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⁵**Q1** IAN JAMES KIDD AND HAVI CAREL

Abstract

Ill persons suffer from a variety of epistemically-inflected harms and wrongs. Many of these are interpretable as specific forms of what we dub *pathocentric epistemic injustices*, these being ones that target and track ill persons. We sketch the general forms of pathocentric testimonial and hermeneutical injustice, each of which are pervasive within the experiences of ill persons during their encounters in healthcare contexts and the social world. What's epistemically unjust might not be only agents, communities and institutions, but the theoretical conceptions of health that structure our responses to illness. Thus, we suggest that although such pathocentric epistemic injustices have a variety of interpersonal and structural causes, they are also sustained by a deeper naturalistic conception of the nature of illness.

1. Epistemic injustice and illness

Experiences of chronic somatic illness, in their many forms, impose a variety of harms, including physical pain, cognitive disorientation, loss of bodily capacities, and emotional and psychological distress, but also a diverse range of wrongs, ranging from social marginalization to professional discrimination. Such negative experiences are abundantly documented in illness pathography, healthcare psychology, medical anthropology, and other sources for the everyday realities of 'onerous citizenship' in what Susan Sontag called 'the night side of life'.¹

The shared features of such experiences have been described in the philosophical literature by S.K. Toombs, who writes about illness as a series of losses, by Fredrik Svenaeus, who characterises experiences of illness as 'unhomelike being in the world', by Matthew Ratcliffe's analysis of altered 'existential feelings', and by Havi Carel, who characterises illness as a fundamental disruption

¹ Susan Sontag, *Illness as Metaphor* (Toronto: McGraw-Hill Ryerson, 1978), 3.

of the body's transparency and to the familiar habits and routines of everyday life.²

Perhaps less obvious, but no less important, are a complex range of epistemically-toned harms and wrongs, defined broadly as disadvantages that occur due to interference with the capacities needed to pursue epistemic interests in the context of ill health. Such negative epistemic experiences manifest, within healthcare discourse and pathographies, in miscommunications between patients and health professionals, complaints by patients of their concerns and interests being ignored, overlooked, or dismissed, in rhetorics of 'silencing', and continued feelings of dissatisfaction, as well as, in some cases, flawed clinical care. These have for a long time been responded to with policy proposals for inclusion of 'patient perspectives' and the instigation of 'patient-centred care', and castigation by patient activists of the communicative failures endemic to healthcare encounters.

The epistemic harms and wrongs suffered by ill persons have several related negative effects. First, they impact upon patients' clinical care, psychological and physical health, social confidence, and lived experience; they are no longer 'at home' within the world, to use a term from phenomenology of illness. Second, experiences of being ignored, dismissed or even silenced, and other wrongs that occur within healthcare contexts, typically compromise the epistemic relationships between ill persons and health professionals. The sense that they are somehow at odds with one another or that their interests and perspectives conflict should be a source of serious concern to healthcare providers.

Third, the injustices experienced by ill persons typically intersect with other axes of oppression, such as gendered, racist, and ageist discrimination.³ Finally, judging by their sheer scale and persistence, the epistemic harms and wrongs experienced by ill persons reflect entrenched, systematic features of our healthcare and social environments. Although these features may appear primarily sociological

² See, inter alia, S.K. Toombs, The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient (Amsterdam: Kluwer, 1993); Fredrik Svenaeus, The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice (Dordrecht: Kluwer, 2000); Matthew Ratcliffe, Feelings of Being: Phenomenology, Psychiatry, and the Sense of Reality (Oxford: Oxford University Press, 2008); Havi Carel, Phenomenology of Illness (Oxford: Oxford University Press, 2016).

The intersectional character of health inequities is the theme of Amy J. Schulz and Leith Mullings (eds.), *Gender, Race, Class and Health: Intersectional Approaches* (Oxford: Wiley, 2005).

or pragmatic in nature, we suggest that they go deeper, because radical epistemic incapacitation is an ineradicable dimension of illness, conceived – following Maurice Merleau-Ponty – as a 'complete way of being'. ⁴

Different conceptual frameworks exist for investigating the variety of epistemic harms and wrongs intrinsic to sustained experiences of illness. Within contemporary philosophy, particular use is made of Miranda Fricker's concept of epistemic injustice – 'a wrong done to someone specifically in their capacity as a knower'. Subsequent work has identified new forms and sources of epistemic injustice and further documented their prevalence throughout the social world. A growing literature now exists devoted to epistemic injustice and a variety of somatic and psychiatric illness, alongside wider themes in medical and healthcare practice.

In this paper, we develop this work by arguing that many of the epistemic harms and wrongs experienced by persons with chronic somatic illness reflect specific forms of *pathocentric epistemic injustice*: ones that target and track people who are, or are perceived as, chronically somatically ill. We use this term to refer to a distinct and relatively stable social group, although are aware of the shortcomings of this definition and its overlap with other categories, such as progressive disease, acute illness with lasting effects, and disability. We bracket these issues here as we wish to focus on the group of people who are significantly and chronically ill, such that they have continued and necessary interactions with health professionals, as well as being exposed to stereotype and stigma of the sort that do not usually affect someone with an acute illness, such as a fractured bone.

⁴ Maurice Merleau-Ponty, *Phenomenology of Perception* (New York: Routledge, 2012), 110.

⁵ Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007), 1.

⁶ An up-to-date account of current work on epistemic injustice is Ian James Kidd, José Medina, and Gaile Pohlhaus, Jr. (eds.), *The Routledge Handbook to Epistemic Injustice* (New York: Routledge, 2017). A bibliography of work on epistemic injustice, illness, healthcare, and disability is available at <www.ianjameskidd.weebly.com>.

On epistemic injustice and disability, see Anita Ho, 'Trusting Experts and Epistemic Humility in Disability', *International Journal of Feminist Approaches to Bioethics* **4**.2 (2011), 102–123 and Jackie Leach Scully, 'From "She Would Say That, Wouldn't' She?" to "Does She Take Sugar?": Epistemic Injustice and Disability', *International Journal of Feminist Approaches to Bioethics* **11**.1 (2018), 106–124.

