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## **DO ILL PEOPLE SUFFER EPISTEMIC INJUSTICE?**

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### **Abstract**

In this paper we argue that ill persons can experience epistemic injustice in the sense articulated by Miranda Fricker (2007). Ill persons can suffer testimonial injustice through the presumptive attribution of characteristics like cognitive unreliability and emotional instability that downgrade the credibility of their testimonies. Ill persons can also suffer hermeneutical injustice because many aspects of the experience of illness are difficult to understand and communicate and this often owes to gaps in collective hermeneutical resources. We then argue that epistemic injustice arises in part owing to the epistemic privilege enjoyed by the practitioners and institutions of contemporary healthcare services – the former owing to their training, expertise, and third-person psychology, and the latter owing to their implicit privileging of certain styles of articulating and evidencing testimonies in ways that marginalise ill persons. We suggest that a phenomenological toolkit may be part of an effort to ameliorate epistemic injustice.

**Keywords** epistemic injustice, illness, patient experience, phenomenology, patient toolkit

## **Introduction**

“That really, really hurts”, says the woman who has just given birth to the doctor. He is sitting by her splayed feet, which rest on stirrups either side of him. He is stitching her vagina, his face inches away from her body. A crowd of doctors and nurses surround the baby lying a few feet away. He is being bundled, rubbed, and his airways cleared by eight health professionals. But none of them hear, or respond to, the woman’s complaint. She repeats: “That hurts. Are you using anaesthetic?”. “No”, the doctor replies calmly, “there is no need to. I’m nearly finished”. The woman is too exhausted to persist and she says nothing more. It is hard to imagine another situation in which we would not offer pain relief to someone having a needle pushed through their genitals. But in this case the woman’s testimony is not taken seriously enough to be acted upon. Her pain is either not fully registered or not considered worthy of response. The woman’s claim about how much pain she feels is dismissed.<sup>1</sup>

Similar situations arise in the context of healthcare provision. Many of us are familiar with stories about doctors who don’t listen, large-scale healthcare systems that are impersonal and bureaucratic, and feelings of helplessness when trying to navigate these systems. Focusing on the epistemic dimension of these situations, we suggest that patients’ testimonies are often dismissed as irrelevant, confused, too emotional, unhelpful, or time-consuming. A common complaint from physicians is that patients’ speech is full of irrelevant information, that patients are (understandably) upset and therefore can be irrational, and that listening for

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<sup>1</sup> This scene was observed by one of the authors (HC), whilst shadowing a paediatrician consultant at Gloucestershire Royal Hospital, UK, on ???.

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medically relevant information precludes listening to other information conveyed in patient speech (such as existential concerns, need for empathy, or emotional content). In addition, since patients are not properly trained in the relevant medical terminology and the particular discourse of health professionals, anything they did say may be judged to be insufficiently articulate.<sup>2</sup> So even if the patient's testimony were relevant, emotionally balanced and so on, what they say is not expressed in the accepted language of medical discourse and will therefore be assigned a deflated epistemic status. As one physician said: "patients say a lot of irrelevant things like 'when I eat lettuce my elbow hurts'. I have to listen carefully for the important stuff and ignore the rest" (personal communication).<sup>3</sup>

We propose submitting this problem to an epistemic analysis, using Miranda Fricker's (2007) notion of epistemic injustice. We argue that ill people suffer testimonial injustice, because they are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable in ways that renders their testimonies and interpretations suspect. We present some examples involving both somatic and mental illness. Ill people also suffer hermeneutical injustice, because the kind of experiences illness affords are often difficult to make sense of and communicate (Carel 2013). Perhaps certain extreme and unique experiences cannot be communicated in any direct, propositional manner, and so are only shareable with persons

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<sup>2</sup> These discourses may vary greatly; we are not suggesting that there is only one such discourse.

<sup>3</sup> Perhaps it is also a sort of epistemic injustice to complain that a person's style of testimony is no good (inarticulate, etc.) but do nothing to ameliorate this (e.g. by critically reflecting upon the reasons that one has for using these unhelpful formats rather than others). Epistemic injustice might arise because (a) one buys into epistemically unjust structures or because (b) one fails to challenge those structures.

whom one recognises to have had similar experiences—those with whom one shares a standpoint or a sense of solidarity, say.<sup>4</sup>

We further argue that health professionals are considered to be epistemically privileged (in both warranted and unwarranted ways) by virtue of their training, expertise and third-person psychology; moreover, they decide which patient testimonies and interpretations to act upon. We contrast cases in which patients have undeservedly low credibility with cases in which patients have undeservedly high credibility. We show that these are two ways in which health professionals' clinical judgement is skewed because they assign too little or too much epistemic credibility to patients. In certain extreme cases of paternalistic medicine patients might simply not be regarded as epistemic contributors to their case in anything except the thinnest manner (e.g. confirming their name or 'where it hurts'). Denying someone credibility they deserve is one form of epistemic injustice; denying them the role of a contributing epistemic agent at all is a distinct form of epistemic exclusion (Hookway 2010).

