

Patient voices: Illness and epistemic injustice

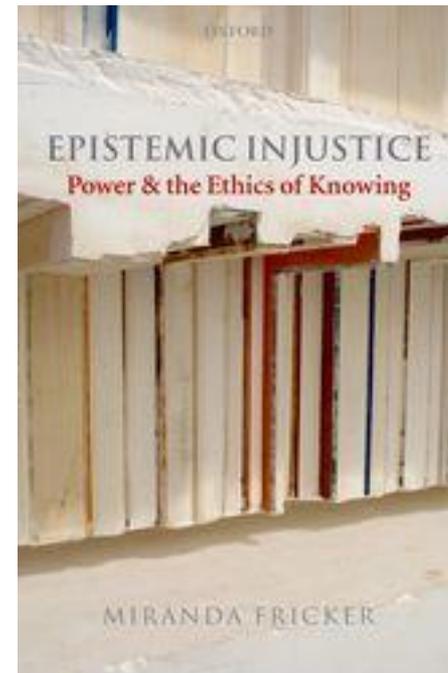
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Epistemic injustice

- “A wrong done to someone specifically in their capacity as knower” (Fricker, *Epistemic Injustice*, 1)
- Epistemic injustice can manifest in different ways and degrees
- Common conceptual core: denigrating or downgrading certain persons’ testimonies and interpretations
- Precise forms of such injustice can vary greatly, ranging from the blunt and brutal to the subtle



Two types of injustice

- **Testimonial injustice**: prejudice causes a hearer to give a deflated level of credibility to a speaker's word
- South African swimmer and lifeguard
- **Hermeneutic injustice**: a gap in collective interpretative resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences
- Sexual harassment
- Certain practices/ social norms/ institutional structures generate injustice

Testimonial injustice: voices not heard

- Patients' testimonies often dismissed as irrelevant, confused, too emotional, unhelpful, or time-consuming
- ill people sometimes regarded as cognitively unreliable, emotionally compromised, or existentially unstable in ways that render their testimonies and interpretations suspect
- 'too upset to think straight'; mental disorder; elderly patients ('institutional ageism' in NHS)
 - Patient testimonies are
 - excluded from epistemic consideration
 - judged irrelevant, insufficiently articulate, etc.
 - subordinated to the authority of healthcare professionals
 - They might also be ignored, rejected, or discounted



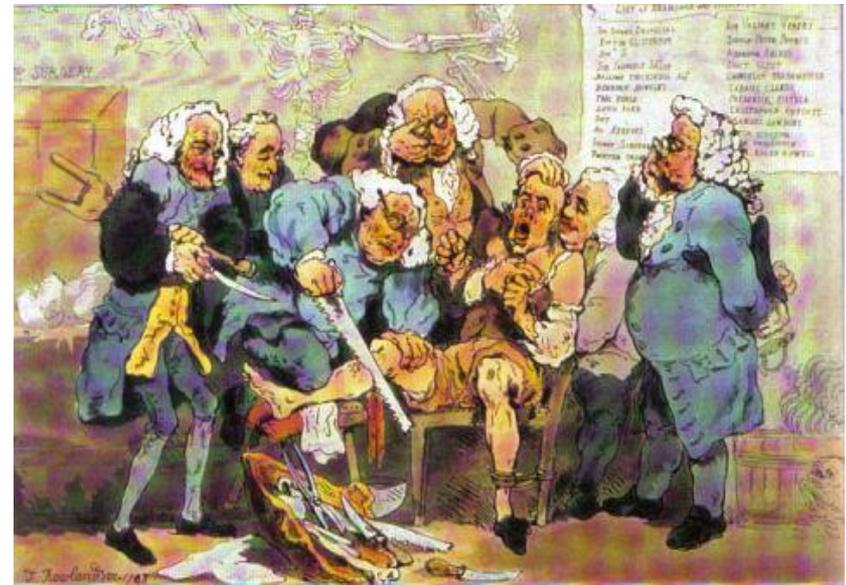
Patient testimonies

- “I don't mention problems because though they are real for me, they're minor in the grand scheme of things.”
- “I had an abnormal cervical smear, so was sent to the large city teaching hospital for a coloscopy. I changed into the usual ties up the back gown, with the usual vital ties missing, and then went through for the examination. Lots of big sighs from the consultant with his head between my legs. Then off he goes, leaving the room. I'm told to follow. So I arrive, naked under a gown which doesn't do up, slightly damp between the legs and a bit stressed as I have to sit down and I'm worried about leaving a wet patch. He goes on to tell me I need an operation. I hear blahblahbla as I'm perching and panicky... And it's very difficult to think without your pants on. I said nothing.”

