

How medical humanities can help challenge ableism and expand inclusion in healthcare

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Disability
Matters

Mentions: eugenics, medical violence, misogyny, ableism

Aims for today

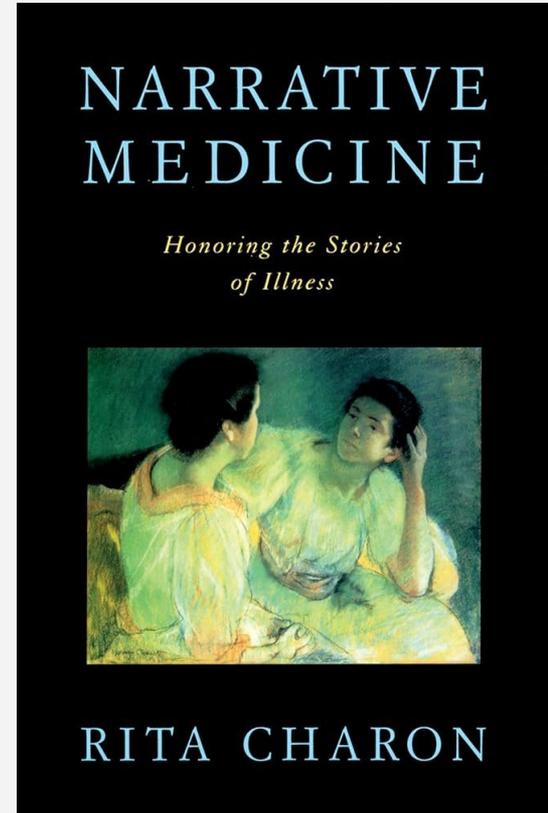
- To learn what is medical humanities is
- To develop an understanding of ableism in medicine and healthcare
- To explore how dialogue between medical humanities and disability studies can expand inclusion and health justice

What is medical humanities?

- Aim to rehumanise medicine and medical education
- Cultivates empathy, compassion, communication and interpersonal skills
- Taught as part of medical curriculum, postgraduate course
- Brings together arts, literature, philosophy, social science
- Key areas of research: Narrative medicine, history of medicine, medical ethics, illness narratives, medical anthropology, philosophy of medicine

Narrative Medicine

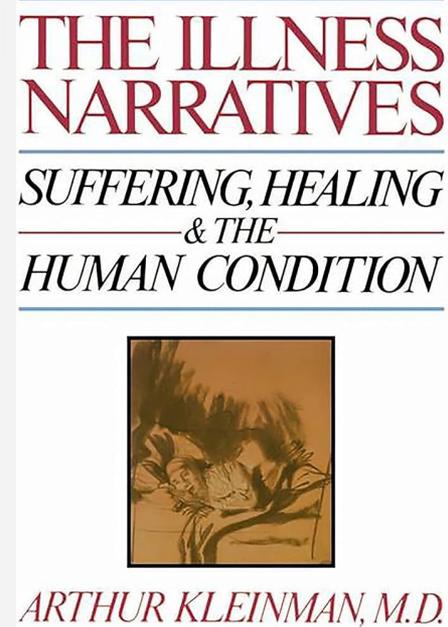
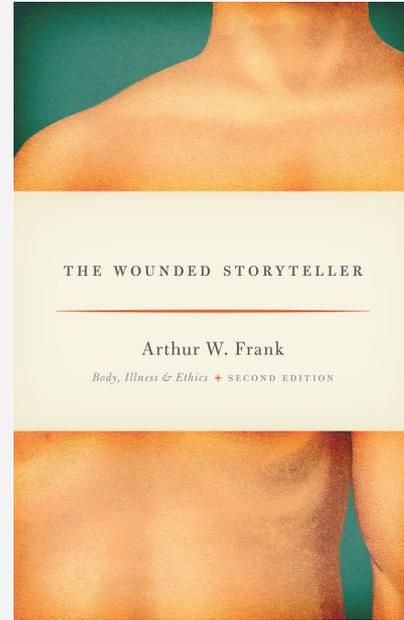
- Developed by Rita Charon, MD and PhD in literary studies
- Influenced by narrative therapy and relational psychotherapy
- Close reading and New Criticism
- Self-reflection and self-evaluation using narrative writing
- Attentive listening, bearing witness
- Narrative humility



Time and again, in the office getting to know a new patient, I have the remarkable and identifiable experience of “tuning in,” of letting what is being said— usually some form of account of illness— wash over me and wash into me. I submit to it, I relax my vigilance regarding the clinical duties that bristle around any new recitation of illness (the frantic search in the mind for the things to look for in a particular disease, the humiliating ignorance of a medication the patient might name, the anxiety to hear about a thorny symptom) to simply absorb all that is being made manifest.

