

# The Predicament of Patients

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## Abstract

In this paper we propose that our understanding of pathocentric epistemic injustices can be enriched if they are theorised in terms of predicaments. These are the wider socially scaffolded structures of epistemic challenges, dangers, needs, and threats experienced by ill persons due to their particular emplacement within material, social, and epistemic structures. In previous work we have described certain aspects of these predicaments, such as pathocentric epistemic injustices and pathophobia. A wider systematic perspective is needed to integrate these and other concepts. By thinking predicamentally, we can better understand the interrelated social, epistemic, and practical obstacles experienced by ill persons and connect the many concepts available for theorising them (microaggressions, epistemic injustices, and so on).

## 1. Being ill

Being ill is hard. It is a time of fear, confusion, and uncertainty. It is often a time of pain, suffering and diminishment of freedom. It involves radical disruption to the ways one experiences the body – which often appears, for the first time, as something alien and other, as *a* body, and no long as *my* body. Those with chronic illness who choose to write illness narratives warn the unsuspecting healthy that their ability to anticipate these disruptions is more limited than they realise. Kathlyn Conway described the gulf between the cool, detached awareness of the inevitability and difficulty of illness and the felt realities of what it is actually like to be ‘propelled into the dreaded world of illness’ (Conway, 2013, p. 134). Havi Carel describes her diagnosis as ‘a physical blow’ and tells of how ‘the realisation that everything was about to change, that a new era was about to begin, seared like burning oil on skin’ (Carel, 2018, p. 5). Sometimes, the only way to really grasp the realities of illness is to experience them, to transition from the confident appraisal of abstract possibilities to the hotly felt intensity of what it is like to move into, and live within, that ‘dreaded world’.

The realities of illness can often be made vivid by considering the intricacies of what for some people become regular experiences that are part of that dreaded world. Consider being hospitalised. This can

bring with it the institutionalised diminution of one's agency – the loss of privacy, dignity, freedom and agency. You enter a ward, are given a bed in a shared bay of six patients – anxious strangers, just like you. Your meals and daily schedule are supplied by others. You lie on that bed, witness to the bodily failures and personal pain of others, only minimally veiled from the sight of their suffering behind a thin blue curtain. Your body put on display to the entourage of doctors – alert and outfitted with the medical gaze – watching you as you speak your lines in the crushingly unfunny pantomime of the ward round. An obedient curio, you answer questions and, if the conditions for open discussion seem good, exchange views with the consultant as a dozen eyes watch intently.

The experience of hospitalisation can be analysed using the languages and concepts of qualitative healthcare research or feminist studies, or other theoretical approaches. Some people, though, will prefer less theoretically involved, more everyday language. If medical language can be alienating for some, so, too, can academic language. Whatever language one wants to speak, the ineradicable reality is that being a patient is hard, and not always in ways one can anticipate. One pivotal hardship is *epistemic*: that is, related to the patient's agency and status as a *knower*. When you become a patient, the views, knowledge, opinions, and preferences that provide the substance and texture of your distinctive individuality are not always sought, taken into account, and acted upon. Even when you offer your views, they can be rejected, ignored, or tuned out by the medical objective, scientific, and practical stance, which can be oblivious to the impact of words, gestures and of course, decisions, on the individual sitting in that hospital bed, wearing that compromising hospital gown, waiting for a life-changing word from the consultant.

The general experience of hospitalisation is, of course, made up of a multitude of encounters. Much can depend on the quality of specific interactions, especially when these turn on decisions, choices and requests. Consider the example of a patient (personal communication) being assessed for an organ transplant, taking a medication that has slowed down the rate of her disease progression. Without that medication, she would die within a few months, although it could potentially interfere with the wound healing process after the transplant. Although the medication would be washed out of the patient's body within a day or two, the theoretical risk has been noted in medical literature. A handful of medical reports discussing this risk in relation to the patient's own disease have been published. The patient had asked the consultant to remain on the medication while

she is on the transplant waiting list, to prevent further deterioration and acute risk to her life. The consultant said he will think about it and let her know. He refused to accept copies of those medical reports from her.

When delivering his decision, the consultant invited the patient into a small room cramped with the entire transplant assessment team, none of whom, bar him, spoke. He then told the patient that she would not be permitted to stay on the drug while on the waiting list. Instead, she will have to choose whether to gamble on the new organ becoming available before her disease relapses, due to her being off the medication, or whether to stay on the drug but not have the transplant option. 'You see,' he explained, 'we want our transplant centre results to stay the best in Europe.'

This episode is a particular, but by no means unique, event in the predicament of the patient. Important, intimate decisions involving you, your body and your life, are made without sufficient tools to handle the differing views, perspectives, and tangible gaps in understanding between the patient's point of view and that of health professionals. Amid the desire for certainty, care, and cure, there is also a powerful desire – a need, even – to be heard, to be able to communicate the reality of one's circumstances and help others to understand. This is not merely a psychological need to be heard, although this is certainly important. It is the critical need for patients to be able to put forth views and preferences in order for these to be an integral part of decision-making process. 'Nothing about me without me', as the slogan goes.