Finally, we suggest that the structures of contemporary healthcare practice encourage epistemic injustice because they privilege certain styles of articulating testimonies, certain forms of evidence, and certain ways of presenting and sharing knowledge, e.g. privileging impersonal third-person reports, in ways that structurally disable certain testimonial and hermeneutical activities. To address this problem we propose that phenomenology, and in particular a phenomenological toolkit (Carel 2012), may provide a useful hermeneutic context within which patients can reflect on and share their illness experience. The toolkit (and similar reflective practices) may improve communication at no cost to health

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<sup>4</sup>For an engaging discussion of the relationship between epistemic injustice, standpoint, and solidarity, see Medina (2012).

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professionals because patients benefiting from the toolkit would be enabled (a) better to articulate their experiences and (b) to thereby be more effective contributors to their care. The phenomenological toolkit can address hermeneutical injustice by providing patients with a framework through which to understand their experiences. It can address testimonial injustice by both helping patients articulate their illness experience and aiding health professionals in understanding it.

The structure of the paper is as follows: section one presents Fricker's notion of epistemic injustice and discusses illness as a case of testimonial and hermeneutical injustice. Section two provides examples from healthcare to support our claims. Section three outlines the epistemic privilege of health professionals and how healthcare practices are structurally disabling. Section four proposes the phenomenological toolkit as one type of remedy for the problem of epistemic injustice suffered by ill people.

## **1. Testimonial and hermeneutical injustice**

Miranda Fricker argues that “there is a distinctively epistemic kind of injustice” which is a wrong done to someone in their capacity as knower (2007, 1). She identifies two such wrongs, testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when prejudice causes a hearer to assign a deflated level of credibility to a speaker's testimony. Hermeneutical injustice occurs when a gap in collective interpretative resources puts a speaker at a disadvantage when trying to make sense of their social experiences (ibid.). We suggest that these two kinds of injustice characterise many attitudes ill people encounter when they try to voice their opinions about their care, convey their experiences, or state their priorities and preferences. In particular we suggest that an ill person may be regarded as

cognitively unreliable, emotionally compromised, existentially unstable or otherwise epistemically unreliable in a way that renders their testimonies and interpretations suspect simply by virtue of their status as an ill person with little sensitivity to their factual condition and state of mind.

Epistemic injustice can manifest in different ways and to different degrees. Although all instances of epistemic injustice will share a common conceptual core, that of denigrating or downgrading certain persons' testimonies and interpretations, the precise forms of such injustice can vary greatly, ranging from the blunt and brutal to the subtle and difficult to spot. In the case of illness, the forms that epistemic injustice can take will be shaped by a range of factors, including particular healthcare policies, diagnostic practices, and even the format of patient feedback forms. Such issues clearly make the task of identifying and characterising the epistemic injustice that ill persons experience much more difficult, but they also offer a double advantage. First, they make it easier to identify the specific practices and policies that generate epistemic injustice in a given case. Second, they help to pinpoint our claim: it is not that modern healthcare practices are epistemically unjust but that certain policies, practices and cultural norms within modern healthcare practice are liable to generate epistemic injustice. We do not argue that, say, the doctor-patient relationship is necessarily and inevitably an epistemically unjust one, but rather that certain of the forms it can take are prone to generate epistemic injustice. We aim to offer a means of identifying practices and biases that lead to epistemic injustice in healthcare practice rather than to criticise this practice *tout court*.

The charge of epistemic injustice can be analysed in terms of the two specific forms which Fricker identifies: *testimonial injustice* and *hermeneutical injustice*. Although some writers, such as Hookway (2010), have identified other forms that epistemic injustice can take, we

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take it that these are supplements to, rather than rejections of, the twin concepts of testimonial and hermeneutical injustice as Fricker defines them.

An ill person can suffer testimonial injustice in one of several ascending ways. At the simplest level, ill people's testimonies can simply be ignored by healthcare professionals, perhaps being heard but neither acknowledged nor considered. Or those testimonies may be heard but excluded from epistemic consideration; so a genuinely sympathetic physician might listen to her patients' testimonies but fail to see that those testimonies may be worthy of epistemic consideration, of being useful or informative, say. Patient testimonies may be heard and acknowledged, but judged to be irrelevant or insufficiently articulate, and so once again excluded from epistemic consideration. A patient may lack the language and concepts to express their situation, perhaps resorting to clichés that physicians judge to be too coarse or idiomatic to be of use, or feeling that they ought to employ formal medical vocabularies in which they know themselves to be inexpert. Or those testimonies may be acknowledged but subordinated to the authority of health professionals, so what the patient has to say is heard, but coupled to the conviction that it is the expressed or implicit view of the health professionals (and in particular physicians) that is authoritative or primary. So the ill person may be judged to be a useful informant but not a participant in the collective practice of interpretation and understanding of their medical situation. These indicate some of the strategies, implicit or explicit, by which the testimonies of ill persons can be excluded or downgraded in a way that secures the charge of epistemic injustice. Importantly, we do not suggest that these strategies are systematically employed consciously or deliberately and certainly not with malice (although they may be). Indeed, Fricker gives the example of a woman who holds explicitly feminist views, but nonetheless discounts female political candidates due to unconscious epistemic bias (Fricker 2007, 38). Rather, we are pointing to a

set of practices and behaviours based on presuppositions and assumptions that are rarely reflected on and seem to be largely tacit.