Pathocentric epistemic injustice intersects with other, more generic forms of epistemic injustice. Our claim is that many of the epistemic harms and wrongs to which ill persons are subjected take the form of specifically pathocentric forms of testimonial and hermeneutical injustice. Such pathocentric injustices are produced and sustained by economies of credibility and intelligibility, themselves sustained by deeper theoretical conceptions of the nature of health – which are often labelled 'naturalistic' conceptions – that epistemically privilege the concepts and methods of biomedical science. Our aim is to show that the privileging of these naturalistic conceptions is an important, fundamental source of these pathocentric epistemic injustices. If that is right, then achieving epistemic justice for ill persons requires more than social and healthcare reform - a complex enough task in its own right – but, at its most ambitious, deep epistemic reform of our most fundamental ways of conceptualising human health, flourishing and wellbeing in ways that transcend and transgress the implicit and commonly accepted idea that health is the *sine qua non* of the good life.

2. Testimonial injustice and pathographic testimony

The core epistemic activities of giving testimony to, and making sense of, one's experiences assume a special complexity in cases of chronic illness. Amid the turmoil of diagnosis, concerns about treatment choices, anxiety about prognosis, and the often-profound changes to previous life, a new urgency inflects our epistemic needs – to speak, be listened to, understood, and to attain a degree of cognitive command over our practical and existential situation.

Diagnosis of a serious illness has been described as biographical disruption and a life changing event, amplified by the intersubjective character of our narrative practices and the essential involvement of other agents whose collaboration cannot be taken for granted. Such disruption gives rise to a deep need to make sense of these profound events and incorporate them into the ill person's life. This process is comprised of narrative and testimony and involves talking about events, decisions, feelings, and practical changes, as well as private narration in the form of writing, videos, and other

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⁸ Michael Bury, 'Chronic Illness as Biological Disruption', Sociology of Health and Ilness **4**.2 (1982), 167–182; Kate C. McLean, The Co-authored Self: Family Stories and the Construction of Personal Identity (Oxford: Oxford University Press, 2015); Havi Carel, Illness: The Cry of the Flesh (Stocksfield: Acumen, 2007).

forms of sense-making. Ill persons often seek support in the form of conversation as well as being required to provide ongoing information to health professionals, information which is often intimate, upsetting, and painful.

Important aspects of this process are the need to be understood and empathised with, help with decision making, and finding solutions for practical concerns. Such discussions may involve family, carers, health professionals, friends, a wider support network as well as social care and other professionals. For all of these, clear communication, and the ability to make oneself heard, understood, and taken seriously, are paramount.

Another significant issue is a sense of isolation, borne of practical constraints, like being house-bound, stigma, the sense of unfairness often experienced when one falls ill, or isolation, an important factor in wellbeing and patient outcomes. Other problems characterising being ill include alienation, bodily estrangement, objectification, and a sense of 'unhomelikeness', which undermine effective and authentic communication while also exacerbating the need for such communication.

Such testimonial and hermeneutical needs can only be recognised and fulfilled through social conditions that sustain appropriately diverse and inclusive economies of credibility and intelligibility. Unfortunately, as we know from work in feminist epistemology and critical race theory, this is rarely what obtains in our social cultures. Injustice is, as Judith Shklar observed, quite the norm, including the specifically epistemic injustices described by Fricker. In Fricker's account, there are two main types of epistemic injustice—testimonial and hermeneutical, pertaining to a discriminatory affordance of credibility and intelligibility, respectively. In what follows, we summarise accounts we have provided elsewhere of what we now call pathocentric epistemic injustices, before moving on to discuss naturalism. ¹⁰

Testimonial injustice occurs when negative stereotyping leads a hearer to prejudicially deflate the credibility assigned to a speaker. The effects include reduced testimonial authority, frustration of practical and social agency, and erosion of the epistemic confidence of the

⁹ Judith Shklar, *The Faces of Injustice* (New Haven and London: Yale University Press, 1990), 15.

Havi Carel and Ian James Kidd, 'Epistemic Injustice in Healthcare: A Philosophical Analysis', *Medicine*, *Healthcare*, *and Philosophy* **17**.4 (2014), 529–540; Ian James Kidd and Havi Carel, 'Epistemic Injustice and Illness', *Journal of Applied Philosophy* **33**.2 (2017), 172–190.

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speaker, which can ultimately lead them to cease trying to communicate altogether. Though originally analysed in its agential forms, subsequent work has recognised structural forms of testimonial injustice, since acts of credibility deflation can be embedded in social structures, alongside the corrupted perceptions and judgments of agents. A variety of negative prejudices and stereotypes can inform testimonial injustice, including the gendered and racialized cases discussed in Fricker's original account. Moreover, further forms of intersectional epistemic injustices are now recognised, many articulated using the conceptual resources of a variety of social justice movements. ¹¹

We propose that ill persons, *qua* ill persons, are especially vulnerable to testimonial injustice because appraisals of their credibility can be corrupted by *pathophobic* prejudices and stereotypes. These arise from tendencies to operate with negative attitudes towards illness or ill persons. Such attitudes include what earlier generations of sociologists described as 'stigma', but a distinctive advantage of the concept of epistemic injustice is its obvious sensitivity to the characteristically *epistemic* dimensions of the injustices experienced by ill persons.

Such epistemic injustices assume particular force within healthcare contexts, for instance because they rely heavily on certain forms of knowledge and information when plotting the course of treatment of an individual patient. And being that patient means that the decision will impact you in the most direct and intimate manner, by influencing how your body will be treated, what will be done to it, and the length and forms of life available to oneself.

To criticise pathophobia isn't to deny the various negative aspects and effects of illness, nor to acquiesce in what Barbara Ehrenreich calls 'bright-siding' – a wilfully myopic insistence on the positive effects, real or imagined, of adversity and suffering. ¹² Instead, it marks an attempt to achieve a more complex understanding of the diversity of forms of experiences of illness. Between resolute pathophobic pessimism and dogmatically optimistic 'bright-siding', one can achieve a subtler perception of chronic illness as what Carel describes as a 'life-transforming process', containing 'plenty of bad, but also, surprisingly, some good'. ¹³

See the essays in Part II and III of Kidd, Medina, and Pohlhaus, Jr., *The Routledge Handbook to Epistemic Injustice*.