Such poignant and painful needs to be seen, heard, and understood are a pervasive theme of the pathographic literature devoted to describing the lived experience of illness, a theme often signalled in their subtitles. Abby Norman's *Ask Me About My Uterus* is subtitled *A Quest to Make Doctors believe Women's Pain* (Norman, 2018). She reflects on the experiences of women whose testimonies about diseased bodies were ignored, citing the example of the American comedian, Gilda Radner, who died of stage IV ovarian cancer after her appeals to her doctors were ignored:

What resonated with me about her story [...] was the deep knowing of her own body as a woman that is seeming unworthy of anyone's consideration or respect. I find that deeply unnerving: that I might be dying, and no-one would believe me, but that feeling of inescapable truth wouldn't leave me no matter how much other people denied it (Norman, 2018, p. 56).

Such cases are appalling and complex and provoke all sorts of moral and critical reactions. In her book, *Doing Harm*, feminist writer and

critic Maya Dusenbery argues that modern healthcare systems cause women to suffer needlessly by trapping them within a ‘knowledge gap’ and a ‘trust gap’ (Dusenbery, 2018, chs. 1 and 2). Escaping that situation has been a key goal of the women’s health movement since its inception, often in alliance with the disability rights and civil rights movements and other progressive groups aimed at radical cultural and institutional change (Edwards, 2013, chs. 3–5).

What these critics emphasise are the many enormous practical and epistemic constraints built into contemporary healthcare systems: the knowledge and trust gaps, the charged power dynamics between the medically trained and the rest, and the complicated relationships between the many actors – health professionals, other staff, managers, service providers, patients, families and sometimes lawyers, social workers and others. There are financial and political forces beyond the control of those acting within the immediate scene. There are the intellectual and moral failings of individual people, which can ramify when they interact with so many others. There are deeply entrenched structures of misogynistic assumptions and practices deeply baked into our social systems and cultural imagination. There is the systematic disenfranchisement of people who are struggling to have their voices heard against an intangible but steely backdrop of stigma and prejudice. Finally, there is the simple yet all-consuming state of being ill, in pain, suffering. A recent Patients Association report states that the top three terms patients used to describe being ill are: ‘frustrating’, ‘frightened’, and ‘vulnerable’.<sup>1</sup>

What this describes is what we shall call the *predicament of the patient*. We take the term ‘predicament’ from José Medina, who uses it throughout his superb book, *The Epistemology of Resistance*. The book offers a sophisticated study of how oppressed people experience, understand, and try to cope with the entrenched systems of interpersonal and structural epistemic injustice that constitute the social world. It offers epistemological analysis in the service of social activism. One of Medina’s convictions is that ‘our epistemic lives are inextricably interwoven with our ethical and socio-political lives’ and the consequent conviction that epistemological analysis must lead to ‘deep personal changes’ and commitment to ‘transformative activism capable of changing social structures and relations’ (Medina, 2012, p. 314). We need epistemology to grasp the full complexity of the systems of oppression built into the social world. But epistemology is not enough by itself.

<sup>1</sup> <https://www.patients-association.org.uk/Handlers/Download.ashx?IDMF=2898fa05-69fa-4e66-b856-c150080d432c>.

We use Medina's work to theorise what we call the epistemic predicament of patients as a way of developing some of our earlier work on epistemic injustice and illness. In what follows we discuss Medina's notion of predicament (section 2) and link this notion to Fricker's account of epistemic injustice, whilst introducing our own application of Fricker's term to illness (section 3). Section 4 develops what we call *pathophobic epistemic injustice*. The closing section offers thoughts on how predicamental thinking can advance and correct some of the limitations of the earlier and more restricted concept of epistemic injustice.

### 2. Predicament

Medina's analyses of gendered and racialized epistemic injustices are deeply informed by generations of excellent research on the intersectional character of our social identities as they play out in the social world. *The Epistemology of Resistance* offers conceptual tools for thinking critically about how best to understand and react to structurally epistemically unjust societies. One of those tools is the concept of a *predicament*. It starts from the foundational claim that people are embodied social agents whose epistemic identity and agency are shaped by their emplacement within systems of roles, relationships, and power relations. *Who we are* deeply shapes the sorts of knowledge we need to get by, the sorts of epistemic skills most useful to us, the sorts of concepts and ideas we need to master, and so on. The abstract figures familiar to many philosophical theories – like 'the knower' or 'the moral agent' – lack the embodied and socialised particularity needed to think properly about effective ways to organise one's epistemic and practical life. Knowers have bodies, genders, racialized identities, and so on, all of which must be included in serious answers to questions about their epistemic prospects and performance.

Medina does not define the term 'predicament', although from his uses of the term we can see what he has in mind. We are told, for instance, that our predicaments include differing degrees of susceptibility to 'lack of access to information', or whether and to what extent we 'lack a credible voice and authority', or whether we are likely to consistently experience 'epistemic exclusions and injustices' (Medina, 2012, pp. 29, 129). In some kinds of predicament, a person will '*struggle to make sense to themselves* of what they cannot yet communicate to others, especially to those who do not share their predicament'. In another kind, a person might face the challenge of being

entrapped by an ‘internalised ignorance that one may not even be able to recognise’ (Medina, 2012, p. 98, original emphasis, p. 206). In these and other instances, Medina is emphasising the many ways our particular material and social circumstances affect the complexity and the quality of our epistemic lives.

