

Epistemic injustice in healthcare: a philosophical analysis

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Abstract In this paper we argue that ill persons are particularly vulnerable to epistemic injustice in the sense articulated by Fricker (Epistemic injustice. Power and the ethics of knowing. Oxford University Press, Oxford, 2007). Ill persons are vulnerable to testimonial injustice through the presumptive attribution of characteristics like cognitive unreliability and emotional instability that downgrade the credibility of their testimonies. Ill persons are also vulnerable to 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. The doctor 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 seem to 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 acted upon. Her pain is either not fully registered or not considered worthy of response.¹

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 (see for example Beckman and Frankel 1984; Korsch et al. 1968; Korsch 1969). Many authors (for example Kleinman 1980; Toombs 1987) have drawn attention to the epistemic aspects of these complaints, and this work informed subsequent changes to healthcare policy, such as the NHS Patient Charter and the NHS constitution. But despite this greater awareness patients continue to voice epistemic concerns, which attest to persistent experiences of being

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¹ This scene was observed by one of the authors (Carel), whilst shadowing a paediatrician consultant at a UK hospital (details redacted to ensure patient confidentiality).

epistemically marginalised or excluded by health professionals (for such published accounts see Frank 2010; Carel 2008). The UK's Patients Association, for instance, lists 'communication' as one of the four most frequent complaints received by the association.

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 clinicians is that patients' speech is full of irrelevant information, that patients are (understandably) upset and therefore can be irrational, and that listening for 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.² 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).³

We propose submitting this problem to an epistemic analysis, using Miranda Fricker's (2007) notion of epistemic injustice. We argue that ill people are more vulnerable to testimonial injustice, because they are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable in ways that render their testimonies and interpretations suspect. We present some examples involving both somatic and mental illness. Ill people are also more vulnerable to 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 with whom one shares a standpoint or a sense of solidarity.⁴

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 are assigned undeservedly low credibility with cases in which patients' credibility is undeservedly high. We show that these are two ways in which health professionals' clinical judgement can be skewed as a result of assigning too little or too much 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, as well as health professionals, can reflect on and share their illness experiences. The toolkit (and similar reflective practices) may improve communication at no cost to health professionals because patients benefiting from the toolkit would be better able to articulate their experiences and thereby be more effective contributors to their care. Similarly, health professionals benefiting from the toolkit would have a more nuanced grasp of patients' illness experience, as well as honing their epistemic sensibilities and skills, such as listening to and understanding multiple perspectives. 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.

Testimonial and hermeneutical injustice

Miranda Fricker argues that "there is a distinctively epistemic kind of injustice" which is a wrong done to

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

³ 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.

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

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 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 the patient-clinician 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 have identified other forms that epistemic injustice can take, we take it that these are supplements to, rather than rejections of, the twin concepts of testimonial and hermeneutical injustice as Fricker defines them.⁵

In addition, we want to flag up cases in which the clinician's epistemic authority is warranted, but where epistemic damage is nonetheless incurred. These include cases where the style of interaction between clinician and patient is one that closes down communication, such that important information is potentially lost. In this paper we focus on cases in which the clinician's assumption of epistemic authority over a patient in relation to matter *x* is mistaken. But we might also find that even when the clinician's assumption of epistemic authority in relation to matter *x* is correct, the clinician's style of interaction is overly dismissive. Her disregard of the patient's perspective on *x* might still be detrimental to the patient's well-being, not least since the judgment that one's testimonies have been disregarded tends to undermine one's ability and willingness to engage in further interpersonal exchanges. This suggests that the style of patient-clinician interactions should involve respect for the patient's perspective, even in cases where the epistemic credentials of that perspective are less than impeccable. Those interactions do not, after all, consist of an atomised series of de-contextualized propositions that can be assessed one after the other. Instead, those interactions involve a dialogical relationship, in which cumulative experiences—of silencing, say, or trusting—affect the structure and content of later stages of the interaction.⁶

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 clinician 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 clinicians 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

⁵ See, for instance, Coady (2010) and Hookway (2010).

⁶ More generally, we are not denying the existence of epistemic asymmetries, but call for discussion on how these should be managed in those cases where they do exist and where clinicians are aware of them. We would agree that a teacher who dismisses students or talks down to them, on the basis of their epistemic inferiority, is not a very good teacher. Dialogical openness is compatible with epistemic asymmetry and can serve to address the imbalance. Distinguishing the stance adopted by a clinician from the perceived and actual epistemic status of claims made by clinician and patient might be useful. We thank an anonymous referee for emphasising this point.

is heard, but coupled to the conviction that it is the view of 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). Rather, we are pointing to a set of practices and behaviours based on presuppositions and assumptions that are rarely reflected on and are largely tacit (cf. Fricker 2007, 38 and Wanderer 2012).

