

Ethics in Social Sciences Research: Gender Perspective

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Outline

- Belmont principles
- Inclusive recruitment
- 'How to' guide
- Special topics

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Belmont Principles

Lays out three basic principles relevant to research

- Respect for Persons. — Respect for persons incorporates at least two ethical convictions: **first**, that individuals should be treated as autonomous agents, and **second**, that persons with diminished autonomy are entitled to protection.
- The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.
 - How do we think of using prisoners in research? Respecting autonomy or needing protection?

Belmont Principles

- Beneficence — Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being.
 - Two general rules have been formulated as complementary expressions of beneficent actions in this sense:
 - (1) *do not harm*: Research must not cause harm to the participants in particular and to people in general (*stop harmful medication; refuse ineffective treatment, do not ask questions on experience of violence in the presence of others/family*).
 - (2) *maximize possible benefits and minimize possible harms*.

Belmont Principles

- Justice — Who ought to receive the benefits of research and bear its burdens?
 - An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly
 - Selection of research subjects; are some classes are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied
 - Fair selection
 - Guard against coercion (threat of harm) or undue influence (which could be??)

Justice: exploitation, exclusion

- Exploitation: certain historical basis for it
 - Nazi camps, men perceived to be gay were used in harrowing medical experiments, supposedly to determine cause of homosexuality to prevent it in the future
 - Laud Humphreys, sociologist (1960s) launched the “Tearoom Trade” to observe the sexual cruising behaviour in men’s public restrooms
 - Recorded licence plates of men who were engaging in same-sex cruising and visited their homes for a follow up survey
 - Concerns with this research? Note, homosexuality was criminalised in the US at that time☹
 - Sims (father of modern gynaecology) and his experiments with Black enslaved women

Inclusive recruitment

- *Ensure there is diversity in participants across gender identities, under represented and marginalised groups.*
 - *Why is this important?*
- Relates to questions of justice (fair selection), equal access to knowledge and equity
 - Some groups are historically underrepresented (transgender)
 - Denies groups an equal opportunity to participate in and benefit from research and scientific knowledge
 - Researchers should not reinforce existing social cleavages and structural inequalities
 - Violates the integrity of research

Inclusive recruitment

- *Ensure there is diversity in participants across gender identities, under represented and marginalised groups.*
 - *Why is this important?*
- External validity (generalizability) is compromised if we include only certain demographic groups
 - Miss out experiences, needs and responses of diverse pop
 - Hinders development of robust and comprehensive knowledge
 - Limits development of effective policies and interventions
- Intersectionality
 - Interaction of multiple social identities (caste, class, religion, region, gender). Avoid oversimplification and recognizes multiple influences

Inclusive recruitment

- *Ensure there is diversity in participants across gender identities, under represented and marginalised groups.*
 - *Why is this important?*
- Clinical trials/medical research
 - Women and other minorities may face unique challenges, specific health disparities, differential response to treatment
 - Medical interventions, diagnostic criteria, and treatment protocols may not adequately account for their needs, potentially leading to suboptimal care
 - Women have lower probability of getting heart attacks (true or false)?
- Safety protocols in auto industry

Inclusive recruitment

- *Ensure there is diversity in participants across gender identities, under represented and marginalised groups.*
 - *Why is this important?*
- Most relevant (in my view),
 - Ethical obligations of researchers to actively work against biases and challenge discrimination in all aspects of research and society
 - Visiblize the invisible
 - Personal responsibility for ethical conduct in research improves trust; increases the likelihood of future research participation by people in that community or at a broader level

Examples

- Agricultural interventions in Sub-Saharan Africa: *His* crop and *her* crop
 - Tobacco planted on women's plots of land to increase her income. But taken over by men as traditionally women plant subsistence crop while men plant cash crop
 - Left women poorer!
 - Lack of involvement of local communities and women led to agricultural investments on women's land being taken over by men.

A 'how to' guide

- Research design
- Study design, field work and data collection

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Research design

- Integrating gender in the research; ensure these perspectives are brought in and thought through adequately
 - How diverse is your team?
- Gender equality as a goal or possible commitment in the research
- Ensure representation that is fair and inclusive for individuals and communities
- Ensure research partners are consulted and are part of the research design; poor rural women feature too often in studies
 - Often there is a power differential among sets of researchers/communities
 - International vs. domestic
 - Researchers vs. civil society/community organisations

Data collection, field work

- Informed consent. Three elements:
 - information
 - comprehension
 - voluntariness

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Informed Consent

- Procedure
 - Brief introduction to the format of the research study
 - Durations: time commitments for participant including both the duration of the research and follow-up, if relevant
 - Risks: Explain and describe any risks that you anticipate. The risks depend upon the nature and type of qualitative intervention, and should be, as usual, tailored to the specific issue and situation
 - Benefits
 - Reimbursements
 - Confidentiality
 - Sharing results
 - Right to refuse or withdraw; emphasize voluntariness
 - Who to contact

Informed Consent

- Two parts: Information sheet & consent form
- Introduction
 - *(Example: I am X, working for the Y organization. I am doing research on the disease malaria which is very common in this country and in this region. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research.*
 - *Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.)*