Pulling this together, we define an *epistemic predicament* as the complex, contingent, and changing structure of epistemically-toned concerns, challenges, dangers, needs, risks, and threats that a person will experience as a result of their particular emplacement within a particular social world. Our epistemic predicament therefore fundamentally determines the kind of epistemic life that we have and the sorts of epistemic functioning, if not flourishing, we could reasonably anticipate.

Once we start to think about how the social conditions the epistemic, we can generate other features of epistemic predicaments. An epistemic predicament might generate ongoing concern with having to balance attempts to pursue one’s epistemic goals while also responding to the hostile reactions and impositions of others. It may raise the challenge of constantly attempting to ensure proper uptake of one’s testimonies among people who lack the appropriate sensibilities and hermeneutical resources. Another feature is the danger inherent in trying to defy oppressive socially entrenched expectations about how one should perform epistemically. There are others, too. The need to develop effective strategies for protecting one’s fragile testimonial credibility in the face of constant efforts by others to erode it. The risk of having one’s social experiences consistently subjected to highly distorting and often deliberate misunderstandings that can be as painful to endure as they can be to try to correct. And the threat of being epistemically downgraded in the eyes of others as a result of one’s defiance of oppressive normative expectations about how one should epistemically behave.

Although we could extend this list, hopefully this suffices to give a sense of what we mean by an epistemic predicament. Looking at the list, it seems clear that many ill persons, and in particular psychiatric patients, elderly patients and child patients, have distinctive and entrenched epistemic predicaments. Illness narratives provide many examples of the new epistemic challenges, demands, needs, risks, threats, and vulnerabilities that come with being chronically ill. Some are spread throughout the social world, while others are confined to specific locations, such as hospitals.

Becoming ill means coming to occupy a new and difficult epistemic predicament. Susan Sontag famously said that to become ill is ‘to take up one’s residence in the kingdom of the ill’. She added that this

kingdom has its own ‘landscape’ – its own stereotypes, prejudices, obstacles, and dangers (Sontag, 1978, p. 3). We can use that metaphor to think about the newly imposed epistemic predicaments of those who have become ill. One suddenly arrives at a strange, hostile new territory complete with new and disturbing features – looming obstacles, thorny thickets, impassable terrain, circuitous paths. One cannot make sense of this new environment and one therefore has to work hard to navigate it. There are medical terms to learn, services to find and new people to reluctantly involve in one’s intimacies. There are decisions to be made, treatment options to consider, and practicalities to sort out. There are profound and bewildering changes to all aspects of one’s life, that require mental energy, attention, emotional resources, and a lot of talking, thinking, and communicating. There is hard epistemic labour in being – and especially in becoming – ill (Carel, 2018).

Some of our existing epistemic skills work well enough, but others do not, so one is often uncertain and confused. The landscape is unfamiliar and it takes real work to survey it. The epistemic terrain is filled with strange new dangers and risks – like having one’s testimonies about one’s bodily condition ignored by other people. One’s prior navigational skills are not always useful in these strange new conditions. New epistemic challenges come into view. New epistemic dangers become salient. Some epistemic risks one formerly encountered but rarely increase in frequency and severity. Epistemic needs that were once easily met now become momentous challenges. One is suddenly forced to make difficult trade-offs – between, for instance, *truthfulness* about the complexities of one’s bodily condition and *acceptability* in the company of healthy people limited in their ability and willingness to understand. In the kingdom of the ill, the terrain is harsh and forbidding and the customs peculiar and so many of the people often cold and cruel to vulnerable strangers, newly arrived to this land.

Sontag’s metaphor of the ‘kingdom of the ill’ can help us get a sense of what it may be like to suddenly occupy a strange and disturbing new epistemic predicament. One is now stuck in a strange land where one’s testimonies and self-understanding suddenly seem to count for little. The interpersonal currency of credibility and trust is devalued. Everyday epistemic tasks become arduous marathons. Confusion is the new norm. The powers and privileges one used to enjoy in the kingdom of the healthy are now lost and the consequence is a frightening new predicament.

Contemporary scholars have described in vivid detail many of the realities of what we call the predicament of the ill. Some of the

relevant phenomena are constant subjection to microaggressions, gaslighting and implicit biases (FitzGerald and Hurst, 2017; Freeman and Stewart, 2018). We agree with those accounts, although we want to interpret them as particular components of the wider predicament we describe here. To be ill is to inhabit a changed world with new challenges, needs, and risks that are tied into a complicated interpersonal world. Coping with their epistemic predicament is a major preoccupation of people with chronic somatic (bodily) illnesses, and of course of disabled people (we acknowledge the considerable overlap between the two groups) in their daily attempts to articulate their needs, pursue their life-projects, and cope with the world. What the concept of a predicament calls into view is the systematic character of these epistemic problems as revealed in the everyday experiences of those in the kingdom of the ill. In doing so, we ensure that we keep an appropriately broad perspective on the many interlinked epistemic problems faced by ill people.