Illness narratives

- Representations of experience of illness and medical treatment
- Narrativisation as therapeutic practice
- Moral lessons in suffering and the human condition
- Fellowship of the sick



From left: Arthur Frank's *The Wounded Storyteller* and Arthur Kleinman's *The Illness Narratives*

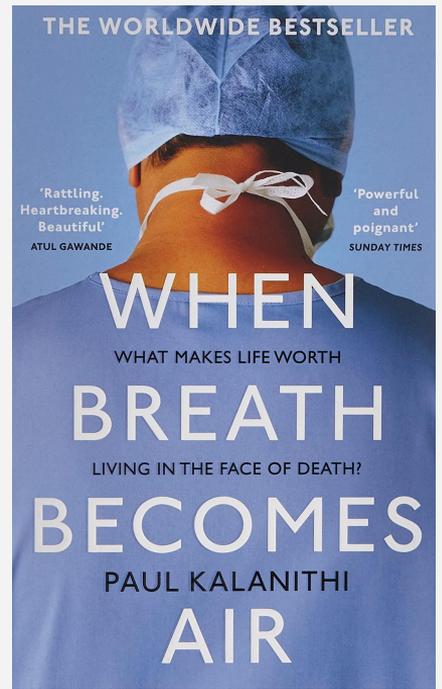
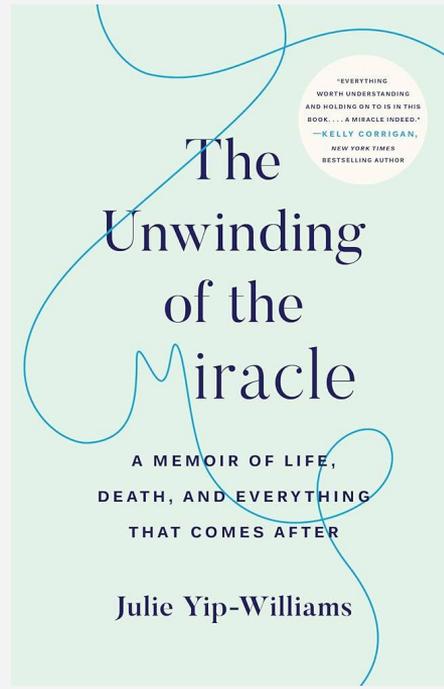
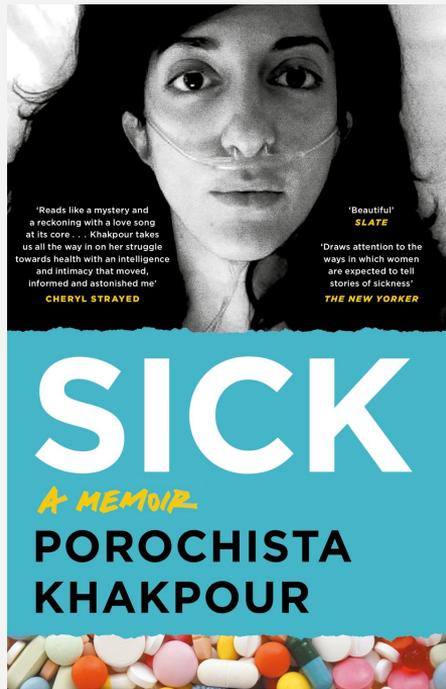
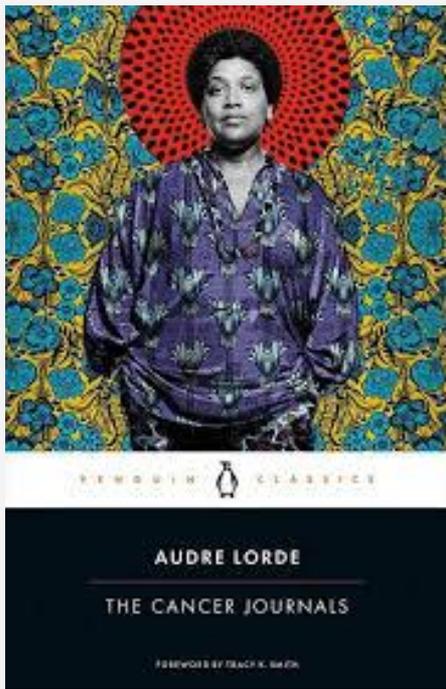
Illness experience

Pain vs suffering

- Modern medicine treats physical pain but not existential and social suffering
- Inability to articulate pain causes suffering

Illness vs disease

- Disease located in the body
- Illness as experienced by person's life and social worlds



Book covers of memoirs. From left: *The Cancer Journals* by Audre Lorde; *Sick* by Prochista Khakpour; *The Unwinding of the Miracle* by Julie Yip-Williams; *When Breath Becomes Air* by Paul Kalanithi.