To demonstrate this point here are two examples of inappropriate credibility assigned to patient testimonies. The first example is that of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) patients, whose disorder is not recognised by many physicians or considered a psychiatric (not somatic) illness. In the 2011 documentary *Voices from the Shadows*, directors Josh Biggs and Natalie Boulton interview ME/CFS patients, who report distinctively somatic symptoms such as pain, sensitivity to light and noise, and fatigue. However, because the medical and nosological status of ME/CFS is contested, these reports are disbelieved or subsumed under a different interpretation (e.g. that the patients suffer from abuse or that they have a psychiatric illness). Here are a few examples. One patient says: “my suffering was belittled” (2:25). Another comments on the high degree of disbelief in the reality of ME/CFS as a bona fide disease (8:00). And a family reports that “belief turns to disbelief when tests come back normal” and describes how “professionals turn against the family” suspecting that the family is harming the child suffering from the condition (34:39). In extreme cases, children with ME/CFS are removed from their family, care proceedings are initiated, and children placed in closed psychiatric units or in foster care. These practices stem from a deep disbelief in the reality of ME/CFS as a somatic medical disease. Given this context, it is not surprising that patient and families’ testimonies are accorded no credibility and their interpretation (that the child has ME/CFS) is rejected in favour of another interpretation (that the child suffers abuse or has a psychiatric disorder).

Contrast this with documented cases of Munchausen Syndrome (factitious disease), in which people produce or feign disease (e.g. by taking laxatives or wounding themselves) for

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complex psychological reasons.<sup>5</sup> In these cases, patients take up physicians' time and are given considerable medical attention although the symptoms are feigned or made up (Savino & Fordtran 2006). Against the backdrop assumption that no one would seek medical help unless they were ill, patient reports of symptoms are normally believed. Only after repeated visits to the doctor, medical facts that contradict the patient's story, or the absence of supporting medical documentation, do health professionals revise the level of credibility assigned to such patients' testimonies. These two examples illustrate the power and discretion exercised by health professionals when listening to patient testimonies and the two ways in which credibility assignment can be faulty: too high or too low. However, this usually tacit epistemic assessment taking place in patient-health professional encounters does not receive attention in medical education and training and indicates the need for attention to this phenomenon.

What would testimonial justice look like? In testimonial justice the testimonies of ill persons are recognised, sought out, included within epistemic consideration, judged to be relevant and articulate (where they are) and, at least in certain respects, judged as epistemically authoritative. The testimonially just health professional is "alert to the possibility that her relative unintelligibility to him is a function of a collective hermeneutical impoverishment, and he adjusts or suspends his credibility judgement accordingly" (Fricker 2007, 7). So a testimonially just physician, confronted with 'subjective', emotionally-charged, existentially-intense patient testimonies whose medical value s/he cannot discern might think: "The fact

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<sup>5</sup> The Baron Münchhausen (1720–1797) was a German war hero who travelled around Germany describing his military adventures. There is no evidence that he feigned disease or duped people into caring for him. As Feldman (2004) notes, Rudolph Erich Raspe appropriated the Baron's name for the title of a 1785 pamphlet of outrageous and patently false tales, *Baron Munchausen's Narrative of His Marvelous Travels and Campaigns in Russia*.

that I don't understand you isn't your fault, but mine; even your best efforts to make yourself understood are failing, not because of their inarticulacy, but because I am untrained in the appreciation of the sort of articulacy you are using, and this hermeneutical context does not provide me with those resources."

Similar considerations apply to cases of hermeneutical injustice; hence our treatment of this will be brief. Hermeneutical injustice occurs when someone's testimony is not squarely disbelieved but a conceptual impoverishment in a particular culture prevents that person from being able to clearly articulate their testimony. This generates what Fricker calls "a gap in collective hermeneutical resources" (ibid.). Fricker gives as an example the case of sexual harassment in a culture in which the concept itself does not exist. How would one go about making the relevant assertions if one lacks the concepts to do so? Importantly, hermeneutical injustice needs to be cashed out in contextual terms e.g. showing what sorts of practices or social norms or institutional structures generate it. Articulating this injustice is the task of this section.