### **3. From epistemic predicament to epistemic injustice**

Experiences of illness are inherently diverse. They are shaped by pathological, psychological, situational, developmental, and socio-cultural factors, which is one of the constant lessons of pathographies and research in the sociology and anthropology of illness. Indeed, one aspect of the epistemic predicament of ill persons is getting others to grasp the complexity and the particularity of their experiences. The problem is the delicate one of using general concepts and familiar tropes while at the same honouring the particularity of a specific ill person's own experiences. Rita Charon's book, *Narrative Medicine*, suggests that when reading illness narratives we are 'looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular' (Charon, 2006, p. 9). Therefore, when thinking about the predicament of patients, we need to ensure that we do justice to the complex layering of personal and general features, to what a group of people share as participants in a common predicament and to the fact that our predicament is, in the final analysis, our *own*.

Before moving on, we offer three comments on epistemic predicaments. First, they are radically *plural*. Our predicaments are shaped by our subjective identity and the complex particularities of our embodied social circumstances. Granted, there will be commonalities among our predicaments, thanks to shared group identities and the



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common social and material structure of the world, as well as shared human features, such as our inherently social nature – what Heidegger calls *Mitsein*, our being-with-others (Heidegger, 1962). Second, predicaments are deeply *ambivalent*; it will always be too crude to characterise them as good or bad. Predicaments are complex structures of challenges and opportunities, deficiencies and resources, encouraging possibilities and forbidding inevitabilities. Third, predicaments are both changing and *changeable*, rather than immutable, permanent features of one's world. Predicaments change in response to changes in our personal character and orientation to the world, as well as changes in the social and material conditions of the world. Crucially, our predicaments can be changed through concerted effort, whether as individuals or as fellow participants in collective projects. Conversely, some people try to worsen the predicament of others deliberately as part of concerted projects of social and epistemic violence (Dotson, 2011).<sup>2</sup> Note that these three features pull together: the plurality and ambivalence of our predicaments ensures their changeability and means one has to reckon with the possibility of changes for better or for worse.

We want to explore the predicament of patients in relation to the well-studied vulnerability of ill persons to what, in earlier work, we have named *pathocentric epistemic injustices* (Kidd and Carel, 2018). These are wrongs done to an ill person specifically in their capacity as a *knower*, originally modelled on the analysis of epistemic injustice given by Miranda Fricker (2007). A flourishing literature has developed over the last decade devoted to pathocentric epistemic injustice in relation to a range of somatic and psychiatric illnesses.<sup>3</sup> Most of that work proceeds within Fricker's terms, specifically those of *testimonial* and *hermeneutical* injustices, although more recent work, this present piece included, explores some of the wider forms and conceptions of epistemic injustice (see the introduction to this volume and also Kidd, Medina, and Pohlhaus Jr. 2017, chs. 1-5).

The phenomenon of pathocentric epistemic injustice is a depressing dimension of the lived experience of ill persons within our societies. Unfortunately, it is but one dimension of their wider predicament. There are wider systems of epistemic violence, for one thing, and also a much broader range of problematic and harmful attitudes, practices, and structures whose collective effect

<sup>2</sup> The term 'epistemic violence' was introduced by Gayatri Spivak (1998).

<sup>3</sup> For a bibliography listing these publications see: <https://ianjameskidd.weebly.com/epistemic-injustice-healthcare-and-illness-a-bibliography.html>.

is to extend and intensify the suffering of those with illnesses. And of course, they are also ill and may be distressed, in pain, fatigued, or fearful, in addition to the epistemic dimension we focus on here. Interestingly, until recently there was no term for the variety of objectionable attitudes and behaviours directed at persons with chronic somatic illnesses. Sanism and ableism describe discriminatory attitudes that pertain to mental disorder and disabilities, while established terms like stigma refer to specific sources of that attitude, rather than the attitude itself.

In an effort to fill that gap, Ian James Kidd offers the term *pathophobia*. It captures the range of morally objectionable attitudes and behaviours directed towards those with chronic somatic illnesses (Kidd, 2019). It can take individual and collective forms and often intersects with other forms of oppression, such as sexism and ableism. Indeed, the deeply intersectional character of pathophobic experiences is often described in the testimonies and narratives of ill people. It is clear, too, that pathophobic attitudes and behaviour are extremely diverse. Kidd groups the main forms into five broad types: aversion, banality, callousness, insensitivity, and untruthfulness. They involve failures of interpersonal interaction and understanding, empathic caring, and sensitivity and truthfulness about the complexities of experiences of illness (Kidd, 2019, §4). Within the pages of pathographies, one finds stark examples of pathophobic attitudes and behaviours, whether at the individual or collective level – aversive behaviour from people on the street, banal ways of talking about illness, the callousness of healthcare practitioners and friends, insensitive comments and questions, and complex failures to communicate honestly with those suffering from chronic illnesses.

Pathophobia has many sources and it plays out in different ways. Its forms, frequency and severity is determined by medical, personal, sociocultural, situational, and structural factors. Some people are ignorant of what it is like to be ill. Some are indifferent to the suffering of others. Some are well-meaning but lack proper sensitivity. Some people struggle to make sense of lives very different from their own. Some people are cruel and selfish. Some people lack attentiveness to others. Other people might want to be sensitive, warm, and compassionate, but lack proper guidance on how to translate that into the right sorts of behaviour. Appreciating all of this once again refers us to the idea of predicaments. The predicaments experienced by many ill persons are embedded within the pathophobic norms, structures, and cultures of the social world. Think of silencing and bright-siding, harms and violence, deflations of credibility and absence of empathy, lack of resources and construction of obstacles,

humiliation and powerlessness; these are built into institutionalised practices, and the coiled webs of stigmatisation and social isolation. This is perhaps what Audre Lorde had in mind in her *Cancer Journals* when she announced her ‘fury at the outside world’s viciousness, the stupid, brutal lack of consciousness or concern that passes for the way things are’ (Lorde, 1997, p. 24).

