural factors that might contribute to epistemic injustice and related harms, in healthcare and beyond.

Elizabeth understood her invalidating healthcare encounters as inextricably linked with both a wider socio-political climate and a particular hermeneutical resource, the narrative of "you get out what you put in" (that hard work and motivation dictate "success"). Elizabeth associated this narrative with her experience of being blamed for not meeting clinical expectations, an experience echoed in patient accounts within the ME/CFS and wider chronic illness arena (Anderson et al., 2012; Lian & Robson, 2017; MEA, 2015). This narrative can be located within biopsychosocial discourse on ME/CFS, where the importance of effort and motivation in recovery are emphasised (Picariello et al., 2017; Sharpe et al., 1997; see also Hunt, 2022). Variations on this narrative have been associated with victim blaming dynamics evidenced in healthcare encounters in the ME/CFS arena and more widely (Hunt, 2023a; Lian & Robson, 2017).

Elizabeth also made sense of her epistemically unjust encounters through her perception of an overarching structural (socio-political) issue: the politics of work and health, specifically those relating to the benefits system and insurance companies. Such agendas have recently been discussed in ME/CFS academic literature, and further situated in a context of neoliberal retrenchment of health and welfare sectors (welfare reform politics) in the UK and beyond (Hunt, 2022, 2023b). This literature is supported in the wider disability sphere by the work of disability activists and scholars (Clifford, 2020; Shakespeare et al., 2017; Stewart, 2022). Indeed, the narrative "you get out what you put in" is permeated with neoliberal and ableist assumptions, championing individual effort and agency in attaining health and happiness and life "success" (see Adams et al., 2019; Hunt, 2022). In this regard, neoliberalism - or "neoliberal-ableism" (see Goodley, 2017) - may be considered a macro-level hermeneutical framework, a structural form of epistemic injustice (see Anderson, 2012), reinforcing dominant explanatory healthcare frameworks such as the biopsychosocial model. In other words, healthcare-related epistemic injustice may be to some extent politically driven.

The diversity of healthcare experiences across participants in this study (with a bias towards unsatisfactory experiences) is supported more widely (Dickson et al., 2007; Gilje et al., 2008; MEA, 2015); however, reasons for such divergence are rarely discussed through a socio-culturally cognisant lens. Variations may be partly elucidated by considering participants' positioning vis-à-vis intersecting layers of socio-demographic advantage and disadvantage (see also Table 1). Art, being a man with a high level of education and relative economic stability (intersection of gender, economic and educative advantage) may be less vulnerable to epistemic injustice than participants living at the intersection of greater social disadvantage (Rosenthal, 2016). Research suggests that women are more likely to be dismissed and/or psychologised than men in healthcare (Hoffmann & Tarzian, 2001), whilst implicit class-based biases of clinicians have been documented in non-ME/CFS research (Diniz et al., 2020). Such biases can be further sited within a socio-cultural context that has been argued to privilege culturally "masculine" qualities (Evans et al., 2023; Lian & Robson, 2017), indicating another possible contributor to structurally biased hermeneutical frameworks and thus to hermeneutical injustice. Given the association between social power and epistemic trustworthiness (Fricker, 2007), it may be that greater epistemic trustworthiness is accorded by clinicians to patients who can be positioned at the intersection of multiple social advantage. Another way of expressing this is that patients with greater identity power and social power (Fricker, 2007) may be less vulnerable to epistemic injustice. This supports Fricker's (2007)

concept of the “credibility economy” (that prejudicial stereotypes are bound up with credibility judgements) and may help to explain our finding that experiences of invalidation in healthcare diverged along the lines of gender.

Finally, we revisit the debate regarding to what extent epistemic injustice operates in the ME/CFS arena, and on what grounds (see Blease et al., 2017; Blease & Geraghty, 2018; Byrne, 2020; de Boer, 2021). Byskov (2021) proposes five conditions which must be met to lay claim to a case of epistemic injustice. The “prejudice condition” holds that the discrimination in question must involve an unfair judgement about the epistemic trustworthiness of the “knower.” The “disadvantage condition” states that a person must suffer epistemic or other social disadvantage owing to the discrimination. This study’s findings demonstrate how these two conditions are met: participants (most markedly, Elizabeth) were negatively and unfairly stereotyped in such a way that their testimony was dismissed (epistemic disadvantage), biomedical examinations were limited, and inappropriate healthcare interventions (such as graded exercise therapy) were prescribed. Elizabeth’s “eroded” life also clearly demonstrates further social disadvantage generated by discrimination. The “stakeholder condition” (Byskov, 2021) holds that a person must be impacted by decisions from which they are excluded; this condition is fulfilled, since participants were personally impacted, occasionally to their benefit but largely to their detriment, by clinical decisions. The “epistemic condition,” which stipulates that a person must hold knowledge relevant for decisions from which they are excluded, is highlighted in this study through the testimony of Elizabeth and Marie. Both women sustained physical harm as a result of clinical dismissal of their testimony, notably where this testimony constituted lived experience of their own body. Lastly, the “social justice condition” suggests that the injustice of epistemic injustices is greater when the person subjected to such also suffers other (pre-existing) social injustices. This condition can be supported by previous discussion of intersectionality and differentiated experiences of epistemically unjust healthcare encounters, exemplified by Elizabeth’s case.