Barbara Ehrenreich, Smile or Die: How Positive Thinking Fooled America and the World (London: Granta, 2009).

Carel, *Illness*, 12. The corrupting effects of 'bright-siding' on narratives of adversity is discussed in Ian James Kidd, 'Adversity, Wisdom, and Exemplarism', *Journal of Value Inquiry* (forthcoming).

Since achieving this understanding requires careful, critical attention to ill persons' testimonies and narratives, ensuring fair appraisal of their credibility is crucial. But credibility judgments are not made in a vacuum: they are shaped by some sense or conception of what counts as credibility within a given domain, relative to a certain set of epistemic and practical interests and concerns—a theoretical conception of health and illness, say, of the sort described later in the paper.

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The credibility of ill persons can be eroded in one or more of at least two ways. First, there is pre-emptive derogation of the epistemic credibility and capacities of ill persons owing to pathophobic stereotyping – a prior view, for instance, of ill persons as being confused, incapable, or incompetent, that distorts an evaluation of their actual epistemic performance. Second, hearers can presuppose that an ill person will be dominated by their illness, unable to reflect on other issues, such that they cannot be perceived as impartial or objective. Since they are preconditions of epistemic credibility and of good decision-making, a presumption that ill persons are dominated by their illness leads to credibility-deflation. As a consequence, ill persons often report the downgrading of their testimonies, including ones which would ordinarily elicit testimonial credibility. Careful, articulate reportage of one's bodily experiences often fails to secure affordances of credibility, as they ordinarily would in epistemic life. Experiencing an inability to persuade others by performing acts of epistemic competence gives rise to 'shock', according to the titular subjects of Robert Klitzman's book, When Doctors Become Patients. 14

Here are two illustrative examples of testimonial injustice within a healthcare context. The first comes from a woman with a severe respiratory disease, reporting a worrying symptom that is laughed off by a physician:

I asked a professor whether being exposed to reduced oxygen levels long-term, the way I am, would have any detrimental effects on cognitive function e.g. would that explain why my memory had rapidly become much worse? He just laughed off my genuine and serious concern by saying he had the same problem and sometimes couldn't even remember his wife's name. I never did get a proper reply to that question.¹⁵

¹⁴ Robert Klitzman, When Doctors Become Patients (Oxford: Oxford University Press, 2008).

This testimony was elicited from a LAM (lymphangioleiomyomatosis) patient mailing list. We are grateful to the patients who responded to our query.

The second example involves a female patient whose symptoms are explained as psychological; intersectionality may be at play here, as her female identity makes it more likely that a psychological explanation for her pain will be accepted, rather than continuing to search for a somatic one. It also illustrates the dismissive attitudes still evident in some healthcare cultures towards pain:

I had acute epigastric pain going through to the back during the night but got no relief. It was implied that it was anxiety, and diazepam was prescribed with no effect. It seemed to me that in view of the massive and rapid changes in my body, a physical cause was quite likely. I felt the interest in me had waned and there was less understanding. No one took the pain seriously. ¹⁶

Since these testimonial injustices are generated by pathophobic prejudices and stereotypes, they target and track ill persons through the social world. The evident tenacity of these prejudices ensures their effects reach far beyond the clinical setting to affect education, housing and employment opportunities, due to biases that are still rife in many cultures. They are abundantly documented by patient activists, researchers, and pathographers who feel compelled to adopt a 'stance of silence', when their 'actual stories' are denied the credibility needed for uptake. This stance describes the thwarted epistemic situation of those ill persons who are consistent victims of testimonial injustice.

3. Hermeneutical injustice and experiences of illness

Experiences of illness involve radical transformation in a person's sense of time, space, embodiment, and intersubjective possibility, manifesting in an altered 'sense of reality' or 'form of existence'. Understanding these changes is the task of a phenomenology of illness informed by careful attention to illness narratives and pathographies. What such attention reveals, we argue, is that a pervasive

'Gwendolyn Austen', quoted in H.N. Mandell and H.M. Spiro (eds.), When Doctors Get Sick (Dordrecht: Springer, 2013), 376.

17 Stephen P. Hinshaw, Breaking the Silence: Mental Health Professionals Disclose their Personal and Family Experiences of Mental Illness (Oxford: Oxford University Press, 2008), 8–9.

The latter two terms belong to the phenomenologies of psychiatric and somatic illness developed by Ratcliffe, *Feelings of Being*, and Carel, *Phenomenology of Illness*, respectively.

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feature of the lived experience of ill persons is subjection to specifically pathocentric forms of hermeneutical injustice.

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In their general forms, hermeneutical injustices occur when the capacity of a person or group to make intelligible certain of their bodily, existential, and social experiences to themselves or to others is unjustly constrained or undermined. The effort to make sense of our social experiences requires an array of hermeneutical practices and resources - appropriate language, metaphors, and images, shared and recognised within a community, through which we can make sense of the structure, significance, and complexities of the lived experience of ourselves and others. Often, creating and actively updating this understanding comes naturally, especially to the members of hermeneutically privileged groups - members of racial majorities, say, whose characteristic social experiences are complexly supported by a rich supporting structure that typically, if not automatically, renders them intelligible. But this is not the case for the hermeneutically marginalised, those who cannot create or share sense of their social experiences in comparably involuntary, lucid wavs. 19

Although such failures to achieve mutual intelligibility affects both hearers and speakers, they are differentially disadvantaged: the more privileged group tends to suffer less, epistemically and practically, and often has an interest in *not* understanding the experiences of the underprivileged. The injustice lies in the harmfulness, unfairness, and discrimination constitutive of these hermeneutical situations in which certain illness experiences have no socially accepted way of being expressed and understood.