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 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 little 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 Munchausen Syndrome (factitious disease), in which people produce or feign disease (e.g. by taking laxatives or wounding themselves) for complex psychological reasons.⁷ In these cases, patients take up clinicians’ time and are

given considerable medical attention although the symptoms are feigned or made up (Savino and Fordtran 2006 and for a recent account see also Cegłowski 2012). 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 epistemic 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-clinician encounters does not receive much attention in medical education and training and indicates the need for attention to this phenomenon.

One may ask in particular whether the status of ‘patient experts’ may prevent epistemic injustice when patients with a chronic condition know their own condition well and have a good grasp of the medical facts and state of the science knowledge about it. That is certainly an important step towards acknowledging informal expertise. However, to assign someone a status of epistemic authority (‘patient expert’) is in itself insufficient unless one also adjusts the wider structure of epistemic norms and practices to ‘build in’ those new authorities. For example, rheumatic patients who are members of a physiotherapy group might be classed as ‘patient experts’, but are still not invited to participate in (for instance) the physiotherapy committee, or consulted about changes to the hydrotherapy service. Expertise can be misconstrued if thought of individually; what is also needed are established roles for patient experts within the wider set of structures and practices of the relevant context.

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 clinician 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 clinician, confronted with an emotionally-charged, existentially-intense patient testimony whose medical value s/he cannot discern might think: “The fact 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.

⁷ 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*.

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 (see, e.g., Anderson 2012). 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 views are not respected or included within policy, thereby withdrawing incentives for 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 clinicians as if those hermeneutical offerings were simply data and so not treated as being an epistemically distinctive form of 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 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 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.⁸ 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.⁹

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 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 behaviour, to make easier the task of correlating forms of injustice to specific policies and practices. Perhaps 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, or asking patients to fill in such questionnaires in public spaces with little time and privacy.

Here are some examples of testimonial and hermeneutic injustice¹⁰:

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.

⁸ <http://www.kgh.on.ca/en/aboutkgh/Patient%20and%20Family%20Advisory%20Council/Pages/default.aspx> (accessed on 10 June 2013).

⁹ Leslie Thomson, KGH Chief Executive, talk at King's Fund on 8th November 2012.

¹⁰ These examples are taken from responses to a query we posted on a patient mailing list in 2012.

I don't mention problems because though they are real for me, they're minor in the grand scheme of things.¹¹

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 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 it as 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:

[Y]ou 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 a psychiatric patient who also has a physical disorder. Here is Elyn Saks' account of her brain haemorrhage:

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.

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

¹¹ 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. .

third-person psychology, such that they occupy the epistemically privileged role of assessing 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 clinicians' attitudes to illness. 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). 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 (Wainwright and Macnaughton 2013). In recent years the terms 'patient centred-care', 'patient expert', and 'patient experience' have become more common in policy documents and mission statements, and we hope that with time these translate into actual improvement to healthcare provision.¹² But healthcare failures are still abundant and reflect the institutionalising and morally paralysing force of current healthcare provision arrangements.¹³ 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.

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 their way of being in complex and subtle ways (Carel 2013). Only they can say whether a certain treatment causes pain, or how well they feel. Clinicians have the scientific, medical and clinical knowledge. Of course the two domains of knowledge do not belong exclusively to one epistemic group. For example, a clinician 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 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 (Kidd 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 (and especially physicians) a high epistemic status that is linked to a professional and widely acknowledged social position.

The term 'epistemic privilege' has three related components. 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

¹² 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).

¹³ 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.midstaffspublicinquiry.com/report> (accessed on 10 June 2013).

the terms for authoritative debates about health and healing.¹⁴ 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’), 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; for instance if health is defined in terms of their performance of physiotherapy exercises rather than their capacity to perform everyday tasks like driving. Second, their epistemic authority is minimised because their status is that of ‘invited observers’ who can be consulted but who have no substantive critical powers. 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 considerable merit—epistemic and otherwise—of medical training and practice. 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. We do not suppose that culpability for epistemic injustice

should be placed at the feet of healthcare practitioners; for instance, the attitudes and actions of those practitioners will be shaped by particular models of the patient-clinician relationship which they were trained in or are required to operate with. It may be that certain models are, however inadvertently, more liable to generate receptive conditions for epistemic injustice than others. Emanuel and Emanuel (1992), in a widely-cited paper, identify four models of the patient-clinician relationship; each incorporates implicit epistemic presuppositions; for instance, a ‘paternalistic model’ establishes a strict epistemic asymmetry in which the doctor authoritatively informs the patient of what is best for them, whereas a ‘deliberative model’ encourages a dialogical exchange between patient and clinician that, at least in principle, affords greater epistemic autonomy to the patient. Indeed, Emanuel and Emanuel (1992, 2226) close their paper by noting that the models may incorporate ‘defective conceptions’ of epistemically charged concepts such as ‘patient autonomy’, and could be criticised on those grounds.¹⁵

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 where 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.¹⁶ Some argue that doctors are exempt from certain charges of epistemic error—e.g. their being hoodwinked by the biases in the academic 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).

