

# Ch.5. ETHICS IN SOCIAL WORK RESEARCH

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# Human Research VS. Nonhuman research

- ★ Would it surprise you learn that scientists who conduct research may withhold effective treatments from individuals with diseases? Perhaps it wouldn't surprise you, since you may have heard of the Tuskegee Syphilis Experiment, in which treatments for syphilis were knowingly withheld from African-American participants for decades. Would it surprise you to learn that the practice of withholding treatment continues today? Multiple studies in the developing world continue to use placebo control groups in testing for cancer screenings, cancer treatments, and HIV treatments (Joffe & Miller, 2014).<sup>1</sup> What standards would you use to judge withholding treatment as ethical or unethical? Most importantly, how can you make sure that your study respects the human rights of your participants?



# Human Research Vs Non Human Research

- ★ The earliest documented cases of research using human subjects are of medical vaccination trials (Rothman, 1987). 3 One such case took place in the late 1700s, when scientist Edward Jenner exposed an 8-year-old boy to smallpox in order to identify a vaccine for the devastating disease. Medical research on human subjects continued without much law or policy intervention until the mid-1900s when, at the end of World War II, a number of Nazi doctors and scientists were put on trial for conducting human experimentation during the course of which they tortured and murdered many concentration camp inmates (Faden & Beauchamp, 1986). 4 The trials, conducted in Nuremberg, Germany, resulted in the creation of the Nuremberg Code, a 10-point set of research principles designed to guide doctors and scientists who conduct research on human subjects. Today, the Nuremberg Code guides medical and other research conducted on human subjects, including social scientific research.

# Informed Consent

**Informed consent** is defined as a subject's voluntary agreement to participate in research based on a full understanding of the research and of the possible risks and benefits involved.

- Subjects may neither waive nor even appear to waive any of their legal rights
  - Subjects also cannot release the researcher, sponsor or institution of legal liability
- Explain mandatory reporting duties
- Describe how they will protect subjects' identities, how, where, and for how long any data collected will be stored, and whom to contact for additional information about the study or about subjects' rights
- Not all potential research subjects are considered equally competent or legally allowed to consent to participate in research
  - Minors or other vulnerable populations may require guardian consent or a special consent form

## 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).

# Protection of Identities

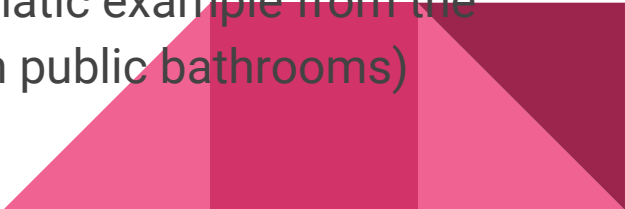
- Protect either *anonymity* or *confidentiality*
  - Anonymity - not even the researcher is able to link participants' data with their identities
    - Difficult in social work because of face-to-face interaction or consent forms
  - Confidentiality - some identifying information is known and may be kept, but only the researcher can link participants with their data
- Confidentiality may be violated to fulfill legal obligations, eg. mandated reporting
- NASW Code of Ethics section 5.02 on research
  - Monitor and evaluate policies, programs, and practice interventions
  - Contribute to the development of knowledge through research
  - Keep current with the best available research evidence to inform practice
  - Ensure voluntary and fully informed consent of all participants
  - Not engage in any deception in the research process
  - Allow participants to withdraw from the study at any time
  - Provide access for participants to appropriate supportive services
  - Protect research participants from harm • Maintain confidentiality
  - Report findings accurately
  - Disclose any conflicts of interest



# Ethics at the Miso, Miso & Macro Levels

Micro Level - consider your own conduct and the rights of individuals participating in research.

Examples:

- Exposing the privacy of individuals who are in a vulnerable population (i.e. queer people in kink culture)
  - Causing distress to individuals in your research (think of emotional or traumatic topics that might come up)
  - Unethical conduct during the research process (dramatic example from the book of the researcher “watching” people have sex in public bathrooms)
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# Ethics at the Miso, Miso & Macro Levels

Meso Level - researchers should think about their duty to groups and to the community.

Examples to consider:

- Research going against ethics at your internship/job
- Violating the social work code of ethics (i.e. violating HIPPA)
- Research that has a negative impact on a community (think about stereotypes that could be perpetuated)



# Ethics at the Miso, Miso & Macro Levels

Macro Level - Researcher must consider impact on society

Examples:

- Meeting the general responsibilities of ethical research in society
- Meeting the expectations of social science research

Table 5.1 Key ethics questions at three different levels of inquiry

Level of inquiry	Focus	Key ethics questions for researchers to ask themselves
Micro-level	Individual	Does my research impinge on the individual's right to privacy? Could my research offend subjects in any way? Could my research cause emotional distress to any of my subjects? Has my own conduct been ethical throughout the research process?
Meso-level	Group	Does my research follow the ethical guidelines of my profession and discipline? Could my research negatively impact a community? Have I met my duty to those who funded my research?
Macro-level	Society	Does my research meet the societal expectations of social research? Have I met my social responsibilities as a researcher?



# Practice of Science vs. Uses of Science

“Doing science” the ethical way:

- Researchers should disclose how they conducted their research so that others who read and build on it can “have confidence” in the process that was used.
- Honesty in research is facilitated by replication.

“Using science” the ethical way:

- Using research in an ethical way means understanding research and your own limitations of knowledge, with an “honest application” of the findings.



# Discussion Questions

- The example of Laud Humphreys collecting data on the “tearoom trade” and acting as a “watch queen” was featured in this chapter. This was a huge violation of privacy. There were many debates about what to do with the results of his research due to how it was collected. What do you all think?
- Scott DeMuth, while performing his dissertation research on a group of animal rights activists, became aware of them vandalizing a research facility and removing animals. DeMuth was asked to reveal the identities of the activists but refused to do so. He was jailed briefly for obstruction and conspiracy. Would you withhold client identities even in the face of legal obligation? If so, under what circumstances?