We think Lorde’s fury was in part sustained by her acute realisation that the forms of pathophobic discrimination against her ill body was continuous with a ‘whole pattern’ of racism and sexism (Lorde, 1997, pp. 24, 11). Central to those patterns were recognisable forms of gendered, racialised, and pathophobic epistemic injustices. The first chapter of the *Cancer Journals* is titled ‘The Transformation of Silence into Language and Action’. It speaks of the harms of the distortions of credibility and intelligibility, of voices silenced or muted and of social experiences obscured. Lorde describes how ‘imposed silence about any area of our lives is a tool for separation and powerlessness’, hence the need to launch ‘a war against the tyrannies of silence’:

I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me, beyond any other effect [...] My silence had not protected me. Your silence will not protect you (Lorde, 1997, pp. 51, 55).

#### 4. Pathocentric epistemic injustice

Armed with this background and the concepts of predicament and pathophobia, let us now turn to an analysis of a specific kind of epistemic predicament afflicting patients – what we have elsewhere called *pathocentric epistemic injustice* (Kidd and Carel, 2018). This is our term for epistemic injustices that target and track those with chronic somatic illnesses. They involve experiences – at once unfair and harmful – where a person is wronged as a *knower*, as a giver of knowledge or an interpreter of experiences. Sometimes we are right not to take someone seriously; and sometimes we cannot make sense of someone’s social experiences, no matter how hard we try – these would not be epistemic injustices. To be an injustice, there must be *harm* and *unfairness*. Think, for instance, of the ways that prejudice can drive us to refuse to recognise someone *as* rational; or cases where contempt for a certain group shows itself as unwillingness to take up the concepts that would render their distinctive experiences intelligible.

A vigorous body of recent scholarship has confirmed and developed our proposal that there are distinctively pathocentric epistemic injustices. Recent work has described the epistemic injustices that track persons with chronic somatic and psychiatric illnesses (see, for example, Blease, Carel and Geraghy, 2016; Byrne, *forthcoming*; Crichton, Kidd and Carel, 2016; for a full list, see footnote 2). In a sense, what is being confirmed is what was being said all along in so many illness narratives, including Lorde's criticisms of 'tyrannies of silence'. Many ill persons continue to report that their testimonies, interpretations and other epistemic offerings are rejected, downgraded, or doubted by hearers, who are affected by negative prejudices and stereotypes about ill persons. The precise forms of those injustices are diverse, and much remains to be done in exploring them. But it is clear that systematic experiences of pathocentric epistemic injustices are an integral part of the predicaments of many ill persons and that ill persons are especially vulnerable to epistemic injustice (Carel and Kidd, 2014; Kidd and Carel, 2016).

Granted, chronic illness can damage cognitive capacities in ways that reduce one's credibility or epistemic authority. But we are clear that those are not cases of epistemic injustice because they are not unfair. The unfairness occurs when, for instance, the default presumption is that to be chronically ill necessarily entails epistemic incapacity, or when a person's testimonies are ignored despite their lucidity and precision, or when a person's efforts at rendering their own experiences intelligible are thwarted by the determination of others to refuse them intelligibility. Some of the tougher cases will involve hard-to-decide situations of fluctuating cognitive capacity, illnesses in penal contexts, epistemic injustices experienced by children, and psychiatric illnesses that involve delusions and other disruptions to epistemic functioning (see Burroughs and Tollefson, 2016; Carver, Morley, and Taylor, 2016; Critchley, 2019; Carel and Gyroffly, 2014).

Here are a few examples of pathocentric epistemic injustice. These come from patient testimonies, but additional examples can be found in healthcare reports, media stories, and the work of charities such as the Patients Association. As one example, we take the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), known as the Francis Report, after its chair, Robert Francis QS. The report documented the mistreatment and neglect of patients in that Trust.<sup>4</sup> It explains the 'appalling suffering of many patients

<sup>4</sup> The Francis Report can be downloaded at <https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry>

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[was] primarily caused by a serious failure on the part of a provider Trust Board. *It did not listen sufficiently to its patients and staff* (Francis, 2013, p. 3, emphasis added). Such serious and systematic failings go far deeper than a lack of etiquette or poor bedside manner. They point to problems of a more global and enduring sort which, when manifested in healthcare environments, lead to the suffering and death (or premature death) of ill persons.

Outside of government reports, other accounts of pathocentric epistemic injustices can be found in illness narratives, blogs and vlogs, in online patient fora, and in the many other places where people testify about their experiences of being ill in an unjust and pathophobic world. Consider the following:

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 (quoted in Mandell and Spiro, 2013, p. 376).