In the case of illness, the interpretations that ill persons make of their own experiences may simply be ignored or not sought out, or implicitly excluded through the establishment of a culture in which patient testimonies are not respected or included within policy, thereby withdrawing incentives to encourage ill persons to offer their interpretations. Or patient interpretations may be heard and considered but judged to be irrelevant or insufficiently articulate, perhaps because they are too bound up with 'subjective' concerns and anxieties or because the practice of taking them seriously is not recognised as being of potential therapeutic value. Or those interpretations may be reductively seen as another source of information that can be assessed or utilised by health professionals as if those hermeneutical offerings were simply data and so not treated as being an epistemically distinctive form of

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knowledge. Later in the paper we appeal to phenomenology to indicate how a tendency to elide first-person accounts with third-person reports can have deleterious consequences. However, it is important to note that as well as being harmful, it is an epistemic error in itself to collapse important distinctions between first-person and third-person reports because it deprives us of sufficiently sophisticated and nuanced epistemic resources.

An ill person experiences hermeneutical justice, by contrast, when the interpretations of ill persons are recognised, sought out, included within epistemic consideration, judged to be relevant and articulate (where they are) and, at least in certain aspects, judged as epistemically authoritative. An example of epistemic justice, incorporating both testimonial and hermeneutical justice, is the case of Kingston General Hospital (KGH) in Ontario, Canada. Following financial failure and high rates of patient complaints, KGH was completely redesigned using patient input at each step. The hospital has a Patient and Family Advisory Council and patient experience advisors are members of key hospital committees.<sup>6</sup> Every decision made at KGH must have a patient included in its consultation or provide a reason why patients were not consulted; patient-health professionals' co-design is fundamental to the hospital's practice.<sup>7</sup>

## **2. Examples of epistemic injustice in illness**

The foregoing accounts are schematic and should not be interpreted as a rigidly categorical description of the 'stages' of epistemic injustice. Epistemic injustice must not be conceived in

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<sup>6</sup><http://www.kgh.on.ca/en/aboutkgh/Patient%20and%20Family%20Advisory%20Council/Pages/default.aspx> (accessed on 10 June 2013).

<sup>7</sup> Leslie Thomson, KGH Chief Executive, talk at King's Fund on 8th November 2012.

terms of abstract epistemological analysis alone, says Fricker, for it must be sensitive to a ‘socially situated account’ which recognises that human beings qua epistemic agents are recognised as “operating as social types who stand in relations of power to one another” (Fricker, 2007, 3). Therefore the epistemic injustice that is experienced by ill persons must be sensitive to their social situation, comparative credibility, and so on, including factors such as intergenerational variation in doctors’ attitudes towards their patients. We also need to identify different degrees of injustice, to help pin certain sorts of injustice to certain persons, to make easier the task of correlating forms of injustice to specific policies and practices. Perhaps certain more conservative and authoritarian doctors might simply ignore patient testimonies, whereas others do not. It also may be the case that health professionals would welcome patient testimonies, but the acceptable formats for collecting such information does not suit the kind of testimony patients wish to share (e.g. using yes/ no questions where nuance and context are essential; giving limited space to describe an event or experience; asking only about specific aspects of healthcare provision; asking patients to fill in such questionnaires in public spaces with little time and privacy to reflect on the experience).

Here are some examples of testimonial and hermeneutic injustice<sup>8</sup>:

‘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.’

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<sup>8</sup> These examples are taken from responses to a query we posted on a patient mailing list in 2012.

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‘I don’t mention problems because though they are real for me, they’re minor in the grand scheme of things.’<sup>9</sup>

‘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. It’s a bit uncomfy but I was ok. 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.’

A disabled person complains that friends always ask “What did the doctor say?” without either the follow-up question “And what do you think about what s/he said?”, or by implicitly treating the ill person as a ‘testifier’ (a source of information) and the doctor as the ‘interpreter and actor’ (who acts on the information) (personal communication). Leontiou concurs when she writes:

‘What I find most striking is that, when I reflect on the good interventions that I have brought to my son, most have been recommendations from other mothers. Doctors don’t offer many ideas for navigating the world of disability. Yet, I am repeatedly asked, “What do the doctors say?” I don’t know exactly how to answer this question. Rather, I’m interested in examining how asking this question places the doctor in a

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<sup>9</sup> Self-censoring is another form of epistemic injustice, in which the negative stereotyping is internalised by the patient herself, leading her to downgrade her own testimony.

central position and gives the impression that the doctor is the only one who knows. I have never been asked, “What do other parents who are in your circumstance say?”” (2010, 2)

More extreme historical examples are the following. The first is the case of curare, a poison that causes paralysis that was used as a general anaesthetic for major surgery in the 1940s under the misapprehension that curare was a general anaesthetic. As Daniel Dennett writes:

‘The patients were, of course, quiet under the knife [...] but when the effects of the curare wore off, complained bitterly of having been completely conscious and in excruciating pain. The doctors did not believe them. (The fact that most of the patients were infants and small children may explain this credibility gap). Eventually a doctor bravely committed to an elaborate test under curare and his detailed confirmation of his subjects’ reports was believed by his colleagues’ (1981, 209).

Another example also involves the use of anaesthetic. David Wootton describes how nitrous oxide was discovered and its analgesic properties noted in 1795, but only put into use as anaesthetic in 1846. He writes:

‘you need to imagine what it was like to become so accustomed to the screams of patients that they seemed perfectly natural and normal; so accustomed to them that you could read with interest about nitrous oxide, could go to a fairground and try it out, and never imagine that it might have practical applications’ (2007, 22-3).