Unsurprisingly, therefore, forms of hermeneutical injustice can be 'wildly heterogeneous', depending, for instance, on whether they arise from an absence of appropriate hermeneutical resources or from prejudices against certain communicative or expressive styles. The injustice may be that people are prevented from *making sense* of their experiences, or of *sharing* that sense with others. Moreover, forms of hermeneutical injustice may be sustained by structural or interpersonal dynamics, which, if sufficiently oppressive, can precipitate the total destruction of hermeneutical agency.²⁰

We propose that ill persons are especially vulnerable to a variety of forms of complexly-related hermeneutical injustices. Although these

¹⁹ Fricker, Epistemic Injustice, ch. 7.

José Medina, 'Varieties of Hermeneutical Injustice', in Ian James Kidd, José Medina, and Gaile Pohlhaus, Jr. (eds.), *The Routledge Handbook to Epistemic Injustice* (New York: Routledge, 2017), 41–52.

share the general features of unfair and harmful constraints on hermeneutical agency, they are specific to certain features of the experience of illness—for instance, the difficulty of talking about one's illness, the traumatic nature of many illnesses, the deep fear and anxiety that accompany illness, and the common tendency to shy away from discussing illness and death can all hamper expressive attempts. Illness itself intrinsically constrains hermeneutical agency, imposing difficult new demands, while disrupting or ruining one's capacities to make and share intelligible understanding of one's experiences.

Even among health professionals, there continues to be an unwillingness to discuss, *inter alia*, death, existential suffering, and subjective symptoms, such as pain, mental distress, and 'contested illnesses', such as chronic fatigue syndrome (CFS/ME). Such active silences are evident in documented cases of epistemic injustice in the case of CFS/ME, increased vulnerability to stigma in the case of mental disorder, and refusals to discuss assisted dying.²¹

But there can also be situations where healthcare practitioners may want to discuss such issues when patients do not, perhaps due to social stigma, or a fear of facing the medical and existential reality in cases of end-of-life care. What ought to be shared hermeneutical agency becomes unidirectional, as either practitioners or patients are unable to reciprocally respond to the other. Indeed, although most analyses of failed communication in end-of-life contexts focus exclusively on healthcare providers, recent research indicates that patients, their families, and healthcare practitioners often 'collude to avoid mentioning death or dying, even when the patient's suffering is severe and prognosis is poor'. ²²

Given the heterogeneity of those injustices and the diversity of lived experiences of illness, our aim here is simply to sketch some of the general features of pathocentric hermeneutical injustice.

Charlotte Blease, Havi Carel, Keith Geraghty, 'Epistemic Injustice in Healthcare Encounters: Evidence from Chronic Fatigue Syndrome', *Journal of Medical Ethics* **43** (2017), 549–557; Paul Crichton, Havi Carel, and Ian James Kidd, 'Epistemic Injustice in Psychiatry', *British Journal of Psychiatry Bulletin* **41** (2017), 65–70; and doctoral research by Paul Teed (personal communication).

Timothy E Quill, 'Initiating End-of-Life Discussions with Seriously Ill Patients: Addressing the "Elephant in the Room", Journal of the American Medical Association 284.19 (2000), 2502–2507. See, further, Dale G. Larson and Daniel R. Tobin, 'End-of-Life Conversations: Evolving Practice and Theory', Journal of the American Medical

Association **284**.12 (2000), 1573–1578.

Unintelligibility, confusion, and other forms of hermeneutical frustration are abiding themes of pathography in two related ways. First, as components of an agent's efforts at self-understanding, and second, as features of their social interactions and experiences. As formerly stable structures of meaning destabilise, the world ceases to be 'a space of salient possibilities', reliably reflective of one's goals and purposes. It is no longer 'a safe context that offers opportunities for activity but [becomes] something one is at the mercy of'. Understood outside the strictures of clinical medicine, illness is experienced as a 'breakdown of meaning', a harsh disclosure of the truth that 'meaning and intelligibility depend on consistent patterns of embodiment' that no longer – and, poignantly and painfully, may never again – obtain. 24

Identifying genuinely pathocentric hermeneutical injustices is a delicate task, given the variety of difficulties or obstacles encountered by ill persons during efforts to make and share meaningful accounts of their experiences. Although some of these are harmful, not all are due to wrongful or discriminative attitudes, actions, or structures. Many of these difficulties and obstacles reflect two phenomenologically distinctive features of chronic illness – *inarticulacy* and *ineffability*.

The inarticulacy arises, typically, from the difficulties of communicating alterations in the structures of one's lived experience, of 'finding the right words'. Since one's sense of the ordinary meanings of things becomes disrupted, as one's relationship to previous habits and lived environment are affected by illness, one's existing hermeneutical resources and competences cease to be effortlessly effective, while developing new ones appears, often, as another set of demands imposed by illness. Toombs explains:

[T]he bookcase outside my bedroom was once intended by my body as a "repository for books"; then as "that which is to be grasped for support on the way to the bathroom", and is now intended as "an obstacle to get around with my wheelchair". ²⁵

In the same way that the meaning of the word 'bookcase' has changed with her increasing limitations, other words and concepts may no longer be part of the shared meaning that underpins the intelligibility of everyday human life. That may form part of a process of

²³ Ratcliffe, Feelings of Being, 113, 115.

²⁴ Carel, *Phenomenology of Illness*, 14, 15.

S.K. Toombs, 'The Lived Experience of Disability', *Human Studies* **18** (1995), 9–23, at 16.

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hermeneutical marginalisation, where meanings become increasingly specific and unshared and may even be experienced as entirely idio-syncratic. Such idiosyncrasy is a powerful hermeneutical obstacle, and if coupled with others' culpable failures to attend to or accept those idiosyncratic meanings, may mark some types of hermeneutical injustice.

Moreover, even for those with robust hermeneutical support, a further difficulty may remain: the ineffability of certain dimensions of the experience of illness, their resistance to any articulable understanding, of a sort shareable with others. Sometimes, one can't find the words, but, at other times, there really are no words – none adequate to the project of cogently conveying to others, in mutually satisfying ways, the dynamics and character of one's new, altered 'way of being'. It may be that certain life experiences are so unique, dramatic, or traumatic, that they are accompanied by a sense of ineffability. Typical examples include giving birth, losing a loved one, or experiencing trauma. Undergoing a major medical procedure, such as an organ transplant or open heart surgery are also such examples. The radically and irreducibly subjective character of such experiences arguably generates fundamental obstacles to the possibility of collective hermeneutical agency – an inability to comprehend and enter into and then imaginatively explore the epistemic and phenomenological standpoint of those undergoing those experiences.