I had an abnormal cervical smear, so was sent to the large city teaching hospital for a coloscopy. I changed into the usual ties up the back gown, with the usual vital ties missing, and then went through for the examination. Lots of big sighs from the consultant with his head between my legs. Then off he goes, leaving the room. I'm told to follow. So, I arrive, naked under a gown which doesn't do up, slightly damp between the legs and a bit stressed as I have to sit down and I'm worried about leaving a wet patch. He goes on to tell me I need an operation. I hear blah blah blah as I'm perching and panicky [...] And it's very difficult to think without your pants on. I said nothing.<sup>5</sup>

An alarming feature of many pathocentric epistemic injustices is that they can nullify a person's capacity to resist the injustice being done. When subjected to an injustice, a natural response is to protest it, for instance, by deploying epistemic tools like arguing, criticising, and offering counter-evidence. But when suffering an epistemic injustice, one may undergo a depletion of epistemic authority. The ill person's testimonies are denied credibility; when

<sup>5</sup> This testimony was provided by a patient on the LAM Action patient support email group.

they make arguments, these are deprived of their force, since they are perceived as coming from an incompetent source.

The costs of epistemic injustice can be severe. Some of our everyday epistemic activities are mundane, but others are critical to our survival. Depending on context, being denied information, for instance, can be irritating or catastrophic. Having a person refuse to believe one's words can be frustrating or fatal. For these sorts of reasons, any impingement on our epistemic capacities can be a very serious problem – so serious that sometimes the results can be suffering and death. At the most extreme end of the spectrum we find simply no attempt to solicit patient testimony at all. The shocking case of Victoria Climbié is the starkest illustration of this stance. She was an eight year old Francophone child who suffered the most horrific abuse at the hands of her carers. The enquiry into her death identified at least sixty opportunities for professionals to intervene in the months preceding her death, when she was taken to hospital, health and social care appointments. Not once was she asked to provide any information about herself or to explain how her injuries were caused. 'At no point during her stay in the hospital did any doctor speak to Victoria in a formal attempt to find out what had happened to her, either with or without the assistance of an interpreter' (The Laming Enquiry, 2003, p. 256).<sup>6</sup>

Such cases painfully show that some of the worst predicaments are fatal. When one is silenced or otherwise invisible, one becomes at ever-greater risk of harm. This is why pathocentric epistemic injustices should be considered in relation to the various forms of pathophobia. Clearly, many of the structural factors that generate the one also generate the other. Pathocentric hermeneutical injustices, for instance, usually involve the absence or marginalisation of the hermeneutical resources and opportunities needed by ill persons. Such hermeneutical gaps will also be implicated in a lot of pathophobic banality – the variety of facile and superficial ways of understanding the particularity and complexity of experiences of chronic illnesses. Kathlyn Conway gives many examples of the banal things people said to her during her cancer:

Some people recount positive stories of survival. I hear about one woman who had breast cancer and bicycled twenty miles a day throughout chemotherapy; another who looked gorgeous the

<sup>6</sup> The Laming Enquiry can be downloaded at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/273183/5730.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/273183/5730.pdf)

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entire time; and a third who told no one of her diagnosis and acted as if her life were absolutely normal. Why are these stories not consoling me? (Conway, 2007, p. 58)

Such trite assurances and glib comparisons underplay the complexity and awfulness of Conway's experience of cancer. They register failures not simply of communication, but of understanding. For that reason, pathophobic banality lies close to hermeneutical injustice. When those failures of interpersonal understanding are continuous and intense, they form part of our predicament. The social norms and structures that function to deprive ill persons of the credibility and intelligibility they deserve also sets them up for aversive, banal, callous, and insensitive treatment. Within the worst predicaments, the constant threats are silence and violence.

Understanding the predicament of patients ultimately means attending to the wider social and epistemic structures that have come to characterise our cultures. There are complex systems of norms, practices, and ways of organising our social practices and resources that tend systematically to harm persons with illnesses. This wider predicament involves an extremely complex interaction of oppressive ideologies and cultures that include pathophobia, misogyny, heteronormativity, and racism, along with others. What is crucial is to appreciate the dynamic conceptual and structural linkages between these invidious phenomena. At that point, we finally achieve a properly cognisant appreciation of the true complexity of the predicament of ill persons, of which pathocentric epistemic injustices are only one, albeit central, manifestation.

It should be clear that thinking predicamentally hugely increases the scale and complexity of the work. Local fixes might help, but only up to a point. Without a properly 'big picture' understanding, we risk becoming trapped in a futile game of ameliorative whack-a-mole that tries to deal with specific pathocentric epistemic injustices and localised instances of pathophobia without altering substantially the wider structures that generate and perpetuate them. We need to change the underlying structures, as the women's health movement has taught us for many decades. The titles of histories of that movement offer aphoristic clues to the sorts of changes we need – *More than Medicine* (Nelson, 2015) and *Into Our Own Hands* (Morgen, 2002). What ultimately needs to change is not just those individual pathophobic people who silence, shame, and harm those with illnesses, but rather what Audre Lorde called the 'outside world's viciousness, the stupid, brutal lack of consciousness or concern that passes for the way things are'.

## 5. Conclusion: thinking predicamentally

In this paper we proposed that our understanding of pathocentric epistemic injustices can be enriched if they are theorised predicamentally, that is, in ways that refer to the wider socially scaffolded structures of epistemic challenges, dangers, needs, and threats arising from the emplacement of ill persons within material, social, and epistemic structures.