Let us offer one final example, that of psychiatric patients who also have a physical disorder. Here is Elyn Saks’ account of her brain haemorrhage:

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‘Quickly, they bundled me into the car and took me to the emergency room. Where a completely predictable disaster happened: the ER discovered I had a psychiatric history. And that was the end of any further diagnostic work. [...] Poor Maria was literally jumping up and down trying to tell anyone who’d listen that she had seen me psychotic before and that this was different. But her testimony didn’t help – I was a mental patient. The ER sent me home’ (2007, 232-3).

Saks also recounts the story of a psychiatric patient who went for weeks with a broken back, because none of the medical staff the patient saw took his pain seriously (ibid., 232). These last examples may seem extreme; we present them in order to demonstrate that epistemic injustice in the case of illness can have devastating effects and can range from the subtle and hard to detect bias to brutal rejection of clear evidence of suffering.

Such iterated experiences give rise to the self-propagating nature of such acts of exclusion: the patient’s testimonials are ignored or downplayed, which upsets the person offering testimony and interpretation. This on its own is wrong and gives rise to the common complaint that ‘the doctor doesn’t listen to me’. But it also affects future epistemic offers, so testimonials may become infused with self-doubt and emotionally-charged, therefore confirming the doctors’ perception of that patient as a poor testifier, leading to a vicious circle of damaging communication.

### **3. Epistemic privilege**

Another side to this discussion of epistemic injustice is the epistemic privilege accorded to health professionals. This privilege is accorded by virtue of their training, expertise or third-

person psychology, such that they occupy the epistemically privileged role of receiving, assessing and deciding which testimonies and interpretations to act upon, as well as deciding what sorts of testimonies to receive, from whom, what form they can take, and so on. In this section we will discuss this, more elusive, kind of epistemic injustice and relate it to the difference between patients' and physicians' attitudes to illness. Moreover, we claim that the structures and discourses of contemporary healthcare practice might encourage epistemic injustice because they privilege certain styles of articulating testimonies, forms of evidence, ways of presenting and sharing knowledge, and so on. We claim that modern healthcare practices privilege impersonal third-person reports and empirical data over personal anecdote and pathographic testimonies in a way that structurally disables certain testimonial and hermeneutical activities. Different kinds of epistemic injustice can occur separately or could be mutually reinforcing; where all three are present and active one has what Fricker calls "persistent systematic epistemic injustice" (2007, 58). It is worth noting that many health professionals might like to spend more time and energy taking seriously patient testimonies, but the pressures – of time, financial resource, task-based organisational processes, etc. – that they operate under forbid it. Many health professionals may be unwillingly epistemically unjust and would have liked this aspect of their work to be different. Structural and hierarchical features of the healthcare system are the cause of the epistemic injustice, rather than any individual's intent.

Both health professionals and ill persons are epistemically privileged for different reasons. But only the health professionals' privileged epistemic status 'really matters' when it comes to healthcare practice and policy. The knowledge of patients is usually confined to the private realm and is not readily incorporated into decision making, intervention design, and policy documents. In recent years the terms 'patient centred-care', 'the patient expert', and 'patient

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experience' have become more common in policy documents and mission statements, and we hope that with time these translate into actual and concrete difference to healthcare provision.<sup>10</sup> But healthcare failures are still abundant and reflect the institutionalising and morally paralysing force of current healthcare provision arrangements.<sup>11</sup> There are several reasons for the epistemic privileging of health professionals, and in particular of physicians. First, on the medical view the goal of medicine is to repair physiological mechanisms. The third-person view dominates this model and has no obvious room for first-person testimonies. Second, in a performance-based target-driven culture patient input has little place. Third, in a large-scale healthcare system in which performance is judged quantitatively, qualitative statements are difficult to utilise. Fourth, patient views are often seen as anecdotal and context-dependent and therefore lacking any long-term utility. Finally, patient views can be as numerous as patients and therefore it is unclear whose views should be acted on.<sup>12</sup>

The knowledge each group might bear is different. Patients have the knowledge of how a particular condition feels, how it impacts on their life, and changes day-to-day activities (Carel 2010). Only they can say whether a certain treatment causes pain, or how well they feel. Health professionals have the scientific and medical knowledge of anatomy, physiology, and so on and knowledge of available treatments. Of course the two domains of knowledge

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<sup>10</sup> See for example the work of organisations such as the King's Fund and the Point of Care Foundation and, for the UK National Health Service, Coulter and Ellins (2006), Greener (2009), and McIver (2011).

<sup>11</sup> A vivid and tragic example is the series of systematic failures which led to the death of hundreds of patients, uncovered by the Mid Staffordshire NHS Foundation Trust Public Inquiry, led by Sir Robert Francis in the UK. See:

<http://www.midstaffpublicinquiry.com/report> (accessed on 10 June 2013).

