Chapter 5

Ethics, power & privilege, protection of human subjects

- 5.1 Research on humans
- 5.2 Specific ethical issues to consider
- 5.3 Ethics at Micro, Meso, and Macro level
- 5.4 The Practice of science versus the use of science

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5.1 Research on Humans

- **Human Research Subjects vs. Non-Human Research Subjects**
  - Human Subjects:
    - Living individuals that are being researched by either professionals or even students by collecting data through interaction or intervention or collecting data through identifiable private information. Can include deceased individuals and human fetal materials in some states (USDHHS).

  - Non-human Subjects:
    - Objects or entities that researchers manipulate or analyze in the research process. Ex: Clinical notes, buildings, newspapers etc.

5.1 Research on Humans (Continued)

- **<u>Historical Lens</u>**
    - Research has not always followed ethical principle
        - Ex: Case of an 8yo boy exposed to smallpox by scientist Edward Jenner to identify a vaccine in the late 1700s.
        - Ex: The tearoom trade social experiment where Laud Humphreys collected data by representing himself as a ‘watch queen’ without disclosing to his subjects that he was a researcher and then documenting their license plate numbers to later track them for further research.

5.1 Research on Humans (Continued)

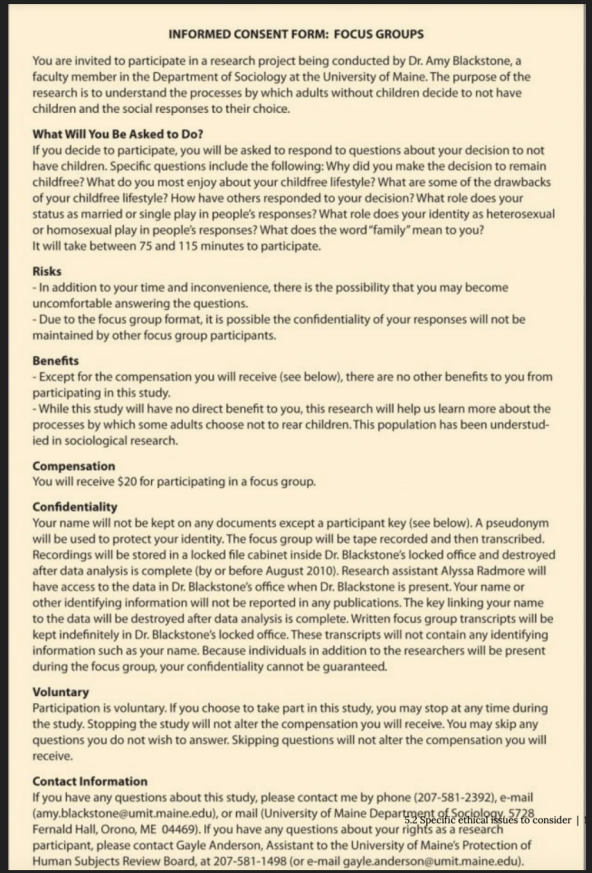
- **Institutional Review Boards (IRBs)**
  - Ensure that all institutions and organizations that receive federal support for research protect the rights and welfare of human research subjects.
  - Members include professionals in areas such as sociology, economics, education, social work communities and include community representatives. Diversity ensures all ethical issues are considered.
  - All researchers, professional and students, are required to submit proposals for review and approval before the research begins.

- **The Three Levels**
  - Exempt Review: (Lowest level) Expose subjects to the least potential harm. Low human subject interaction. Ex: Social work researchers review public data or secondary data - Research by another that has been de-identified by the collector.
  - Expedited Review: (Middle level) Does not have to go before full IRB because subjects are exposed at minimal risk. Studies must be reviewed by a member of the IRB committee. Ex: Social work use of existing medical records gathered for research purposes.
  - Full Board Review: (Highest level) Involves multiple members of the IRB evaluating your proposal. When submitting a proposal, the full board will meet and invite the researcher to discuss and defend the proposal. Can sometimes involve people of vulnerable populations for insight.

5.2 Specific Ethical Issues to Consider

- **Informed Consent:**
    - Subjects must voluntarily agree to participate in a research study while being fully informed of all the risks, benefits, purpose and process of the research.
    - Subjects cannot waive or appear to waive their legal rights.
    - Researchers must explain thor mandatory reporting duties.
    - Researchers must inform subjects they can stop their participation at any point of the process.
    - Social workers are not to act as clinicians. Its best to refer out.
    - Researchers are responsible to explain how they will protect their subjects identity.
    - How, where and for how long data is being collected must be explained.
    - A consent form can wither be signed or a copy can be given to subject
    - Not all subjects are competent or legally able to consent participation.
    - Vulnerable populations such as minors and prisoners or parolees require more complex consent processes

5.2 Specific Ethical Issues to Consider (Continued)



INFORMED CONSENT FORM: FOCUS GROUPS

You are invited to participate in a research project being conducted by Dr. Amy Blackstone, a faculty member in the Department of Sociology at the University of Maine. The purpose of the research is to understand the processes by which adults without children decide to not have children and the social responses to their choice.

