

Introducing Critical Disability Studies: Indian Contexts, Global Perspectives

Research Orientation: Sensitive Topics, Vulnerability and Power

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Aims of today's session

- Explore what makes research 'sensitive'
- Think about what we mean by 'vulnerability' and power in research
- Think about ways to conduct sensitive research ethically
- Critically engage with the concept of sensitivity, vulnerability and power
- Reflect on our own research practices, positionality, reflexivity

**What do you think
'sensitive research'
might be?**



What is sensitive research?

There is no one definition of "sensitive" research: social context, cultural norms and values.

McCosker et al (2001) identify three different types of sensitivity:

1. Topics that are private, stressful, or sacred (e.g. sexuality or death)
2. Issues that if revealed might cause stigmatisation or fear, (e.g. research that may reveal illegal behaviour).
3. Presence of a political threat where researchers may study areas subject to controversy or social conflict. Sensitivities can emerge in lots of other areas of social research, however, (e.g. race and ethnicity) (Caballero, 2009; Winddance Twine and Warren 2000).

The sensitive nature of the research may not be apparent at the start of the research, OR sometimes a subject presumed to be sensitive, actually isn't.

In some cases sensitive research "... poses a substantial threat to those who are or have been involved." (Lee 1993: 4)

The nature of risk to participants in the research process (including researchers/supervisors) is often varied (McCosker et al, 2001) .

Institutional Definitions of 'Sensitive' Topics and Potentially 'Vulnerable' Participants

The following statements are designed to highlight whether your research involves any particularly vulnerable participants or addresses any highly sensitive topics. You should consider how the potential risks posed by these participants and/or topics can be mitigated

Highly Sensitive Topics

This includes, but is not restricted to:

- 'race' or ethnicity
- political opinion
- trade union membership
- religious, spiritual or other beliefs
- physical or mental health conditions
- sexual orientation or sex life
- abuse (child, adult)
- nudity and the body
- criminal or illegal activities
- political asylum
- conflict situations
- personal violence
- personal finances
- genetics
- biometrics (where this is used to identify someone)

Potentially Vulnerable Participants

This includes, but is not restricted to:

- a. People whose competence to exercise informed consent is in doubt, such as:
 - infants and children under 18 years of age
 - people who lack mental capacity
 - people who suffer from psychiatric or personality disorders, including those conditions in which capacity to consent may fluctuate
 - people who may have only a basic or elementary knowledge of the language in which the research is conducted
- b. People who may socially not be in a position to exercise unfettered informed consent, such as:
 - people who depend on the protection of, or are controlled and influenced by, research gatekeepers (e.g. school pupils, children and young people in care, members of the armed forces, young offenders, prisoners, asylum seekers, organisational employees)
 - family members of the researcher(s)
 - in general, people who appear to feel they have no real choice on whether or not to participate
- c. People whose circumstances may unduly influence their decisions to consent, such as:
 - people with disabilities
 - people who are frail or in poor health
 - relatives and friends of participants considered to be vulnerable
 - people who feel that participation will result in access to better treatment and/or support for them or others
 - people who anticipate any other perceived benefits of participation
 - people who, by participating in research, can obtain perceived and/or real benefits to which they otherwise would not have access

Doing sensitive research

Researchers should not shy away from conducting sensitive research but simply engage with it in a sensitive way (Reed, 2019).

In order to do so, we need to critically engage with the concepts of 'sensitivity' and 'vulnerability'.

**Critically engaging with
concepts of ‘sensitivity’
and ‘vulnerability’**

**Who would you
consider 'vulnerable'?**



‘It is important to treat them not just as data sources but as human beings with their own distinctive individuality and autonomy’ (Smythe and Murray, 2000: 317)

Rethinking 'vulnerability'

- Vulnerability as individual characteristic vs structural/relational (Minatti & Nicole-Berva, 2025)
- Deficit-based understanding vs Rights based understanding
- Protection focused vs Agency focused
- Who is the 'expert': disabled people as knowledge creators

Nothing about us without us is for us!

- How do our definitions/conceptualisation of 'vulnerability' shape our research approaches?
- Researching sensitively as one response to researching 'vulnerabilised' participants

Doing research sensitively matters for *all* stages of the research process...