<sup>12</sup> A recent analogous example is a 'student satisfaction' survey at a UK university, in which some students stated they wanted to be able to use their mobile phones in the library. As a result the use of mobile phones was permitted in the library, no doubt to the detriment of the many students who wanted the library to be a quiet place of study. Patient views may be similarly in tension with one another.

do not belong exclusively to one epistemic group. For example, a physician with an extensive experience of treating a particular disease may have excellent knowledge of the limitations on daily living it may impose on patients although she has no first person experience of the disease. Similarly, the ‘patient expert’ may develop a deep understanding of their condition and its causes, as well as be an authority on available and experimental treatments, trials, and research in the field. Moreover, the two groups may work collaboratively to integrate and promote both kinds of knowledge (Rosenbaum 2012). These two domains of knowledge are different also in how such knowledge is gained (Carel 2013).

What is taking place in the epistemic domain with respect to these two groups and these two kinds of knowledge needs to be related to broader issues concerning the relationships of priority and power – as well as reciprocity – between different epistemically privileged groups. Thus for example patients are expected to be told what to do by doctors, but doctors are not expected, bar some rare cases, to be told what to do by patients. There is an asymmetry in the relationship owing to an implicit hierarchy assigning the health professional (normally a physician) a high epistemic status that is linked to a professional and widely acknowledged social position.

The term ‘epistemic privilege’ has three related components; parsing them will allow us to offer a more fine-grained account of the epistemic relationship between ill persons and health practitioners. A person or social type (‘doctor’, ‘consultant’) may be epistemically privileged because they have the authority to establish, and where necessary to enforce, the standards and norms for epistemic exchange in a given community. For instance, the medical community is epistemically privileged because it can define and characterise medical concepts (like ‘health’ and ‘disease’) and so sets the terms for authoritative debates about

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health and healing.<sup>13</sup> Although this does not prevent ill persons from having parallel debates, it ensures that their debates are not considered authoritative.

A person or social type may be epistemically privileged because they occupy an authoritative procedural role in epistemic exchanges, for instance by acting as gatekeepers controlling which persons and groups are included, and what degree of credibility and authority they are assigned, and acting to enforce discipline within the epistemic community. For instance, a hospital review committee is epistemically privileged because it has the authority to decide how to populate the committee, who are permanent and who are invited members, which persons have secondary status (like ‘observer’ or ‘invited participant’), who acts as chair, what the agenda for debate is, and so on. A person or social type may be epistemically privileged, finally, if they have what one might call power of decision, that is, if it is their privilege to decide when an issue is settled, when enough evidence has been presented, when a particular issue has been given sufficient time and attention, and so on.

These three forms of epistemic privilege are likely to arise together and be mutually reinforcing. Consider a hypothetical case in which a group of patients with chronic rheumatic disease are invited to sit on a committee reviewing the physiotherapy provision available to them. Those patients might suffer epistemic injustice in this case because they lack epistemic privilege in the three ways articulated above. First, they are denied any opportunity to determine whether or not the definition of the concept of ‘health’ being used is appropriate or consonant with their experiences or reflective of their testimonies; for instance if health is defined in terms of their performance of physiotherapy exercises rather than their capacity to

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<sup>13</sup> The fact that the medical community has these forms of social and epistemic power does not, of course, entail that they always exercise that power in a robustly procedural manner (see Kidd forthcoming a).

perform everyday tasks like driving. Second, their epistemic authority is minimised because their status is that of ‘invited observers’ who can be consulted (e.g. about the utility of current physiotherapy arrangements) but who have no substantive critical powers (e.g. they can raise objections, but only ‘for the record’). Third, those rheumatic patients lack any decisive role in the review committee because they have no power of vote and so cannot enforce their insistence that certain issues be readdressed or discussed more thoroughly.

We do not wish for this debate to sound one-sided or blind to the great epistemic merit of medical training and practice. We do wish to draw attention to the type of procedures and structures, as well as culture and discourse, common in Western healthcare and the resulting epistemic injustice. We do not aim to attack any specific epistemic group, but point to the current arrangements that give rise to epistemic injustice at a considerable cost to patients and possibly to health professionals who are constrained by these very practices. To this end we claim that it is useful to distinguish between warranted and unwarranted epistemic privilege, e.g. healthcare professionals warrant epistemic privilege in their interpretation of a CT scan, but not in deciding how a patient should die (e.g. in hospital or at home). We fully acknowledge that certain persons and professions are epistemically privileged (at least in certain cases). But there may be cases where the epistemic privilege of health professionals is unwarranted; for instance if the assignment of epistemic privilege is grounded in the presumptive judgement that there are no other plausible candidates for privileged epistemic status in the context of certain forms of patient care. Many religious persons who experience depression naturally turn to those persons they recognise as having clerical authority and who are, in their judgement, charged with their spiritual and personal care (cf. Scrutton forthcoming and Kidd forthcoming b). Some argue that doctors are exempt from certain charges of epistemic error – e.g. their being hoodwinked by the biases in the academic

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literature concerning the efficacy of drugs – because they are simply too busy to perform the long and complex processes of survey and analysis (cf. Goldacre 2012).