Overall, we suggest that people with ME/CFS are indeed subjected to epistemic injustices within healthcare, but that there are many nuances. Some people with ME/CFS are subjected to greater epistemic injustice than others, different meanings are ascribed to the experience of epistemic injustice, and the impact on wellbeing differs from person to person, likely mediated to some degree by the intersected social positionality of those subjected to epistemic injustice. Lastly, some drivers of healthcare-related epistemic injustice may be external to healthcare, and beyond the awareness of patients and clinicians. This final point is an important consideration in countering a noted tendency within some literature to employ the concept of epistemic injustice in the service of “doctor-bashing,” that is, holding healthcare professionals fully accountable for all aspects of epistemic injustice (Kidd, 2024). Our findings support the notion that more complex structural forces are involved (Kidd & Carel, 2014).

Limitations and directions for future research

Members of patient organisations may have more severe and enduring experiences of ME/CFS relative to the wider ME/CFS population (Shepherd, 2017), may take a more critical and politicised stance towards healthcare and may be more willing to participate in critical research. This, along with the first author’s positionality and the explicit focus in this study upon injustice, may be argued to bias the sample towards more marked experience of epistemic injustice. On the other hand, feedback from people with ME/CFS expressing an interest in the study suggested that the exclusion criteria of psychological co-morbidities and fibromyalgia may have excluded those with more complex, severe and enduring experiences of ME/CFS, alongside more negative healthcare experiences. Further, although the study included one very severely affected person with ME/CFS, this sub-group is often excluded from research and

marginalised with regards to healthcare policy and provision. Taken together, these considerations suggest that the study has not fully captured the potentially wide variation of experiences of epistemic injustice within the ME/CFS population.

Moreover, whilst a relatively homogenous sample was sought, the resulting lack of socio-demographic diversity (notably regarding race and ethnicity, since all participants were white) suggests that more pervasive experiences of epistemic injustice among people with ME/CFS have not been fully captured. Research suggests that racial and ethnic disadvantage may impact on stigma and discrimination within healthcare, notably increasing likelihood of being psychologised (Annamma et al., 2013; de Carvalho Leite et al., 2011), whilst this study's findings suggest that intersected social positionality impacts on the experience of healthcare-related epistemic injustice. Future research could draw upon socio-demographically diverse samples, including participants with multiple social disadvantage, taking a deliberately intersectional approach. Equally, in-depth analysis of how particular, marginalised sub-groups of the ME/CFS population experience healthcare-related epistemic injustice is warranted, for example very severely affected people with ME/CFS, and Black, indigenous and people of colour with ME/CFS. Finally, whilst a small sample size is necessary for an in-depth analysis that facilitates conceptual development, findings are not generalisable in a statistical-probabilistic sense. Larger scale studies examining the impact of epistemic injustice on this patient population are indicated.

In revisiting reflexivity, it is again acknowledged that the “double hermeneutic” in IPA includes the unique interpretative lens of the researcher(s), signifying that other researchers would likely interpret participants' meaning-making differently. This point is particularly salient given the first author's positionality as a person with a diagnosis of ME/CFS, who has many years of experience within this community, largely as a patient, but also as a psychological therapist. This dual perspective has influenced all stages of the research process, including analysis. For example, politics and power were explicit, dominant and recurring motifs in Elizabeth's experience of epistemic injustice, whilst negotiation of power dynamics (in particular epistemic hierarchies) represented a group-level motif. Yet, it is possible that a researcher with a different standpoint would have thematised differently. The first author has lived experience and interest in many aspects of ME/CFS, including politics and power dynamics within healthcare and broader social arenas; these interests have developed and evolved during the research process and continue to evolve (see Hunt, 2022, 2023a, 2023b). Whilst such interests indubitably attuned the first author to some data patterns over others, conscious efforts were made to “bracket” preconceptions and the authors sought to include generous amounts of data extracts in presenting results, in view of enhancing transparency and rigour (see Smith et al., 2009; Yardley, 2015). Consonant with (“big Q”) qualitative research, the study was approached with a valorising of researcher subjectivity (see Coyle, 2016) whilst remaining mindful of the pitfalls of projecting unacknowledged bias into the research process (Berger, 2015). Accordingly, whilst certain measures were taken to mitigate bias (see earlier section on reflexivity), the first author's background was considered of value in facilitating greater sensitivity to context, notably the language and culture of the ME/CFS community (see Berger, 2015; Yardley, 2015).

