

How do people who suffer chronic breathlessness experience epistemic injustice?

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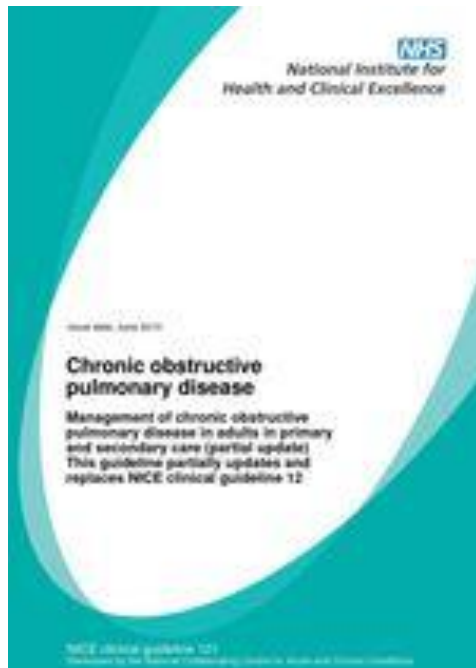
Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word

Miranda Fricker (2007)

“So it’s gradually, little things were in my head but not enough to go to the doctor. You can’t go to the doctor and say “I can’t dance.” It’s a strange thing to say to the doctor.”

Gysels and Higginson (J. Pain and Symptom Management, 2008)

Is a qualitative perspective missing from COPD guidelines?



NICE

National Institute for
Health and Care Excellence

THE LANCET Respiratory Medicine

Megan Wainwright and Jane Macnaughton

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What's in a name?



Hermeneutical injustice occurs ...
when a gap in collective interpretive
resources puts someone at an unfair
disadvantage when it comes to making
sense of their social experiences

Miranda Fricker (2007)

SATS
Breathless
Wheeze
Alveolitis
Nebuliser
Dyspnoea
Embolism
Cancer
Pneumothorax
Pneumonia
Infection
Oxygen
Obstruction
Exacerbation
Smoking
Inhaler
Emphysema
Pulmonary
PFEVI

How to evoke the experience of breathlessness?

Total breathlessness (Booth, S., et al. 2006)

Chronic refractory breathlessness (Johnson,
Abernethy and Currow, 2012)

Breathlessness (Johnson, Currow and Booth, 2014)

Living a life with breathlessness

The impact of addressing epistemic injustice



References

- Abernethy and Wheeler (2008). Total dyspnoea. *Current Opinion in Supportive and Palliative Care*, 2(2), 110
- Booth, S. and Dudgeon, D. (2006). *Dyspnoea in advanced disease: a guide to clinical management*. OUP.
- Booth, S., et al. (2006). The impact of a breathlessness intervention service (BIS) on the lives of patients with intractable dyspnea: a qualitative phase 1 study. *Palliative & supportive care*, 4(03), 287-293.
- Booth, S., Silvester, S. and Todd, C. (2003). Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. *Pall SuCare*, 1(4), 337.
- Carel, H. (2008). *Illness: The cry of the flesh*. Acumen.
- Carel, H. (2012). Phenomenology as a Resource for Patients. *Journal of Medicine and Philosophy*, 37(2), 96.
- Carel, H. and Kidd, I. J. (2014). Epistemic injustice in healthcare: a philosophical analysis. *Medicine, Health Care and Philosophy*, 1-12.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. OUP.
- Galvin, K. M. and Todres, L. (2012). *Caring and Well-being: A Lifeworld Approach*. Routledge.
- Gysels and Higginson (2008). Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *Journal of pain and symptom management*, 36(5), 451
- Johnson, M. J., Abernethy, A. P. and Currow, D. C. (2012). The evidence base for oxygen for chronic refractory breathlessness: issues, gaps, and a future work plan. *Journal of pain and symptom management*.
- Johnson, M. J., Currow, D. C. and Booth, S. (2014). Prevalence and assessment of breathlessness in the clinical setting. *Expert Review of Respiratory Medicine*, (0), 1-11.
- Saunders, C. (1963). The treatment of intractable pain in terminal cancer. *Proceedings of the Royal Society of Medicine*, 56, 195.
- Wainwright, M. and Macnaughton, J. (2013). Is a qualitative perspective missing from COPD guidelines? *The Lancet Respiratory Medicine*, 1(6), 441-442.



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