4. Exclusionary practices and expressive restrictions

Although inarticulacy and ineffability are intrinsic to chronic illness, they can be amplified by obstacles or difficulties imposed by the agents, practices, and structures of the social world. Only in these cases would an ill person be experiencing pathocentric hermeneutical injustice. Unfortunately, this appears to be a common occurrence: our social and healthcare cultures have features that impede the hermeneutical agency of ill persons. Since there are many such features – including those discussed in the following section – our aim is, again, only to sketch some of the general features of pathocentric hermeneutical injustice. Specifically, we examine two of the ways that they are generated.

First, there is a range of *exclusionary practices*, inherent in social and healthcare systems, that act to exclude ill persons from the authoritative sites and practices in which social meanings are created, legitimated, and enacted. The exclusion may be physical, epistemic, social, or some combination of these, simultaneously or in succession.

Whatever the order, such exclusion prevents ill persons from participating in shared hermeneutical practices. An example would be the exclusion of patients from certain socially authoritative places of deliberation and decision, such as hospital committees or policy writing.

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Second, attempts by ill persons at participation in hermeneutical practice may be thwarted by expressive restrictions. Corresponding to what Medina calls the 'performative' forms of hermeneutical injustice, these take the form of restrictions on the types of expressive styles affirmed to be epistemically legitimate. Typically, in the case of illness, legitimacy is confined to the norms, language, and terminology of biomedicine which may promote an impersonal, 'objective' expressive style. Such a style is stripped of the existential particularity, affective depth, and contextual richness of lived experience. It also reduces the amount of discomfort health professionals experience when exposed to highly personal and emotive expressive styles. Most healthcare interactions are between people who are strangers to each other, and whose considerations, interests and perspectives are vastly different. This creates a fertile ground for shutting down expressive attempts that diverge from the standards accepted in healthcare discourse.

The expressive styles judged by ill persons to be adequate for the task of conveying their existential and social experiences are quite different – anecdotal, episodic, autobiographical, rich in affective and existentially complex description and full of difficult emotions such as anger and grief. Within modern healthcare systems these styles and the content they are especially apt to convey are typically excluded or derogated as irrelevant to or ineffective for the epistemic needs of clinical practice. Thus, a physician may wait until the patient stops crying in order to proceed with the epistemic act of asking about a symptom. This is particularly significant when breaking bad news or discussing a poor prognosis. This tendency to derogate certain expressive styles when describing illness is often reinforced by philosophers who advocate a tacit set of 'objective' communicative norms.²⁶

Pathocentric hermeneutical injustices occur when ill persons suffer limitation to their capacity to participate in collective hermeneutical

For criticisms of the derogation of typical pathographic expressive styles, see Mikel Burley, 'Emotion and Anecdote in Philosophical Argument: The Case of Havi Carel's *Illness*', *Metaphilosophy* **42** (2011), 33–48; Ian James Kidd, 'Exemplars, Ethics, and Illness Narratives', *Theoretical Medicine and Bioethics* **38**.4 (2017), 323–334.

agency due to practices of exclusion or expressive restrictions. Such injustices map on to and exacerbate the hermeneutical difficulties of inarticulacy and ineffability, which are intrinsic to chronic illness. Despite progress one may make in addressing those, a further set of limitations is generated by unjust hermeneutical practices and cultures. The typical situation is that communities of ill persons have effective hermeneutical resources but these are deprived of the socially sanctioned legitimacy that would enable them to feature in authoritative practices of social meaning-making, specifically, in healthcare practice and policy.

Such unjust hermeneutical situations can obviously be challenged, in various ways; these include patient activism, academic research, and better uptake of the perspectives of health professionals who come to occupy the social role of 'ill person' themselves. Reflecting on the testimonies of doctors who become patients, Klitzman says that, very often, 'only the experience of becoming seriously ill finally compels them to change their thinking, and see themselves and their work more broadly, and from a different vantage point.'²⁷ Much current scholarship on epistemic injustice and illness is devoted to finding effective ways to enhance the receptivity of those who currently inhabit what Sontag called 'the kingdom of the well' to the very different lived experiences of those in 'the kingdom of the sick'.²⁸

We are hopeful about the prospects for such work. A study of epistemic injustice should always be motivated by a desire to promote epistemic justice. But this requires a sufficiently deep understanding of the sources of the problem. In the case of pathocentric epistemic injustice, these extend beyond negative stereotypes, invidious communicative norms, and cultures that impose 'stances of silence'. There is, we suggest, a more fundamental source, one that helps sustain and license the pathocentric epistemic injustices which underlies norms, practices, and cultures. This is the entrenchment of a certain theoretical conception of illness. If so, analyses of pathocentric epistemic injustices must extend beyond individual and collective agents and institutions, right down to the theoretical conceptions that structure our thinking about illness, to which we now turn.

5. Naturalism, disease, and epistemic injustice

Within modern healthcare systems, the dominant conception of the nature of disease is largely tacit, but is variously described as

Sontag, Illness as Metaphor, 3.

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Klitzman, When Doctors Become Patients, 12.

naturalistic or biomedical. Most famously articulated within philosophy by Christopher Boorse, this family of theories conceives of health in terms of biological function, defined as statistical norms within a relevant reference class.²⁹ Integral to such naturalistic conceptions is, we suggest, an epistemic privileging of the values, concepts, and terminologies of biomedical science. It reflects the conceptualisation of health as being, in Lennart Nordenfelt's words, a set of 'internal processes' relevant to 'reproduction and survival', that excludes consideration of 'extra-biological' factors – 'intentional actions', 'goals', and other integral aspects of human life.³⁰

In response to this naturalistic conception, a group of alternative accounts emerged, variously described as normativist, humanistic, or 'holistic'. Some phenomenological approaches are explicitly characterised as anti-naturalist and hence offer an alternative to the naturalistic model, while others suggest that a phenomenological approach should augment, rather than replace, those naturalist frameworks. Indeed, the phenomenologists' talk of augmenting and enriching our available ways of conceptualising illness means their criticism is confined to claims that naturalism alone contains the necessary resources to provide an exhaustive description and understanding of illness. A vocabulary of *enrichment* and *augmentation* is intended to underscore the critics' target, which is the distinctively *philosophical* confidence that, for the project of understanding and responding to human experiences of health and illness, what naturalism can offer is 'exclusively sufficient.'³³

Most of the approaches that are critical of naturalism about the definition of disease aim to restore attention to what their advocates urge are integral dimensions – axiological, existential, conceptual – of

See, for instance, Christopher Boorse, 'Health as a Theoretical Concept', *Philosophy of Science* **44**.4 (1977), 542–573. An important critical response is Rachel Cooper, 'Disease', *Studies in History and Philosophy of Biological and Biomedical Sciences* **33**.2 (2002), 263–282.