As discussed in sections 3 and 4, Pathocentric epistemic injustices have come to be analysed in Miranda Fricker's (2007) terms of testimonial credibility and hermeneutical intelligibility, although since her original account many new forms of epistemic injustice have been identified. Moreover, some of the features of that account were amended (see Medina, 2017; Polhhaus Jr., 2017). Our earlier publications proceeded within Fricker's original framework (Carel and Kidd, 2014; Kidd and Carel, 2016). It's therefore salutary to consider ways that analyses of pathocentric epistemic injustices might be thickened to take advantage of new insights from within and beyond epistemic injustice studies.

Consider Fricker's discussion of cases where people with undiagnosed or poorly understood medical conditions suffer hermeneutical marginalisation. Other people cannot make proper sense of their social behaviours, seeing them as strange or erratic, which causes all sorts of interpersonal problems. Fricker suggests this is a case, not of hermeneutical injustice, but of 'circumstantial epistemic bad luck' (Fricker, 2007, p. 152). Against that judgment, Shelley Tremain suggests that this *is* an injustice: the social and hermeneutical disadvantages are sustained by stable background conditions that prevent others from making sense of those social behaviours – in which case, they amount to a hermeneutical injustice (Tremain, 2016, pp. 177–78). Interpreting those disadvantages situationally and individually as bad luck, rather than as systematic and structurally generated failings, is one way of concealing the full realities of the predicament of those with the relevant sorts of conditions and disabilities. As Nora Berenstain eloquently puts it, the problem is 'portraying medical gaslighting itself as a result of mere 'epistemic bad luck' rather than as the predictable and enduring consequence of the medicalization of disability within a materially harmful and ableist system of medical meaning-making' (Berenstain, [forthcoming](#)).

We need to appreciate that the predicaments of ill persons often include different sorts of obliviousness on the part of other people. Such obliviousness has at least three dimensions, each pertinent to properly understanding pathocentric epistemic injustices. First, one



can fail to grasp the *enormity* of predicaments, maybe by supposing that cases of being ignored or silenced are occasional and irritating episodes, rather than constant problems. It can also include failures to appreciate how individually irksome limitations can, within the context of a predicament, become something far more significant. In her memoir of cancer, doctor Kate Granger reflects on the unfolding loss of putatively minor comforts and habits, like being able ‘to sleep on my side, to have a bath, to share a bed with my husband’ (Granger, 2014, p. 93). This restriction would not matter for a night or two, but becomes significant when enduring, and combined with the other miseries of illness.

Second, one might fail to grasp the *complexity* of predicaments, maybe by thinking that coping with illness is mainly a matter of seeking treatment and managing pain, rather than fighting to be believed when one talks about one’s experiences. Coping with breast cancer is not just a matter of radiotherapy, scans, and tumours. It also involves coping with changes to one’s relationship to a body that might now feel ‘traitorous’ and rethinking one’s sexuality, as well as working out how one wants to relate to the public cultures of breast cancer. Barbara Ehrenreich speaks of the relentless ‘bright-siding’ built into the pink ribbon cancer cultures in the United States (Ehrenreich, 2009); Ann Boyer talks of the oppressive gendered pressures intrinsic to what she calls ‘the cancer pavilion’ (Boyer, 2019). Coping with cancer means coping with scans, treatment, and pain, but also with sexual identity, self-confidence, altered sense of embodiment, and so much more – all requiring epistemic, moral, and emotional labour, which largely goes unacknowledged.

A final sort of obliviousness to the predicaments of ill persons concerns the many ways that being an ill person intersects with one’s social identities. An ill person is never just an ill person: they will have a gendered identity, a racialised identity, a sexual identity, a professional identity, and so on. Moreover, these many social identities are intersecting and not isolated from one another. Working class black women, for instance, suffer not just the individual costs of classism, racism, and sexism, but the compounded effects of those forms of discrimination. In a classic essay on intersectionality, Kimberlé Crenshaw emphasises that ‘the failure to embrace the complexities of compoundedness is not simply a matter of political will, but is also due to the influence of a way of thinking about discrimination which structures politics so that struggles are categorized as singular issues’ (Crenshaw, 1989, pp. 166–67).

By thinking predicamentally, we stand a much better chance of understanding pathocentric epistemic injustices in ways that honour

their enormity, complexity, and intersectional detail. Our initial studies of pathocentric epistemic injustice did speak of *ill persons* as such, although more recently work has started to become more sensitive to the need for intersectional texture when studying the epistemic predicament of ill persons. Speaking of epistemic microaggressions, Freeman and Stuart emphasise much will depend on whether the patient is, for instance, an upper-middle class, white, heterosexual man or a working class, black, lesbian woman (Freeman and Stuart, 2018, p. 439). Our studies of pathocentric epistemic injustice should become more sensitive to the complexities and particularities of our intersectionally structured social identities. It is not just a matter of our diseased bodies, but of the ways they sit within wider structures of power, identity, and ideology.<sup>7</sup>

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## References

- Nora Berenstain, 'White Feminist Gaslighting' *Hypatia* (forthcoming).  
Charlotte Blease, Havi Carel, and Keith Geraghty, 'Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome', *Journal of Medical Ethics* 43 (2017), 549–57. doi:10.1136/medethics-2016-103691  
Ann Boyer, *The Undying: A Meditation on Modern Illness* (London: Penguin, 2019).  
Michael D. Burroughs and Deborah Tollefson, 'Learning to Listen: Epistemic Injustice and the Child', *Episteme* 13.3 (2016), 359–77.  
Eleanor Alexandra Byrne, 'Striking the Balance with Epistemic Injustice in Healthcare: The Case of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis', *Medicine, Health Care and Philosophy* (forthcoming).  
Havi Carel, *Illness: The Cry of the Flesh*, (London: Routledge, 2018).  
Havi Carel and Ian James Kidd, 'Epistemic Injustice in Healthcare: A Philosophical Analysis', *Medicine, Healthcare and Philosophy* 17(4) (2014), 529–40.