With a view to more fully exploring the impact of epistemic injustice on people with ME/CFS (and other patient groups), further work is required to develop a way of measuring this concept (Carel & Kidd, 2014). In this regard, using stigma research (Hatzenbuehler et al., 2013) as a springboard, both in terms of developing measures and in terms of delineating different manifestations of epistemic injustice, may prove fruitful. For example, whilst concepts such as internalised stigma and intersectional stigma have been established (Hatzenbuehler et al., 2013; Turan et al., 2019), this study suggests that the possibility of parallel concepts pertaining to epistemic injustice should be explored. In a similar vein, the

notion of epistemic injustice as a chronic stressor, again in parallel to stigma, cannot be ruled out. In this regard, it is interesting to note that Elizabeth, with the most severe and enduring ME/CFS among participants, was also subject to the most markedly invalidating encounters, warranting further research.

The study's findings indicate that more attention should be paid to the broader structural (here, socio-cultural and political) context within which epistemically unjust healthcare encounters occur. This suggestion is supported by Fricker's contention that systematic epistemic injustice arises from "structural inequalities of power" (Fricker, 2007, p. 156) and points towards structurally competent (socio-culturally and politically cognisant) approaches to health and illness (see Metzl & Hansen, 2014). Greater emphasis on structural context, which should also be considered when assessing the clinical trajectory of people with ME/CFS and the effectiveness of healthcare interventions, may give rise to a "deeper sense of *structural epistemic injustice*" (Carel & Kidd, 2017, p. 344, original italics), which has been identified as an important consideration in future research. Accordingly, exploration of structurally competent variants of, or alternatives to, the biopsychosocial model is recommended. Additionally, since it is likely that practitioners are largely unaware of the political backdrop to ME/CFS healthcare as highlighted in this study, we extend our recommendations beyond calls for greater reflexivity in medical school curricula, and support the case made for more emphasis on structural competency (see Hunt, 2022, 2023b). Additionally, we propose that such considerations are extended to broader clinical (physiotherapy, psychotherapy) training. This suggestion is consistent with Anderson's (2012) argument that structural-level epistemic injustice requires structural-level remedies in addition to individual efforts to cultivate epistemic virtue.

Finally, the study's findings, together with points raised in the discussion, may hold relevance for other health conditions that can be framed through the lens of "medically unexplained symptoms" (Deary et al., 2007) or "energy limiting conditions" (Hale et al., 2020). In both cases, similar dynamics of dismissal and disbelief in the healthcare arena are evident (Evans et al., 2023; Merone et al., 2022). Importantly, this currently includes patient sub-groups of the long Covid umbrella. Patient testimony among people with long Covid where biomarkers are lacking indicates dynamics of disbelief and psychologisation similar to those documented in ME/CFS, whilst similar structural drivers of epistemic injustice have been proposed (Hunt, 2022, 2023b). The experiences of some of the participants in this study offer a stark account of the possible impact of healthcare-related epistemic injustice over the long-term, pointing towards an urgency in ensuring that history does not repeat itself with long Covid. In this way, although the study's findings are not statistically generalisable, they may be considered not only analytically generalisable, in supporting findings in extant literature, but also tentatively transferable to contexts outside of ME/CFS (see Polit & Beck, 2010; Smith et al., 2009).

Conclusion

The study's findings suggest that healthcare-related epistemic injustice can lead to marginalisation and multi-faceted yet varied harms. Intersection of social disadvantage may impact vulnerability to epistemic injustice and its varied consequences, warranting further research. Whilst extant literature underlines the potential harms of epistemic injustice via delayed diagnosis, inadequate or inappropriate healthcare provision and associated loss of patient trust (see Blease et al., 2017), this study highlights another possible pathway of harm via the impact of epistemic injustice on identity and personhood. Additionally, the possibility that epistemic injustice operates as a chronic stressor cannot be ruled out and is worthy of further investigation. Finally, the study reveals possible macro-structural (political, socio-cultural) drivers of epistemic injustice in the field of ME/CFS, drivers that may hold relevance

to other “contested” conditions. Further exploration of these structural influences would likely facilitate a deeper appreciation of structural epistemic injustice in the realm of ME/CFS and beyond, and may also highlight the need for more structurally competent healthcare models, clinical education and practice.

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