Lennart Nordenfelt, 'The Opposition Between Naturalistic and Holistic Theories of Health and Disease', Havi Carel and Rachel Cooper (eds.), *Health, Illness, and Disease: Philosophical Essays* (New York: Routledge, 2014), 23–36, at 25.

For an anti-naturalist stance, see Fredrik Svenaeus, *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive* (London: Routledge, 2017). For the augmentative stance, see Carel, *Phenomenology of Illness*.

See, for instance, Carel, *Illness*, 10.

Bas van Fraassen, *The Empirical Stance* (New Haven: Yale University Press, 2002), 155.

illness. The dimensions nominated, along with the concepts and vocabularies deployed, are diverse – health as, for instance, 'homelike being-in-the-world', a stable 'rhythm of life', that sustains 'a sense of order and meaningfulness' or, like Rachel Cooper, the unluckiness and badness of being ill, relative to structures of social resources and expectations. ³⁴ Such conceptions point to and legitimate a set of epistemic resources distinct from the biomedical sciences, though without denying their usefulness to healthcare.

Given the language of augmentation and enrichment, phenomenologists of illness face three related tasks. First, to identify the aspects of illness (and, derivatively, of health) occluded or excluded by naturalistic conceptions. Second, to demonstrate the epistemic and practical significance of those aspects, for instance to clinical practice or for what Carel calls 'reflective coping' with one's illness. Such demonstrations can cooperate as a two-part strategy, addressing both the advantages of inclusion and the costs of exclusion.

The third task is to identify effective practices for the inclusion or restoration of the occluded aspects, while also giving conceptual tools, like those provided by the concept of epistemic injustice, to expose and interdict entrenched exclusionary practices. This is a complex set of intellectual and practical objectives, pointing to a larger agenda for a humanistic philosophy of illness and healthcare. In the present context, our interest is in the relationship of these tasks to the amelioration of pathocentric epistemic injustice. Our question is: does the entrenchment and privileging of naturalistic conceptions of health tend to generate or exacerbate pathocentric epistemic injustice? Pending a fuller analysis, which will be carried out in future work, we confine ourselves in what follows to sketching an affirmative answer.

We claim that naturalistic conceptions of health are epistemically unjust insofar as they promote and require the exercise of epistemically unjust behaviours. This has two advantages for the study of epistemic injustice in healthcare. The first is that it allows us to identify the ultimate source of those pathocentric injustices. Rather than attacking health professionals, charges of epistemic injustice should

Svenaeus, The Hermeneutics of Medicine and the Phenomenology of Health, §§2.7–2.8, passim; Cooper, 'Disease', 276f.

³⁵ Carel, Phenomenology of Illness, 214.

The scope and agenda for such a project in the philosophy of illness is sketched by Ian James Kidd, 'Phenomenology of Illness, Philosophy, and Life', *Studies in History and Philosophy of Biological and Biomedical Sciences* **62** (2017), 56–60.

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attend to the operative background conception of health. The second advantage is ameliorative. Assuming our analysis is correct, then reform of all agents perpetrating pathocentric injustices would not be enough. The deep source of those injustices – the theoretical conception – must be changed, otherwise it will continue to generate those injustices. Ultimately, the background system must be changed, since merely interdicting specific components (e.g. individual actors, such as health professionals) is unlikely to permanently resolve the problem. More specifically, analysis and amelioration must go 'all the way down', to the deep theoretical structure generating those epistemic harms and wrongs.

We propose that naturalistic conceptions of health can be described as epistemically unjust in one of two ways. First, promotion: a conception will be epistemically unjust if it promotes epistemically unjust attitudes, actions, and assumptions. There are many ways to promote epistemically unjust behaviours - for instance, they could be valorised as the clinically proper or professionally correct thing to do. Thus, for example, clinicians often point to a need to remain 'objective' as a rationale for unempathic cold behaviour towards patients. When curare was widely used as an anaesthetic, many patients complained of their being entirely conscious during surgery: their reports were ignored by surgeons, until finally one brave doctor volunteered for a test. His testimonies confirming the patients' reports were believed. In this case, testimonial authority was entirely confined to the doctor, as a professionally accredited trained expert, enabling him to 'confirm' the reports of the patients, whose avowals were ignored until 'confirmed'. Such maldistributions of testimonial authority are consequences of a naturalistic conception of health, where a capacity for first-person avowals are rendered nugatory, unless and until they are confirmed by those whose professional credentials owe to that conception.³⁷

Second, *exercise*: a conception will be epistemically unjust if its employment or enactment requires exercise or performance of epistemically unjust dispositions or acts. If putting that way of thinking about illness into practice requires people to exercise injustice, then that way of thinking is unjust. Consider the privileging of testimonial styles that are cool, 'objective', and impersonal: in practice, this leads health professionals to systematically downgrade the credibility of testimonies given in a more anecdotal, emotional, personal style. Internalising the conception's testimonial norms translates, in

Quoted and discussed in Daniel Dennett, *Brainstorms: Philosophical Essays on Mind and Psychology* (Cambridge, Mass.: MIT Press, 1981), 209.

practice, to an active deflation of the credibility of anything said in alternative styles. Both the promotion and exercise of epistemic injustice can be seen in epistemic relations within a healthcare context.