What Will You Be Asked to Do?
If you decide to participate, you will be asked to respond to questions about your decision to not have children. Specific questions include the following: Why did you make the decision to remain childfree? What do you most enjoy about your childfree lifestyle? What are some of the drawbacks of your childfree lifestyle? How have others responded to your decision? What role does your status as married or single play in people's responses? What role does your identity as heterosexual or homosexual play in people's responses? What does the word "family" mean to you?
It will take between 75 and 115 minutes to participate.

Risks
- In addition to your time and inconvenience, there is the possibility that you may become uncomfortable answering the questions.
- Due to the focus group format, it is possible the confidentiality of your responses will not be maintained by other focus group participants.

Benefits
- Except for the compensation you will receive (see below), there are no other benefits to you from participating in this study.
- While this study will have no direct benefit to you, this research will help us learn more about the processes by which some adults choose not to rear children. This population has been understudied in sociological research.

Compensation
You will receive $20 for participating in a focus group.

Confidentiality
Your name will not be kept on any documents except a participant key (see below). A pseudonym will be used to protect your identity. The focus group will be tape recorded and then transcribed. Recordings will be stored in a locked file cabinet inside Dr. Blackstone's locked office and destroyed after data analysis is complete (by or before August 2010). Research assistant Alyssa Radmore will have access to the data in Dr. Blackstone's office when Dr. Blackstone is present. Your name or other identifying information will not be reported in any publications. The key linking your name to the data will be destroyed after data analysis is complete. Written focus group transcripts will be kept indefinitely in Dr. Blackstone's locked office. These transcripts will not contain any identifying information such as your name. Because individuals in addition to the researchers will be present during the focus group, your confidentiality cannot be guaranteed.

Voluntary
Participation is voluntary. If you choose to take part in this study, you may stop at any time during the study. Stopping the study will not alter the compensation you will receive. You may skip any questions you do not wish to answer. Skipping questions will not alter the compensation you will receive.

Contact Information
If you have any questions about this study, please contact me by phone (207-581-2392), e-mail (amy.blackstone@umit.maine.edu), or mail (University of Maine Department of Sociology, 5728 Fernald Hall, Orono, ME 04469). If you have any questions about your rights as a research participant, please contact Gayle Anderson, Assistant to the University of Maine's Protection of Human Subjects Review Board, at 207-581-1498 (or e-mail gayle.anderson@umit.maine.edu).

Copy of informed consent form

5.2 Specific Ethical Issues to Consider

- **<u>Anonymity and Confidentiality: Protection of Identities</u>**
  - **Anonymity - The researcher cannot attach the collected data to the identity of the subject bc the identity of the subject is not disclosed.**
  - **Confidentiality - All data collected must be kept between the researcher and subject and never to be disclosed to the public as it pertains to identity.**

Micro level ethical issues in social scientific research

- Consider their own behavior and the rights of individual research participant.
- Ask you self a question as you were the participant at the research
    - Did you behave ethically when researchers allow you to think they were operating electronic shock to other participants other than you.
    - Did you behave ethically when researcher trick you that their research make you second guess on your ability.
- Participants should not be subjected to harm in any way.
- Most importantly, were the right of participants in your study protected.

Meso level ethical issues in social scientific research

- Consider your responsibility to the social work profession.
- Take responsibility and ready to answer questions to target population might have on your experiments
- Researchers should think about their duty to the community.
- Research results should benefit a target population.
- In an research, your study might carry negative label about an target population that you are focusing on.
- Another issue may occur is that it might damage your reputation and their reputation.
- Take into consideration that participants are vulnerable.

Macro level ethical issues in social scientific research

- Take into consideration that did you research relate to the societal level questions of ethnic.
  - Ex: Did the research reach public expectation?
  - Ex: Is your research relate to the current challenges that society are facing.
    - COVID, Immigration, Food Insecurity, and Vaccination
- Researchers should consider the duty, and the expectations of society.
  - Ex: Should vaccination research data be use despite that there no one hundred percent guarantee after 10 of thousands of human experiments?
- Questions to ask yourself:
  - Is your research unethical?
  - Did it bring any benefit to society level or communities?
  - Does my research meet societal expectations of social research?
  - Have you met your social scientific researcher responsibilities?

5.4 The Practice of science versus the use of science

- What ethical principles should researchers follow?
- Honesty is the best policy
    - Based on replication (also informs reliability and validity)
    - What are some examples of research studies that may not be easily replicated
- Awareness and disclosure at the end of a research study

5.4 The Practice of science versus the use of science (continued)

- How exactly should we use science (aside from ethically)

- What are examples of conflict of interests?

- What are the effects of ethical scientific research ?

the end.