Informed Consent

- Purpose of research
 - *(Example: Malaria is making many people sick in your community. We want to find ways to stop this from happening. We believe that you can help us by telling us what you know both about malaria and about local health practices in general. We want to learn what people who live or work here know about the causes of malaria and why some people get it. We want to learn about the different ways that people try to stop malaria before someone gets it or before it comes to the community, and how people know when someone has it. We also want to know more about local health practices as it may help us better control malaria)*

Informed Consent

- Type of research intervention
 - *(Example: This research will involve your participation in a group discussion that will take about one and a half hour, and a one-hour interview).*
- Participant selection
 - *(Example: You are being invited to take part in this research because we feel that your experience as a social worker (or as a parent, or as a responsible citizen) can contribute much to our understanding and knowledge of local health practices.)*

Informed Consent

- Voluntary participation
 - *(Example: Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all services you receive at this Centre will continue and nothing will change.*
 - OR
 - *The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.)*
- As Bettina Judd, assistant professor of gender, women and sexuality studies at the University of Washington, points out, consent isn't always about *“whether you can say yes; it's also whether you can say no.”*

Informed Consent

- Compensation
 - Ensure that compensation does not unduly influence participation
 - Gendered angle:
 - Given to participants in a safe place
 - Does not create or worsen intrahousehold tensions
 - Cash or kind? Who will use it?
- Pay attention to power dynamics in local settings
 - Before talking to women, you may need to talk to an elder person in the household and ask for informal consent to interview
 - Women in certain situations can be particularly vulnerable – widows, or daughter-in-law in joint family households

Informed Consent

- Certificate of consent
 - Written
 - Challenges?
 - Verbal
 - Minimal risk, group participation, naturalistic observation, signature could constitute a breach of confidentiality (domestic violence)
- Teach back method when there is low literacy or when the language is different from researchers
 - Ensures aim of the research is comprehended by participants, and they are aware of the voluntariness and freedom to withdraw from the study at any point of time

Other issues

- Interview protocols
 - Same sex enumerator
 - Timings
 - Place of interview; if one needs transport to reach, then it limits access to those who have access to transport and are able to travel
- Who is the respondent, whose perspective is being collected?
How does this impact your results?

Minimizing possible harm (*beneficence*)

- Sensitive questions may trigger tensions in household, can be traumatic for respondent (economic status, assets, decision-making within household, experience of violence)
 - Enumerator training
 - Alternate sets of questions
 - Local counselling services available to participants
- Safety of respondent and team should never be compromised

Privacy during data collection

- Pretty hard to ensure privacy in general, even trickier if talking to a woman. Some ideas that have worked (GAGP study)
 - Dummy questions for other household members
 - Talk to woman at her place of work
 - Keep your supervisors nearby to defuse situations

Adverse events

- Any unfavorable, untoward physical, psychological or social event that occurs during the study period or thereafter, which can reasonably be attributed to the subject's participation in the survey
- Ranges from simple emotional distress to extreme physical pain
- At individual or community level

Common causes of adverse events

- Participant is emotionally disturbed by questions
- Interviewer is disrespectful or insensitive towards participant
- Breach of confidentiality/privacy/anonymity of participant
- Undue pressure on respondents to participate or continue with survey
- Repercussions or fear of repercussions due to participation

Mitigation strategies

- Comprehensive informed consent form
- Provide your or the research group's contact details / provide information of support services
- Depending on subject of survey and context, keep local authorities/professionals informed and armed to take suitable action
 - Local administration
 - Police
 - Doctor
 - Lawyer
 - NGO

Special topics

- Phone surveys
 - Saw a proliferation during Covid
 - Privacy concerns are can be hard
 - Ensure your respondent has privacy
 - Or they are not on a speaker
 - Or Your calls will not put them at a disadvantage
 - If interested in gender-related research, then phone surveys are not ideal as women may not have access to an independent phone for themselves

Special topics

- Big data: the 3 Vs
 - Volume, velocity, variety
 - Large and complex data sets, sometimes being collected in real time
 - Come from many sources, forms and flavours (web searches, internet, chat, email, mobile connections, social media, and so on)
 - Extremely valuable as they contain lot of personal information and thus, also open to risk of misuse
- Data privacy and confidentiality issues
- No informed consent
- Usually not representative, specially of marginalized groups

Online surveys

- No different from regular in person surveys. All guidelines must be adhered to for protection of participants. Often personal and demographic information is collected, so ethical principles and guidelines apply
 - Protection of participants
 - Informed consent
 - Privacy and confidentiality
 - Data handling and storage
 - Avoidance of deception or harm
 - Overall, adherence to ethical guidelines

Acknowledgements & references

- Naureen Bhullar, IRB coordinator, IIMB
- Considering gender in research: an ethics and standards toolkit
<https://cgspace.cgiar.org/bitstream/handle/10568/121973/Toolkit.pdf?sequence=1&isAllowed=y>
- CITI Program Research, Ethics, and Compliance Training:
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