These two modes of epistemic injustice differ in their strength. A conception that promotes epistemically unjust actions increases the risk of epistemic injustice, while one that requires or necessitates the exercise of unjust actions increases the incidence of epistemic injustice. Although both should invite concern, there will be a greater degree of urgency with the latter, since they are actively inscribing epistemic injustice into the practices and structures of the communities they govern.

6. Credibility, relevance, and intelligibility.

We further analyse these two ways of causing epistemic injustice by examining how testimonial and hermeneutical injustice operate within naturalistic conceptions of health and the healthcare practices that emerge from it. Starting with testimonial injustice, naturalistic conceptions of health can entrench discriminative economies of credibility, ones that define *relevance*, *salience*, and similar norms to a delimited range of knowledge, experiences, and methods. Credibility becomes confined to, because defined in terms of, the methods and deliverances of biomedical science, to the exclusion of, for example, detailed first-person accounts of changes to one's embodiment. The significance of the body to health and illness is not exhausted by its physiological functions and pathologies, an object among others for scientific investigation.

Bodies are, more fundamentally, the abiding condition for all experience, agency, and understanding, a fact disclosable only through phenomenological analysis of subjective embodiment. But insofar as a conception of health confines credibility to the third-person stances of scientific enquiry, it deprives subjective accounts of altered embodied experience of the weight and attention they need to achieve uptake into healthcare systems. The significance of ill bodies being 'obtrusive', 'intrusive', and 'obstinate', for example, or the ways in which the lost transparency of health creates a state of occluded attention, cannot gain purchase within an exclusively naturalistic conception of health: those terms track

See, inter alia, Edmund Husserl, Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy. Second Book, trans F. Kersten (Dordrecht: Springer, 1982); Merleau-Ponty, Phenomenology of Perception, Part I; Carel, Phenomenology of Illness, chs. 2–4.

phenomenological rather than physiological dimensions of the process of illness. The distinction between *disease* and *illness* as biological dysfunction and as the lived experience of those dysfunctions – is intended to honour that difference.³⁹

The concerns about testimonial injustice arise because altered bodily experience is central to the lived experience of illness, but judged irrelevant to medical science. Our claim here is not that health professionals do not care or do not notice subjective symptoms and limitations; of course, they do. But if these are not placed within an interpretative framework that allows them to be understood as part of a general embodied experience that has gone awry in significant ways, and hence modifies the entire lifeworld of the ill person, understanding remains limited.

Arguably, the problem is not that testimonies to altered embodiment are deprived of *credibility*, but of *relevance*. Doctors might regard such testimonies as perfectly credible, yet irrelevant to clinical practice. This attitude is at the very least strongly linked to a naturalistic conception of disease and the forms of professional education and training it informs.

The attempt to move beyond this attitude underpins much work in qualitative health research, patient-centred care, and other humanist and phenomenological approaches which aim to improve and humanise patients' experience of illness and of receiving healthcare within a naturalistically based healthcare system. Such amelioration depends, however, on a robust rethinking of the economies of intelligibility, relevance, and credibility assigned to the variety of experiences and testimonies that emerge within the context of human health. In her classic book, *Heartsounds* – an account of her husband's heart condition – Martha Weinman Lear describes how reports of the subjective dimensions of illness tend to be reduced to epistemically uncertain 'things':

The thing fits no clinical profile. It yields no diagnosis. It submits to none of their tests, invites no techniques, and so what are they to do? [...] Whatever cannot be diagnosed or treated by technique is suspect, vaguely inauthentic, and quite possibly does not exist.⁴⁰

Havi Carel, 'Conspicuous, Obtrusive, and Obstinate: A Phenomenology of the Ill Body', Darian Meacham (ed.), *Medicine and Society: New Perspectives in Continental Philosophy* (Dordrecht: Springer, 2015), 105–123, informed by Jean-Paul Sartre, *Being and Nothingness* (London: Routledge, 2003).

Martha Weinman Lear, *Heartsounds: The Story of a Love and Loss* (New York: Simon and Schuster, 1980), 187.

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Here, a naturalistic conception of health renders certain experiences and testimonies as 'suspect', obscure items of epistemic ephemera, deprived of salience. It is for this reason that the entrenchment of naturalistic conceptions generates and exacerbates pathocentric hermeneutical injustices.

Specifically, those conceptions can give a socially authoritative theoretical rationale for a variety of exclusionary practices, while also licensing expressive restrictions. Illness is primarily construed as a biomedical and clinical problem, and only secondarily, if at all, as one of existence, meaning, and suffering. Issues such as addiction, treatment compliance, mental disorder and chronic pain are not easily understood under such a problem-based scientifically-oriented perspective (which is often aligned with naturalism about disease) and such diseases as well as existential dimensions of other conditions are most often excluded from the medical purview.

A conception of health is hermeneutically influential in two related ways: it affects which experiences can be candidates for discussion and interpretation and, secondly, shapes the forms of intelligibility applicable to them. Experiences of feeling 'estranged' from one's body might not register as intelligible, such that they ought to be dismissed, or they may be judged intelligible, but as inchoate expressions of anxiety or distress. If so, the active exclusion of those experiences and the expressive styles appropriate to them will seem to be epistemically and pragmatically sensible, for no sense could obtain that anything of value was being excluded.

Moreover, such conceptions are not only institutionally entrenched within healthcare and the social world, but can also be internalised by ill persons. Many pathographies include a form of self-censoring, such as one patient who opted not to 'mention [certain] problems because though they are real for me, they're minor in the grand scheme of things' – an instance of what Kristie Dotson calls *testimonial smothering*, whereby speakers limit or shape their testimony to make it conform to the expectations of a socially dominant type of audience. In this case, the patient omitted to mention problems they judged irrelevant to scientifically informed clinical practice. ⁴¹

One may respond that exclusion from medical discourse is justified because these kinds of experiences lie outside the domain of clinical practice and therefore are, and should remain, external to it. Exclusion of such expressions, the response may go, thus supports the focus and clarity needed in order to provide good clinical care;

Kristie Dotson, 'Tracking Epistemic Violence, Tracking Practices of Silencing', *Hypatia: A Journal of Feminist Philosophy* **26**.2 (2011), 236–257.

exclusion is not in itself objectionable, since there can be good pragmatic, moral, or other reasons for the legitimate exclusion of certain claims or perspectives.

