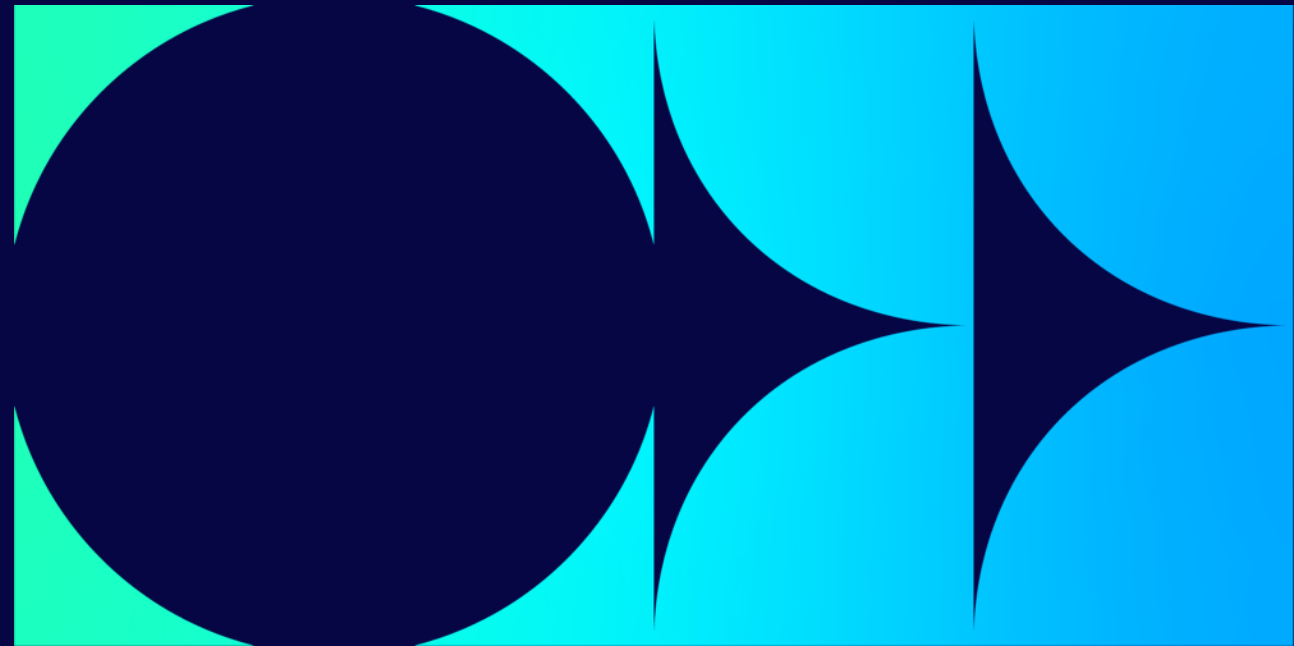


Why is uncovering/discovering lived experience in mental health research so difficult?

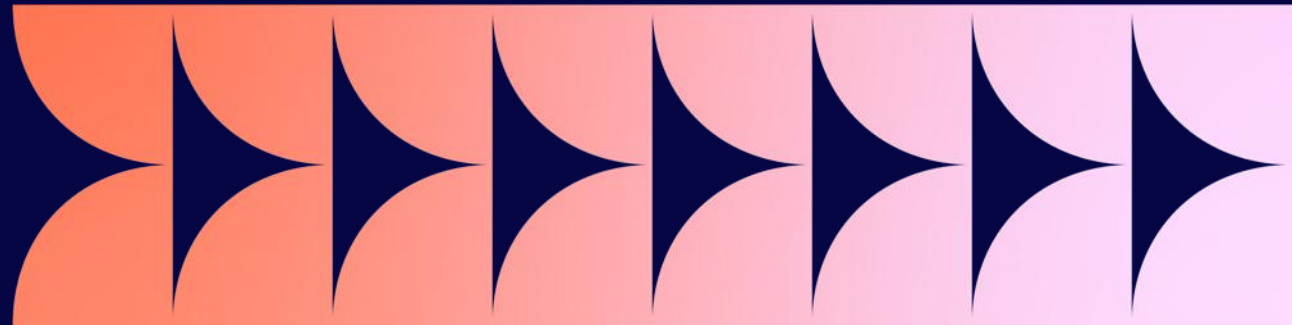
Rajvinder Samra

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Content note:
light themes of suicidality, depression
psychiatric hospitalisation
Borderline personality disorder



About me

- Developed mental health problems in adolescence (12 yo+)
- Repeated admissions to in-patient settings 18-23 years
- Uni transition at 18 ☹️
- Community-based care from 23 to now
- BSc, MSc, and PhD in Applied Psychology
- → Mentalisation-based Treatment (2021-2025)
- PD not treatable (2002) to treatable (2022) in NHS.