#### **4. Addressing epistemic injustice: a phenomenological patient toolkit**

So far we have examined epistemic injustice in illness. We argued that illness might give rise to testimonial injustice, when patients' claims are ignored or rejected, and to hermeneutical injustice, when patients do not have the concepts with which to articulate their illness experiences. In this section we claim that not only is this epistemic injustice unwarranted, but that certain experiences of illness can afford epistemic privileges to the ill person that are not otherwise available to (and perhaps not fully shareable with) persons not ill. This idea has important ethical implications: it calls us to take seriously the standpoint of ill persons, militates against paternalism, and acknowledges the essential role that ill persons should play in the formulation and implementation of healthcare policy. We suggest that a particular approach to illness, phenomenology, can give us the essential tools for overcoming epistemic injustice and can therefore contribute to explicating the experience of illness. We further suggest that phenomenology is intimately connected to issues of epistemic justice, since two core phenomenological ambitions are to (i) identify and articulate the tacit structures that underpin one's experience and engagement with the world and (ii) to provide a means of taking seriously the (often radically different) experiences of others (cf. Ratcliffe 2012).

The idea behind the toolkit is that philosophical concepts can be a useful aid for patients who are trying to make sense of their illness. Patients may have ethical, existential or metaphysical concerns that have a distinctive philosophical flavour, but are not conceptualised as such. For example, those nearing the end of life may reflect on its shortness

of life, and wonder whether they have lived a good life. Developing and articulating such reflection is a distinctively philosophical activity, albeit of a unique sort. These reflections are foisted upon the ill individual by their unwanted illness; the context in which this philosophical activity takes place is difficult and physically and emotionally taxing; and such reflection stems from concrete and idiosyncratic concerns rather than from engagement with abstract questions. In order to enable this philosophical activity a toolkit has been developed, which helps patients understand the impact illness may have on their life as a whole (Carel 2012). It provides philosophical concepts through which the impact may be understood. These concepts are taken from phenomenology and are utilised in order to provide an account of the holistic and all-encompassing nature of illness (Carel 2008). The practice of philosophy may help in this particular case to ameliorate epistemic injustice by giving patients the ability to conceptualise and articulate their knowledge and interpretation of their illness experiences, thus addressing the hermeneutical gap Fricker laments.

This toolkit is not intended to replace medical knowledge or treatment but to supplement it. It answers a need identified by many patients as well as health professionals to better understand the illness experience of individuals and groups with particular conditions. For example, a GP pointed out the need for narrative humility among physicians, and the personal growth that listening to patients in a holistic way would bring (personal communication).<sup>14</sup> There is a knowledge that arises from having a particular illness experience that should not be dismissed as irrelevant or too emotive, as it crucially interlaces with and illuminates the medical facts. We propose that adding first-person accounts of the illness experience to the overall medical picture may make diagnostic, therapeutic and

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<sup>14</sup> These ideas were brought up in a toolkit workshop conducted on 14 and 21 September 2012 in Bristol.

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empathetic contributions to healthcare provision. Incorporating patients' insights can help with the diagnosis and treatment of illness and also enrich health professionals' empathy as well as guard against alienation.

This involves the transition from the 'informational perspective', which sees the speaker as a "potential recipient or source of information" to the 'participant perspective', in which we see the quest for knowledge as a shared enterprise and the patient speaker as "competent to carry out some particular activity that has a fundamental role in carrying out inquiries" (Hookway 2010, 156-7). As Hookway suggests, "there could be a form of injustice related to assertion and testimony that consisted, not in a silencing refusal to take the testimony to be true or expressing knowledge, but in a refusal to take seriously the ability of the agent to provide information that is relevant in the current context" (2010, 158). It seems to us that it is frequently the ill person's ability to offer relevant assertions is being questioned, rather than their ability to make assertions at all.<sup>15</sup> The patient in such cases is "recognised as unable to participate in activities whose content is intrinsically epistemic" (Hookway 2010, 159). A forum in which patients can gain epistemic confidence and order and discern their experiences of illness might help tackle epistemic injustice by supporting patients' transition from informational to participant perspective.

Here is a brief outline of the toolkit (for a fuller account see Carel 2012). The toolkit provides a flexible individual tool which patients can use to develop their understanding of their illness. It includes three steps: the phenomenological reduction, thematizing illness, and reviewing the ill person's being in the world. Serious illness removes our conventional understandings and expectations and is thus an opportunity to examine and re-evaluate

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<sup>15</sup> The case of some mental disorders, e.g. psychosis, would be different. In these cases the patient may be considered altogether irrational and unable to make true assertions at all.

choices, routines, and habits. Merleau-Ponty (1964) says that reflection “slackens the intentional threads which attach us to the world and thus brings them to our notice” (xiii). Illness enables such withdrawal, which is often imposed on the ill person. Phenomenology is committed to making explicit aspects of experience that are overlooked by other approaches and may be poorly understood. A phenomenological approach to the experience of illness requires a suspension of a “natural attitude” of implicitly accepting the background sense of belonging to a world and various interpretive dogmas along with it. Bracketing the natural attitude is a withdrawal from the ordinarily implicit commitment to the reality of the world (Ratcliffe 2008, 4). As Husserl says, this is not a sceptical or idealist position. Rather, this ‘inhibiting’ or ‘putting out of play’ of the natural attitude exposes “the universe of phenomena in the phenomenological sense” (Husserl 1999, 20). This suspension allows under-theorized aspects of experience to become an object of inquiry because it enables us to shift attention from the given object to the way in which it is given and its modes of appearance to us.