We reply that this swings both ways: the exclusion of existential experiences of ill persons from healthcare theory and practice must be justified, not least in the face of the ample and articulate accounts, by patients, activists, and researchers, of the importance of inclusion of sensitivity to the lived experience of illness. ⁴² Often, these accounts make clear the many ways that existential and phenomenological issues are integral to clinical practice and medical theory. ⁴³ Many decisions made on putatively 'pure' clinical grounds necessarily interact, and often conflict, with ill persons' goals, values and desires, for instance, while any actual or perceived neglect of these by health professionals will tend to erode their relationship with patients.

Such relationships are constituted and sustained by moral and epistemic trust, testimonial credibility, and active efforts to achieve and sustain mutual intelligibility – all marks of epistemic justice. Insofar as naturalistic conceptions of disease tend to erode or diminish the possibility of these dynamics of trust, credibility, and intelligibility, they are sources and amplifiers of pathocentric epistemic injustice.

7. Conclusion

Although our criticisms of the entrenchment of exclusivist attitudes towards naturalistic conceptions of disease are intended correctively, several clarifications are in order. First, we are not arguing that there is anything necessarily or intrinsically epistemically unjust about naturalistic conceptions—much turns on the contingent ways those conceptions come to be institutionally realised and culturally reinforced. We suggest that the real source of the problems is *exclusive privileging* of those conceptions, the conviction that these alone do or could

Aside from the literature cited throughout this paper, influential examples include Rita Charon, *Narrative Medicine: Honouring the Stories of Illness* (Oxford: Oxford University Press, 2006), Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*, 2nd ed. (West Layayette: Purdue University Press, 1999), and the rich resource that is <www.patientvoices.org.uk>.

See for example Alison Tressider's study of experiences of diagnosis with lymphangioleiomyomatosis (unpublished PhD dissertation, Northampton University, 2018). The delays in diagnosis, misdiagnosis, and poor professional practice are a central theme in the interviews she conducted.

provide the relevant sorts of conceptual and epistemic resources, something now entrenched in much of contemporary clinical and biomedical science and throughout healthcare systems.⁴⁴

A second clarification is that the pathocentric epistemic injustices generated by those conceptions and systems, although widespread, are not at all totalising or all-pervasive. There are many critics internal to biomedical science and healthcare systems who call for enriched estimations of the sorts of epistemic resources pertinent to the understanding and amelioration of illness. Such expansions of the imagination are obvious in the rise of 'humanistic', 'personcentred', 'values-based', and 'participatory' healthcare. Finally, our criticism of exclusive privileging of naturalism about health does not entail any denial of the epistemic and practical results that this approach has yielded. Our claim is that additional methods offering different results are possible, many of which, moreover, are only accessible through inclusion of a wider conception of illness that draws on resources outside the sciences.

There are many obstacles to the exploration and development of these sorts of enriched epistemic resources, including many of a practical and economic sort. An essential strategy for overcoming those obstacles will be to secure acceptance of the fundamental claim that there are essential roles for inclusion of the lived experience of illness in their variety of forms. Such acceptance is itself apt to be blocked by a set of further obstacles, many of which are either generated or amplified by the set of pathocentric epistemic injustices that prevent recognition and uptake of the insights and understanding of ill persons. As long as ill persons are deprived of credibility and intelligibility by epistemically unjust agents and structures, they will continue to face epistemic harms and wrongs, including those pathocentric epistemic injustices that obstruct possibilities for epistemic enrichment and activity while also contributing to their epistemic oppression.

James Marcum refers to this attitude of problematic and exclusive privileging of naturalistic models of health as 'medical scientism'. *The Bloomsbury Companion to Contemporary Philosophy of Medicine* (London: Bloomsbury, 2017), 22–23.

Influential examples include Atul Gawande, Being Mortal: Illness, Medicine, and What Matters in the End (London: Profile, 2014); K.W.M. Fulford, Ed Peile, and Heidi Carroll, Essential Values-Based Practice: Clinical Stories Linking Science with People (Cambridge: Cambridge University Press, 2012); James A. Marcum, An Introductory Philosophy of Medicine: Humanizing Modern Medicine (Dordrecht: Springer, 2008).

We explored some of the assumptions, stereotypes and conceptions that underpin what we have termed *pathocentric epistemic injustices* – ones that target and track those who are ill. These particular types of injustice occur when the testimonies, narratives, interpretations, and self-understanding of ill persons are unfairly excluded from and marginalised within medical discourse.

After sketching the general forms of pathocentric testimonial and hermeneutical injustice, we argued that both are pervasive within the experiences of ill persons during their encounters in healthcare contexts and the social world. Although they have a variety of interpersonal and structural causes, they are also generated and amplified by a deeper naturalistic conception of the nature of health. If this is right, then studying pathocentric epistemic injustice requires scrutiny of the more fundamental ways of conceptualising disease that inform our medical science and healthcare systems. Although those injustices have many social and psychological causes, they are also amplified, disguised and legitimated by the ways of conceptualising disease that we have contingently inherited – ones that come to inscribe a set of pathophobic prejudices, stereotypes, and preconceptions.

Identifying these requires us to go 'all the way down', into the deep socio-epistemic structures of our biomedical and healthcare systems, and 'all the way back' through the contingent histories that shaped them. Such genealogical projects, familiar from other critical discourses, are often directed toward the achievement of epistemic justice. ⁴⁶ There is therefore good reason to hope for progress in the amelioration of the epistemic harms and wrongs suffered by ill persons, including those classifiable as pathocentric epistemic injustices. ⁴⁷

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⁴⁶ Amy Allen, 'Power/Knowledge/Resistance: Foucault and Epistemic Injustice', Ian James Kidd, José Medina, and Gaile Pohlhaus, Jr. (eds.), *The Routledge Handbook to Epistemic Injustice* (New York: Routledge, 2017), 187–194. Alongside Foucault, an important role should be made for Georges Canguilhem, *On the Normal and the Pathological* (London: Dordrecht, 1978).

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