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,

¹⁴ 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).

¹⁵ Indeed, the issue of culpability for epistemic injustice is complex, for instance because it varies according to whether the particular form of injustice is *agential* or *structural*. See, further, the exchange between Riggs (2012) and, in reply, Coady (2012).

¹⁶ Many religious persons who experience depression will often consult persons they recognise as having spiritual authority—priests, say—as well as to psychiatrists and other mental health professionals (cf. Scrutton forthcoming and Kidd forthcoming b).

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 damaging, 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 (1) identify and articulate the tacit structures that underpin one's experience and engagement with the world and (2) 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, as well as to health professionals caring for them. 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 and wonder whether they have lived a good life. Developing and articulating such reflection is a distinctively hermeneutical activity, albeit of a unique sort. These reflections are foisted upon the ill individual by their 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 hermeneutical 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 of illness, and of caring for the ill, may be reinterpreted. These concepts are taken from phenomenology and are utilised in order to provide an account of the total nature of illness (Carel 2008). The practice may help ameliorate epistemic injustice by giving patients the ability to interpret and articulate 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 clinicians, and the personal growth that listening to patients in a holistic way would bring (personal communication). There is a knowledge that arises from having a particular illness experience that should not be dismissed as idiosyncratic 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 empathetic contributions to healthcare provision. Incorporating patients' insights can help with the diagnosis and treatment of illness and also enrich clinicians' empathy as well as guard against alienation (see also Toombs 1999).

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 that is being questioned, rather than their ability to make assertions at all.¹⁷ 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 discern their experiences of illness might help tackle epistemic injustice by supporting patients' transition from informational to participant perspective.

The toolkit is a patient resource, but it is also aimed at training clinicians. If clinicians are trained in this way and, consequently, become more open to patients' experiences and better able to interpret them, this would be yet another way to address the hermeneutical gap discussed above. Ideally the shared use of the toolkit would help promote epistemic symmetry, in which the patient is more empowered and articulate and the clinician more aware of the richness and value of first-person accounts.

Here is a brief outline of the toolkit (for a fuller account see Carel 2012). It provides a flexible individual tool which patients and clinicians can use to develop their understanding of their illness experiences. It includes three steps: bracketing the natural attitude, thematizing illness, and

¹⁷ 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.

reviewing the ill person's being in the world. Serious illness removes our conventional understandings and expectations and is thus an opportunity to examine choices, routines, and values. Merleau-Ponty (1962) 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, because it imposes such a re-evaluation on the ill person. 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 of the everyday, routine understanding of illness allows its under-theorized aspects to become an object of inquiry because it enables us to shift attention from the disease entity to the way in which it is given and its modes of appearance to us.

The first step of the toolkit, 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, to both patients and clinicians. We usually take the disease entity for granted and posit it as the source of the illness experience. This approach is particularly common within healthcare professions. 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 explore how illness appears to the ill person, and what essential features it might have.

The second step in the toolkit is thematizing illness. 'Thematizing' refers to the act of attending to a phenomenon in a way that makes particular aspects of it explicit (Toombs 1987, 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 clinician 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 both patients and clinicians because it enables moving away from prescriptive

pronouncements toward a more tentative, 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. A mixed workshop, with both patients and health professionals, would be ideal for carrying out this thematizing. 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 emerging from these two steps, and examine how it changes one's being in the world. Being in the world includes the biological entity, the person, and her environment and meaningful connections (Heidegger 1962). 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. The third step enables participants to move away from a narrow understanding of illness as a biological process, towards a thick account of illness as a new way of being in the world.

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. 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.¹⁸ Such a toolkit would allow a space for grieving and would enable patients to take responsibility for their understanding of illness by enhancing their self-knowledge. We are not suggesting that the toolkit is a sole way of addressing epistemic injustice; far from it. We suggest it as an example of one possible practical measure that in conjunction with other measures may begin to address the problems outlined in this paper.

Conclusion

We conclude that epistemic injustice is a common, possibly pervasive, feature of healthcare. This points to two

¹⁸ These comments were collected during three consultative sessions: one with a group of GPs took place on 14 June 2012 and two patient group sessions took place on 14 and 21 September 2012, all in Bristol, UK.

areas for future study. The first is to establish a methodology or metric for measuring epistemic injustice, in healthcare or in any other context, so that the vast body of anecdotal reportage can be developed into a substantive empirical basis. The second is then to determine the extent of epistemic injustice in healthcare. Certainly our initial studies indicate that it is much more likely to be systematic and extensive, rather than local and minor. It would be interesting to consider the possibility of epistemic injustices that might arise in other contexts—for instance, between social workers and ‘clients’, prison inmates and wardens, and police officers and suspects. Such comparative analyses might expose some similarities in styles of epistemic exclusion that characterise particularly asymmetrical power relations, although of course there are important and deep differences between each domain and we are not proposing an analogy between any of these groups. 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:

[P]rejudice 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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