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# Representing Epistemic Injustice

Posted on [May 6, 2021](#) by [Chris Pak](#)

Blog by Sarah Marie Graye

It is said that knowledge is power. So what happens when the knowledge of your own body is ignored or dismissed?



This is how I felt when I was told I had asthma and I *knew* something else was going on.

Eventually, I ended up in hospital having emergency surgery for a tension pneumothorax (collapsed lung), which turned out to be just the latest of many. The damaged section of lung that was removed was biopsied and the histopathology report gave me a diagnosis of “emphysema with focal collapse and fibrosis”.

So not asthma.

The reasoning behind my initial misdiagnosis (and delayed correct diagnosis) was that collapsed lungs are rare in females. This is not the case. While a pneumothorax is more common in men, they are not a common diagnosis in either gender (Gupta et al, 2000: 666).

When I complained about this to other sick people (because when you’re sick, you get to meet *a lot* of other sick people), I discovered my situation was far from unique. I met many people who’d had their beliefs about their own bodies dismissed by specialists who assumed they knew better.

This experience has a name: epistemic injustice.

From a health perspective, epistemic injustice is where “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” (Carel & Kidd, 2014: 529). Much of the research in this area has focused on how those who are not part of the dominant group (i.e. white cis males) experience health stigma and substandard healthcare (Buchman et al, 2017: 37). Pozo & Rich (2021: 90) discovered the health testimonies of black patients were not being taken seriously, whereas Buchman et al (2017: 37) found that both females and the elderly were amongst the groups reported to consistently receive a lower standard of healthcare.

Even in the media, there are many examples of epistemic injustice: black tennis star Serena Williams’ brush with death while giving birth; the blanket use of “do not resuscitate” orders on elderly patients with Covid in England; and heart attacks being missed in women because of the standard symptom list being based on how men experience cardiac arrest.

Given the problems mentioned above, it becomes clear that epistemic injustice results in a lack of access to healthcare even when people *superficially* have access: they get to see the doctor, but they don’t get the healthcare they need.

One of the areas where epistemic injustice research has been focused is “pain bias”, which sees only young white cis men being treated specifically for the pain they go to their doctor about, while other groups are treated differently. There are “major inequities in the prevalence, treatment, and outcomes for chronic pain across race, ethnicity, gender, and class” (Buchman et al, 2017: 31).

Although my health issues resulted in surgery, my delayed diagnosis meant that I lived with unexplained sharp chest pains for seven years: pain that would probably have been diagnosed earlier if I were male.

As part of my healing process, I have written poetry about my experiences of epistemic injustice. And I wish to share with you a poem that attempts to reveal the various ways people experience pain bias.

### ***Pain Bias***

*“I’m in pain,” you tell the doctor  
but he doesn’t believe  
You.*

*You’re not a  
White  
Cis  
Male  
in your  
Thirties.*

*You’re a woman in your  
Early twenties  
and your doctor knows that a  
Female  
of your age is probably  
Emotional.*

*So you're sent away with anti-depressants.  
(Not the painkillers you hoped for.)*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You're a woman in your  
Mid-forties  
and your doctor knows that a  
Female  
of your age is probably  
Hormonal.*

*So your doctor gives you a leaflet about HRT.  
(Not the painkillers you hoped for.)*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You're a cis male in your thirties  
but you're  
Black*

*and your doctor knows that  
Black people  
don't suffer pain as much as  
White people.*

*So he sends you home with  
Nothing  
and tells you to come back if it  
Gets  
Worse.  
(And you don't get the painkillers you hoped for.)*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You're a white male in your thirties  
but you're  
Gay  
and your doctor knows that  
Homosexual men are prone to a  
Disease  
that others are not.*

*So he sends you for  
Blood tests.  
(And you don't get the painkillers you hoped for.)*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You're a white cis male  
but you're in your  
Eighties  
your hearing isn't what it was  
you simply need him to talk  
Louder  
but your doctor knows that someone of your  
Age  
is probably  
Confused.*

*So he talks to your carer over your head  
and you never  
Hear  
what he has to say about  
Your health.*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You're a six-year-old  
Girl  
who is a little  
Precocious  
and can't sit  
Still  
and your doctor knows that a  
Child  
of your age is probably eating too much  
Sugar.*

*So, your mum is given  
Diet advice.  
No  
More  
Sweets.  
(And not the painkillers you both hoped for.)*

*"I'm in pain," you tell the doctor  
but he doesn't believe  
You.*

*You have  
Bipolar  
and your doctor knows those with a  
Mental health diagnosis could be experiencing  
Psychiatric symptoms.*

*So he increases the dose of your  
Bipolar drugs  
(And you don't get the painkillers you hoped for.)*

*Your doctor?  
He's a  
White*

*Cis  
Male  
in his  
Thirties.*

*He has no idea of his medical  
Privilege.*

*Let's hope you didn't need those  
Painkillers.*

### **So why poetry?**

Poetry uses language in a compact but complex way. It can capture multiple stories in a few words – and through those stories, poetry breeds empathy. It allows us to take one step back from any facts and figures and revisit the situation from the point of view of “the other”. In my poem, I use repetition to share my experience as a common one:

*“I'm in pain,” you tell the doctor  
but he doesn't believe  
You.*

Each time it's “You” – and you are put in the shoes of the next individual. Each time, you don't know who you are now representing, but the repetition underlines that this is a recurring problem that many different groups of people face. The repetition of a lack of painkillers becomes a motif for lack of access.

My poem starts a new line each time a word is significant. These words start with a capital letter and stand alone on a line. This layout makes it easier for certain words to be connected. For example: “black” with “nothing”; “female” with “emotional” and “hormonal”; and “mentally ill” with “psychiatric”.

These words have been specifically chosen to match the circumstances highlighted in epistemic injustice research: the dismissal of pain complaints by black patients as drug-seeking behaviour (Pozo & Rich, 2021: 91); a woman being stitched up without the use of anaesthetic after giving birth (Carel & Kidd, 2014: 529); and a brain haemorrhage being missed in a patient with a psychiatric history (ibid: 534).

Research in the area of epistemic injustice and healthcare is vitally important because “ill people are more vulnerable to testimonial injustice [than other groups] because they are often regarded as cognitively unreliable, emotionally compromised, or existentially unstable in ways that render their testimonies and interpretations suspect” (ibid: 530).

Until epistemic injustice is eradicated from healthcare, marginalised and minority groups will continue to suffer pain – and other symptoms – unnecessarily.

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