Historical example

- Nitrous oxide invented in 1795, but only put into use as anaesthetic in 1846

“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” (Wotton, *Bad Medicine*, 22-3)

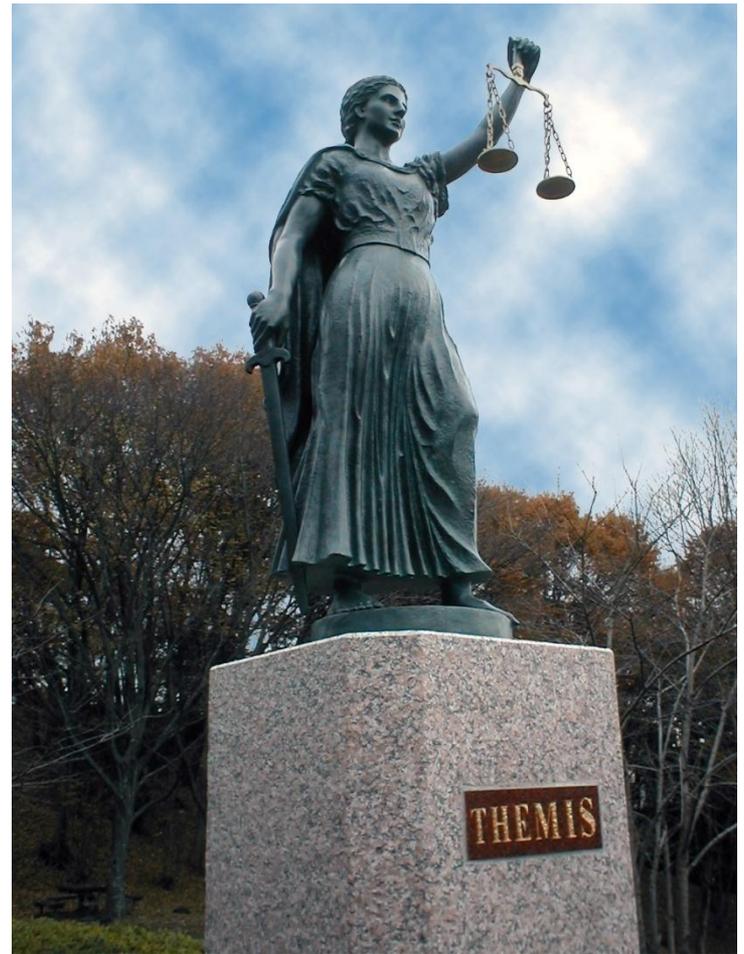


Another example

“In the 1940s some doctors fell under the misapprehension that curare was a general anaesthetic and they administered it as such for major surgery. 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” (Dennett, *Brainstorms*, 209).

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.



Hermeneutic injustice: patient interpretation lacks recognition

- Illness experience not easily understood; difficult to communicate
- Patient *interpretations* unrecognised and ignored
- Patient interpretations recognised but excluded from epistemic consideration (e.g. by not being sought, respected, included in policy, etc.)
- Patient interpretations considered but judged irrelevant, insufficiently articulate, etc.
- Patient interpretations considered as relevant and articulate but subordinate to epistemic authority of healthcare professionals

Hermeneutic justice

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Epistemic privilege

- Healthcare professionals are seen as epistemically privileged by virtue of their
 - training
 - Expertise
 - third-person psychology ('objectivity')

They have the power to decide which testimonies and interpretations to act upon

Epistemic privilege can be warranted or unwarranted

Epistemic privilege

- Both healthcare professionals and ill persons are epistemically privileged
- But only the healthcare professional's epistemic status 'really matters' in health practice and policy (is this changing?)
- Priority, power and reciprocity: asymmetrical relationships between different groups
- An implicit hierarchy
- Many healthcare professionals would like to spend more time taking seriously patients testimonies, but cannot because of resource pressures

Individual interactions add up

Some 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 a way that *structurally disables* certain testimonial and hermeneutical activities

A remedy: patient toolkit

- Aimed at helping patients think about their illness experience and articulate it
- Helps to make sense of a confusing set of experiences, trauma, loss and grief
- Helps articulate the impact of illness on one's life as a whole



Conclusion

- Epistemic injustice appears in many domains, not just healthcare
- But healthcare particularly important
- Importance of hearing patient voices
- But also of thinking of patient experience as embodied