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- Havi Carel and Gita Gyroffy, 'Seen but not heard: children and epistemic injustice', *The Lancet* 384 (2014), 1256–57.
- L. Carver, S. Morley and P. Taylor, 'Voices of Deficit: Mental Health, Criminal Victimisation and Epistemic Injustice', *Illness, Crisis and Loss* 25 (2016), doi: 10.1177/1054137316675715
- Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford University Press, (2006).
- Kathlynn Conway, *Beyond Words: Illness and the Limits of Expression* (Albuquerque: University of New Mexico Press, 2013).
- Paul Crichton, Havi Carel and Ian James Kidd, 'Epistemic Injustice in Psychiatry', *BjPsych Bulletin* 41(2016), 65–70.
- Kimbelé Crenshaw, 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics', *University of Chicago Legal Forum* 1.8 (1989), 139–67.
- Harry Critchley, 'Epistemic Injustice and Medical Neglect in Ontario Jails: The Case of Pregnant Women', Ben Sherman and Stacey Goguen (eds.) *Overcoming Epistemic Injustice: Social and Psychological Perspectives* (New York: Rowman and Littlefield, 2019), 237–51.
- Ian James Kidd and Havi Carel, 'Epistemic Injustice and Illness', *Journal of Applied Philosophy* 3 (2016), 172–90.
- Kristie Dotson, 'Tracking Epistemic Violence, Tracking Practices of Silencing,' *Hypatia* 26.2 (2011): 236–57.
- Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick* (New York: HarperCollins, 2018).
- Laurie Edwards, *In the Kingdom of the Sick: A Social History of Chronic Illness in America* (London: Bloomsbury, 2013).
- Barbara Ehrenreich, *Smile or Die: How Positive Thinking Fooled America and the World* (London: Granta, 2009).
- Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing*, (Oxford: Oxford University Press, 2007).
- C. FitzGerald, and S. Hurst, 'Implicit Bias in Healthcare Professionals: A Systematic Review', *BMC Med Ethics* 18, (2017).
- The Francis Report (2013) ISBN 9780102981476, HC 947 2012-13.
- Kate Granger, *The Other Side* (Kindle edition, 2014).
- Lauren Freeman and Heather, Stewart, 'Microaggressions in Clinical Medicine', *Kennedy Institute Ethics Journal*, 28, (2018), 411–49.
- Martin Heidegger, *Being and Time*, (London: Blackwell, (1962 [1927])).
- Ian James Kidd, 'Pathophobia, Illness, and Vices', *International Journal of Philosophical Studies* 27.2 (2019), 286–306.

## Ian James Kidd and Havi Carel

- Ian James Kidd and Havi Carel, 'Epistemic Injustice and Illness', *Journal of Applied Philosophy* 3 (2018), 172–90.
- Ian James Kidd and Havi Carel, 'Pathocentric Epistemic Injustice and Conceptions of Health', Benjamin R. Sherman and Stacey Goguen (eds.) *Overcoming Epistemic Injustice: Social and Psychological Perspectives* (New York: Rowman and Littlefield, 2018), 153–68.
- Ian James Kidd, José Medina, Gaile Pohlhaus, Jr. (eds.), *The Routledge Handbook to Epistemic Injustice*, co-edited with (New York: Routledge, 2017).
- Laming Report, *The Victoria Climbié Inquiry* (London: HMSO, 2003).
- Audre Lorde, *The Cancer Journals* (San Francisco: Aunt Lute Books, 1997).
- H.N. Mandell and H.M. Spiro (eds.), *When Doctors Get Sick* (Dordrecht: Springer, 2013).
- José Medina, *The Epistemology of Resistance: Gender and Racial Oppression, Epistemic Injustice, and Resistant Imaginations* (Oxford: Oxford University Press, 2012).
- Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969–1990* (New Brunswick: Rutgers University Press, 2002).
- Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (New York: New York University Press, 2015).
- Abby Norman, *Ask Me About My Uterus: A Quest to Make Doctor's Believe in Women's Pain*, (New York: Nation Books, 2018).
- Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978).
- Gayatri Spivak, 'Can the Subaltern Speak?', in Cary Nelson and Lawrence Grossberg (eds.), *Marxism and the Interpretation of Culture* (Urbana: University of Illinois Press, 1998), 271–313.
- Shelley Tremain, 'Knowing Disability, Differently', Ian James Kidd, José Medina, and Gaile Pohlhaus, Jr. (eds.) *The Routledge Handbook to Epistemic Injustice* (New York: Routledge, 2016), 175–83.