Bracketing the natural attitude toward illness suspends the belief in the reality of an objective disease entity. Shifting the focus away from the disease entity and toward the experience of it can disclose new features of this experience. We usually take the disease entity for granted and posit it as the source of the illness experience. But in fact, for the ill person the illness experience comes before the objective disease entity (Toombs 1987). Once the belief in the objective disease entity is bracketed and we are distanced from our usual way of experiencing, we can begin to explore how illness appears to the ill person, its structure, and its essential features.

The second step in the toolkit is thematizing illness. ‘Thematizing’ refers to the act of attending to a phenomenon, which makes particular aspects of it explicit (Toombs 1987,

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222). A theme for a particular consciousness is that upon which it focuses its attention. But this does not simply denote the intentional object. It also takes into account the kind of attentional focus given to an entity. Thematizing may include attending to the cognitive, emotive, moral, or aesthetic aspects of a phenomenon. A patient may thematize her illness as a central feature of her life, attending to her symptoms as pervasive, while the physician may thematize the illness as a 'case of cancer', attending to symptoms as diagnostic clues (ibid.). The understanding that illness is not an objective entity and the exercise of thematizing may help patients because it enables moving away from prescriptive pronouncements toward a descriptive mode. Thematizing can be used for bringing out the multiple perspectives on one's illness that patient, family, health professionals, and others may have, as each will thematize an illness differently. The patient may thematize her illness emotively, while a health professional will thematize it cognitively. A family member may thematize illness as an experience of empathy. Exploring the different thematic centres illness may have can illuminate its multiple ways of appearing.

The third step of the toolkit is to take the new understanding of illness (as a form of distancing that has been thematized) and examine how it changes one's being in the world. The term 'being in the world' is used by Heidegger (1962) to denote the human being in the broadest sense. Being in the world includes the biological entity, the person, and her environment and meaningful connections. This term provides a rich account of what it means to exist as a human being. The toolkit uses being in the world to capture the pervasive effects illness may have on one's sense of place, on one's interactions with the environment and with other people, on meanings and norms, and on the nexus of entities, habits, knowledge, and other people that makes up one's world. By moving away from a narrow understanding of

illness as a biological process, a thick account of illness as a new way of being in the world can be developed by patients.

The toolkit has been shared with patient groups as well as with a group of GPs in a consultative process. Initial reactions to it demonstrate the feasibility and helpfulness of such a tool.<sup>16</sup> For example, the GP group consulted suggested the toolkit would be of particular use with elderly patients and those suffering from depression. Patients suggested that the toolkit would help them by empowering them to “speak their mind” and offering an opportunity for reflection rather than self-pity. Such a toolkit would allow a space for grieving and would enable patients to take responsibility for their understanding of illness via enhancing their self-knowledge. We are not suggesting that the toolkit is a sole way of addressing epistemic injustice, but suggest it as one possible remedy, that in conjunction with other measures may begin to address the problems outlined in this paper.

## **Conclusion**

We would like to conclude by suggesting that on closer inspection it seems that the epistemic injustice identified by Fricker is much more widespread than we would like to think. Fricker herself comments: “I believe that there are areas where injustice is normal and that the only way to reveal what is involved in epistemic injustice (indeed, even to see that there is such a thing as epistemic injustice) is by looking at the negative space that is epistemic injustice” (2007, viii). It would be interesting to view exchanges between social workers and ‘clients’,

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<sup>16</sup> These comments were collected during three consultative sessions. One, with a group of GPs, took place on 14 June 2012 in Bristol. Two patient group sessions took place on 14 and 21 September 2012 in Bristol.

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prison inmates and wardens, police officers and suspects, to expose some similarities in the styles of epistemic exclusion that characterise particularly asymmetrical power relations. We hope we have begun this task by discussing the case of epistemic injustice in ill health and in the exchanges between patients and health professionals.

Fricker writes:

‘prejudice tends to go most unchecked when it operates by way of stereotypical images held in the collective social imagination, since images can operate beneath the radar of our ordinary doxastic self-scrutiny, sometimes even despite beliefs to the contrary [...] our everyday moral discourse lacks a well-established understanding of the wrong that is done to someone when they are treated in this way’ (2007, 40).

It is our hope that this paper will contribute to the effort of lifting stereotypes and biases about ill people and about illness from the unconscious collective imagination to the conscious level and therefore make it available to the careful scrutiny it deserves.

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