Framing research and research questions: who decides what the question is? How can they be sensitively articulated? For whom?

Recruitment: framing recruitment and sampling strategies; equity, diversity and inclusion strategies for involvement; turning people away and responsibility for 'non' participants'; self-identification processes; dangers of over promising

Data collection: sensitivity and suitability of methods; conduct of researcher; ways to 'gather' or 'capture' data; storing data; destroying data; time, place and location; follow up and communication after the 'event'; transcription and listening (Melrose, 2002; Reed and Towers, 2021);

Doing research sensitively matters for *all* stages of the research process...

Analysis: reading, feeling and absorbing sensitive data and participants stories - carrying, remembering, ghosts and haunting (Smart, 2014) affect within archives (Steedman, 2001) and sensitivity of secondary data analysis (Jackson et al. 2013)

Writing: sensitively crafting how we write about or with others and topics


Dissemination: how do we share our research; when; where; what format and medium is sensitive and appropriate to the area? What happens when research 'ends'? Who reads it? Who hears it? How will it affect them?

Archiving and Open Data: how do we respond to the open science movement in ways that are respectful of participants' data?

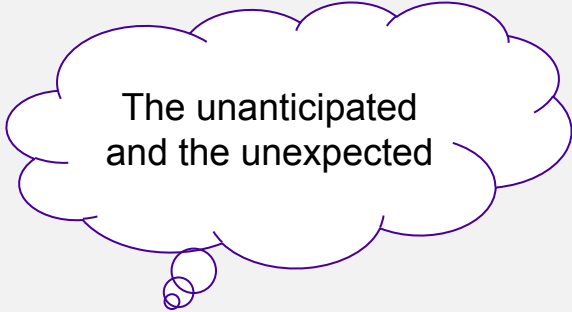
What else might we count as 'sensitive'?



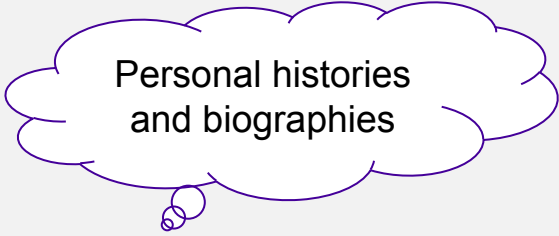
Topics



Moments in
time



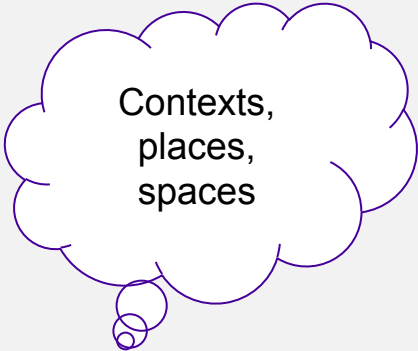
The unanticipated
and the unexpected




Personal histories
and biographies



Ethically
important
moments



Contexts,
places,
spaces



Emotional
labour and
demands of
research

Ethics

**What's the first word
or thought you have
when you hear the
word 'ethics'?**



Research ethics refer to rules, regulations, and principles that govern how we do research that aim to protect the 'dignity, rights, and welfare of research participants' (WHO, 2025).

Institutional/Procedural Ethics - Historical Context

- Narrative of the origin of 'institutional' (Euro-Western) ethics: Nuremberg Code, 1947; The Declaration of Helsinki, 1964
- Sensationalist lens on high-profile cases such as Stanley Milgram's obedience experiment, 1961, Laud Humphreys' 1970 book *The Tearoom Trade*, Philip Zimbardo's Stanford prison experiment, 1971
- Tuskegee Syphilis Study (1932-1972): while and after Nuremberg Code (1947), Helsinki Declaration (1964)
- Response: codes, guidelines, Research Ethics Committees/Institutional Review Boards (RECs/IRBs), form- universal, value-free, free of politics, do no harm
- RECs: top-down, unaccountable, bureaucratic, focus on institutional protection (Kara, 2018)

Contemporary Research Ethics

- Key principle of 'do no harm'
- Bureaucratic processes and research protocols
- Key areas we consider in these processes include:
 - Anonymity and confidentiality
 - Consent and right to withdraw
 - Deception
 - Distress
 - Safeguarding
- Ethical grey areas/variation in standards (e.g., disability research – pathologising approaches and dehumanising language persist and receive ethical approval from institutions).