Disability studies and medical humanities

- Medicine's historical and ongoing complicity in eugenics
- Medical model of disability still dominates
- Alliance with medicine makes it hard to criticise ableism in medicine
- Recent developments in critical medical humanities call for engagements with queer studies, feminist studies, disability studies and postcolonial studies
- But still lack of awareness of ableism in medical humanities itself

MEDICAL HUMANITIES

DISABILITY STUDIES

Arts as therapy

Concerned with
health and
disability

Disability activism

Medical model

Representations
of pain, disease,
illness

Social model

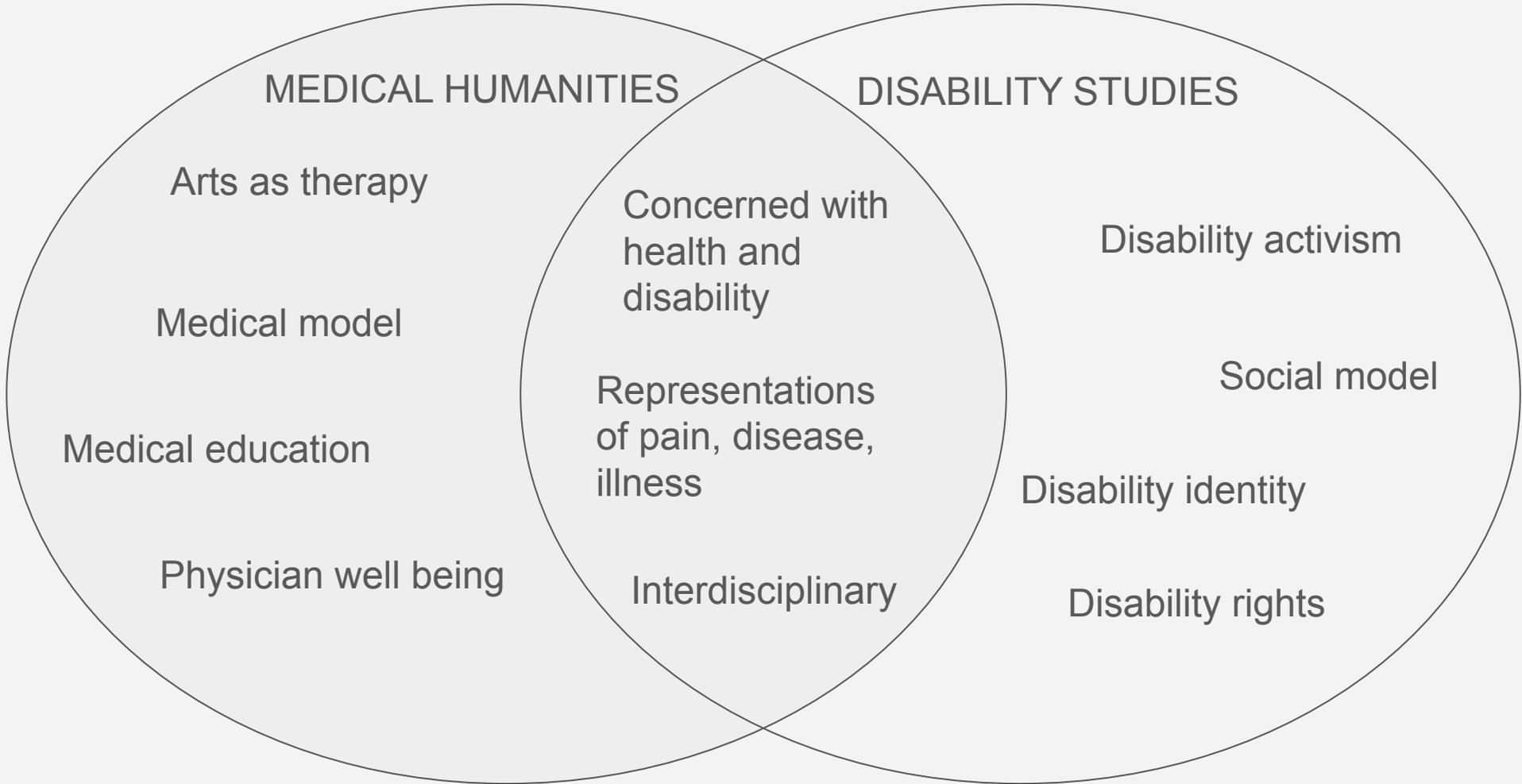
Medical education

Disability identity

Physician well being

Interdisciplinary

Disability rights

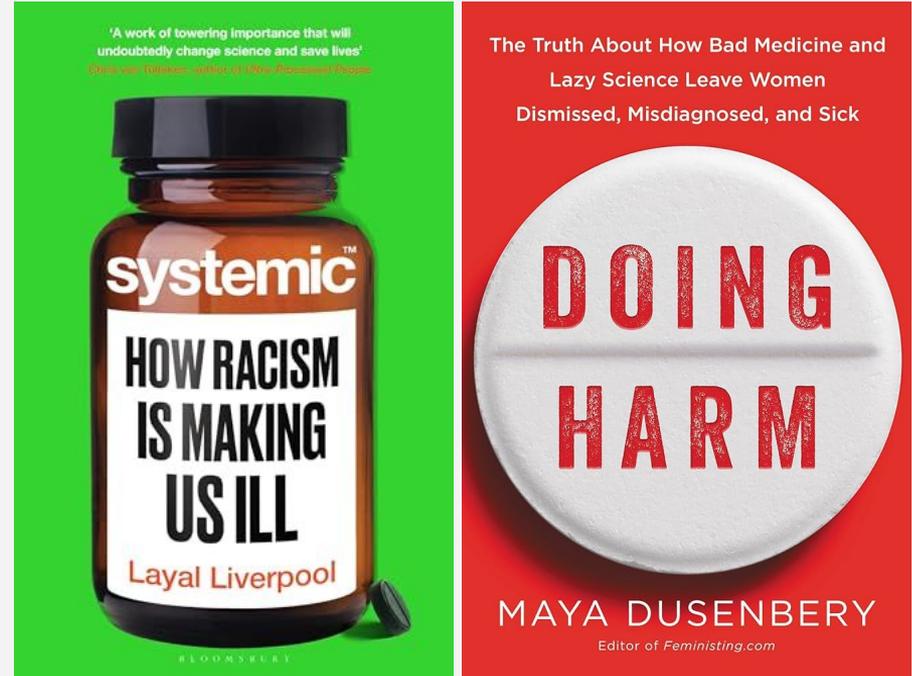


Barriers to healthcare

- **Architectural/physical**
 - Inaccessible facilities, equipment, buildings
 - E.g. no wheelchair access, no height adjustable examination beds, no automatic doors
- **Social/attitudinal**
 - Ableism from staff and doctors, intrusive questions and assumptions
 - E.g. condescending attitude, talks to accompanying family/partner instead
- **Structural**
 - Lack of long-term sustainable care and personalised support
 - E.g. shortage of care workers, inaccessible applications for benefits

Intersectionality

- Medical ableism intersecting with racism, sexism, ageism, trans/homophobia, religious and class discrimination
- Structural inequalities in access to healthcare
- Biases in medicine and clinical research



From left: Loyal Liverpool's *Systemic: How Racism is Making Us Ill* and Maya's Dusenbery's *Doing Harm*

Missing Billion presents: Dis-Inspirational Quotes by Women with Disabilities