3 different thinkers ideas about this topic

- Miranda Fricker
- Jijian Voronka
- Me



Miranda Fricker: Epistemic Injustice

- Miranda Fricker (2007) Epistemic Injustice: Power and the ethics of knowing.
- Epistemic injustice is ignoring the contribution of people and communities based on their social location (e.g. women).
- **Testimonial injustice** – silencing, ignoring, dismissing, discrediting their accounts often based on perceptions of trustworthiness or credibility.
- **Hermeneutical injustice** – denying collective resources for meaning making.
- Sexual harassment
- Postpartum depression (MH hard)

Voronka: Big concepts

- **Jijian Voronka (2016) Mad and disability studies.
- Peer workers
- “The Politics of ‘People with **Lived Experience**’: Experiential Authority and the Risks of Strategic Essentialism”
- ‘**Lived Experience**’ – Self-reflective awareness (reflexive), practical, interactional knowing, situational and embodied awareness → Part of knowledge

More big concepts: Experiential authority

- “The Politics of ‘People with Lived Experience’: **Experiential Authority** and the Risks of Strategic Essentialism”
- **Experiential authority** – whose experience is relevant, important and matters
- Working in mad spaces ~ too professional vs too mad.
- To have authority you need to perform the appropriate level of mad experience or in a way that the system finds it useful/acceptable/digestible
- Lose own authenticity to perform, so you have ‘authority’. (MH hard)
- Raj example

More big concepts: Strategic essentialism

- “The Politics of ‘People with Lived Experience’: Experiential Authority and the Risks of **Strategic Essentialism**”
- **Strategic Essentialism**– when people with ‘lived experience’ are treated as a single group or uniform group.
- Groups people together that may not share things in common
- Obscures race, gender and class inequalities that contribute to mental health problems
- Can promote tick box exercise towards inclusion of PWLE
- Erase differences between mental health differences – something universal about PWLE group? (MH hard)

One of my problems for MH: ontological

- Mental ill-health diagnoses are an **ontological** categorisation (Kecmanović, 1983).
- Ontological – relating to reality or social reality
- MH condition relates to emotions, senses, perceptions and interactions with reality...
- Raj example: BPD/EUPD
- How to deal with the problem that knowledge is sought from someone who might be deemed to be ontologically different?
- **Testimonial injustice** –dismissing/discrediting their accounts often based on perceptions of trustworthiness or credibility. (MH hard)

Another problem I have with MH research: Not knowing

- Systematic review of 35 international studies found 45 per cent of patients in psychiatric settings lacked capacity.
- Even if it relates to making a decision, it is still about an 'impairment' or 'disturbance' in one's mind or brain (England & Wales, 2005).
- Mixed messages about people being knowers and treated as not knowing.
- Research participants - confusing 😞

Another problem I have with MH research: Assumption of goodness and knowledge gathering

- Goodness of knowledge accumulation - extraction?
- Hierarchies of power in knowledge – studies not attracting racialised minorities (20 years of UK mad studies).
- Amplifying exclusion?

Another problem I have with MH research: Responsibility and Blame for One's Distress Experiences

- Individuals are responsible for managing their physical and mental health -Responsibilization (Foucault, 1977; Rose, 1999).
- Transgressions are personal failures.
- What happened to you, but also what you did.
- Childhood trauma and mental ill-health in adulthood.
- Sharing adult experiences may be shameful or guilt inducing, etc.
- Raj example
- **BUT** different temporalities to awareness and understanding of traumatic experiences (MH hard)

Directions for resolving problems...

- Exploring lived experience as lived **realities** and knowledge
- Ontological: Reality as wrong, different & changing
- Cross-sectional interviews → develop more **ongoing dynamic** methods for capturing lived realities.
- Developing nuanced ethics around **ongoing involvement** (cooperative inquiry?)

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Thank you!



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