Ethics beyond 'do no harm'

- Difficulty of emergent nature of research in fitting into the institutional process (Flicker & Guta, 2008; Manzo & Brightbill, 2007)
- Messiness, creativity, flexibility: real world/everyday ethics
- Indigenous research ethics: relational accountability, communality of knowledge, reciprocity, benefit sharing: journey as important as destination

Relational ethics involves researchers acting with their 'hearts and minds', acknowledging personal bonds, respect for others and maintaining relationships ([Ellis, 2007](#))

Ethics and Equity, Diversity and Inclusion



A series of videos outlining the opportunities & challenges of doing inclusive & ethical research, based on reflections from participatory & collaborative research projects across the University



Where are 'we' in the research?

**Thinking about positionality,
reflexivity and insider/outsider
perspectives**

Thinking through positionality, reflexivity and our status

Reflexivity (oversimplified) = critical reflection plus conscious action (Freire, 1972)

Not Insider/Outsider, An In-betweener: a dynamic continuum (Chhabra, 2020)

Having an affiliation with the community under investigation (Coghlan and Brannick, 2005)

‘embrace and explore the complexity and richness of the space between’ (Dwyer and Buckle, 2009: 62)

Neither in nor out but alongside participants (Rowling, 1999)

Question how your experiences frame the research lens (Pearce, 2010)

Some guiding questions/reflection points for researchers

- What is my relationship with this community, why am I doing this work, who does it serve?
- What assumptions do I bring about disabled lives?
- What privileges do I carry into this space?
- How can I centre disabled people's expertise?
- What insider knowledge do I bring?
- What are my responsibilities to the disability community, not just now but also to the future generations?
- How will I make myself accountable to the community who is granting me access to their knowledge and experience?
- Who is still missing from these conversations?
- How will this research contribute to disability justice?

Power and Research with “Vulnerable” Participants

Thinking about power and your experiences as students, in what ways do you as students have power, and to what extent does the teacher have power?



Power and research

- Given (2008) distinguishes between:
 - Power to vs Power over
 - Organisational, individual, and cultural power
- Inherent power imbalances in research (Kelly 2010)
 - Researcher chooses the questions, asks the questions, decides what happens with the data
 - Power imbalances specific to researching people deemed “vulnerable” and marginalised
 - Power relationships involving gender, race, ethnicity, dis(ability), class, caste, education, geographies, contexts etc.
- Power and context
 - E.g., healthcare settings (Kelly 2010), schools, prisons, etc.

Attempting to disrupt power imbalances in research

- Co-production and transformative, participatory approaches (Freire, 1972)
- Creative methods, inclusive methods, dynamic methods
- Ethical approval processes - bureaucratic responses
- Fully informed consent
- Consultees for people who are deemed to lack capacity to consent
- Assent processes with children
- Reflexivity and taking a self critical approach
- Epistemological approaches informed by feminist, post colonial, and critical theories
- Open questions, “giving voice”

Not a panacea though...

'Giving' voice and empowering participants

- “Encouraging participants to speak in their own ways can, at times, shift power in interviews; although relations of power are never equal, the disparity can be diminished. (Riessman, 2008, p. 24)
- But ultimately, “we cannot give voice” as we “do not have direct access to another’s experience. We deal with ambiguous representations of it – talk, text, interaction and interpretation” (Riessman, 1993:8)
- Being subjective and interpretative is unavoidable – this applies to both researcher and researched (Hollway & Jefferson, 2013). We are not neutral and objective observers, participants are not neutral, objective and perfect reportees.

Reflection time!

- How do our definitions/conceptualisation of 'vulnerability' shape our research approaches?
- As soon-to-be student researchers, what responsibilities do you have when thinking about these ideas of power, 'vulnerability', and ethics in research?
- What are the key ethical considerations you need to think about when doing research with 'minoritised' and 'vulnerabilised' people?



Thank you!

Do you have any questions?

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