I WILL SURVIVE!
If the healthcare
system doesn't
KILL ME FIRST

Fact: Women living with disabilities receive poor treatment 2x more often than women without disabilities (Source: Missing Billion Initiative)

Missing Billion presents: Dis-Inspirational Quotes by Women with Disabilities

Life is short.
Mine is 25%
shorter.

Fact: Women with disabilities have 10-20 years shorter life expectancy compared to women without disabilities (Source: Missing Billion Initiative)

Posters by *The Missing Billion* DisInspiration campaign. LEFT: I will survive! If the healthcare system doesn't kill me first. RIGHT: Life is short. Mine is 25% shorter.

<https://www.instagram.com/disinspirationalquotes/>

Health inequities for women with disabilities

- Routine procedures like smear tests, mammograms are frequently inaccessible, leading to missed early diagnoses and delayed treatment
- Modern medical equipment are not designed for female bodies or disabled bodies
- Lack of disability awareness and training in medical staff
- Paternalistic attitude towards disabled women undermining autonomy and agency
- Assumptions about disabled people's sexuality denying access to sexual health and fertility services
- Gender inequality - women expected to still be caring for others even if ill

Anti-ableist medical humanities

1. Disabled leaders

- Cultivate disability literacy

2. Intersectional identities

- Disability politics of identity and access to healthcare

3. Disabled knowledges

- Foster epistemic humility

4. Decentering the western medical gaze

- Local health priorities and contexts

Thank you!

For more information and updates, visit:

<https://www.sheffield.ac.uk/ihuman/disability-matters>

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