

Ethical and sensitive issues in healthcare research
How do we do ethical nursing research?

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Fall 2021

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Ethics as a Concept

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Learning Outcomes: by the end of the session, the student will ...

- Understand ethics as a concept
- Be able to identify key ethical principles
- Understand the influence of history on research ethics
- Understand considerations when researching sensitive issues
- Recognise ethical issues to consider in relation to experiments, questionnaires, interviews & observational studies

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Role of research in nursing

- Disciplinary body of knowledge
- Role in professionalization

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ETHICS AS A CONCEPT: Definitions

'The purpose of ethics is to inquire into the nature of good, bad, right and wrong in human actions. It is not 'legal' law, hospital etiquette, hospital policy, public opinion, following the orders of a superior, or even mere "gut response"

Johnstone (2008)

'Ethics is designed to illuminate what we ought to do by asking us to consider and reconsider our ordinary actions, judgements and justifications'

Beauchamp and Childress (1989)

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Ethics in Research

- Umbrella over whole process, much like clinical practice
- First principle to determine quality of a study
 - *If it's not ethical, it's not good research, full stop.*
- Complex and difficult to navigate in practice
- Be aware of your own ethical stance, and that individuals do not always agree
- There may be more than one answer, and that there may not be a clear 'right' or 'wrong'

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ETHICS AS A CONCEPT: Principles

- CONSEQUENTIALISM (Utilitarianism): *the rightness or wrongness of an action is determined by the goodness or badness of results that flow from it (consequences critical)* – Jeremy Bentham (1748-1832); J.S. Mill (1806-1973)
 - *The end justifies the means*

- DEONTOLOGY: *the morality of an act must be judged by the intention or motive of the agent to comply with, or not, a moral duty (consequences less important)* – Kant (1724-1804) *The journey is more important than the destination*

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Key Ethical Principles

- BENEFICENCE: the principle of conveying benefit, or *'to do good'*
- NON-MALEFICENCE: the principle of protecting participants, or *'to do no harm'*
- AUTONOMY: the right to self-determination, respect, dignity and informed consent
- JUSTICE: the right to fair treatment, and to privacy and confidentiality which uphold fairness

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Legacy of Bad Research

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Content warning: This lecture discusses the Holocaust, racism, sexism, and violence

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Legacy of Bad Research

- Tuskegee Syphilis study
- Stanford Prison Experiment
- Milgram Obedience Experiments
- Mengele's experiments at Auschwitz

• While there are lots of glaring examples, ethical violations can also be subtle

• Not just relics of the past...unethical research happens today (i.e. Wakefield MMR)

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**HISTORICAL BACKGROUND:
Nuremberg Code 1947**

- Post- WWII: direct response to Nazi experiments
- 10 medical research standards covering moral, ethical and legal obligations
- These form the basis of current medical, nursing and midwifery codes of practice
- Focus is on informed consent

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DECLARATION OF HELSINKI:

- Policy statement of the World Medical Association
- First version adopted in 1964
- Revised six times since – latest review 2013
- Sets out the ethical principles for medical research involving human subjects
 - *Required reading in the course materials*

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Bad research impacts current practice

- Reason for all of our approvals
- Why are some groups of people hesitant to access COVID-19 vaccines? Consider past history of medical experimentation on women/racialized groups
- Like clinical practice, each of us is responsible for change

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How do we do research ethically?

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Role as Researchers

- Responsibility for ethical practice lies with the researcher, not the participant
- Ethical duties to research participants as strict as those towards clinical patients, including confidentiality
- *Research relationships are NOT therapeutic relationships!*

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Essential ingredients for ethical research

- Research must be necessary and contribute to further knowledge
- Participants must receive full explanation of their involvement in the research, and provide consent (*some exceptions, with strict rules*)
- The right to refuse to participate must be made clear
- Confidentiality must be maintained

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Essential ingredients for ethical research

- The researcher must be trained and qualified in the appropriate research method
- Participants must be protected from undue pain, harm, suffering, and injury
- The relationship between the sponsor of the research and the researcher must be made clear
- Ethical issues must be reviewed throughout the study, not just at the beginning

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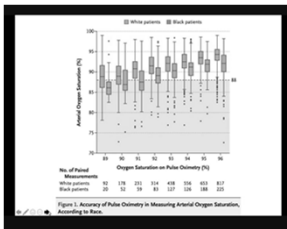
Ethics Throughout the Research Process

- Planning
- Approvals/Funding
- Recruiting participants
- Collecting data
- Analysis
- Sharing findings

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Equity is Central to Research



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Vulnerable groups as participants in research

- Children
- Pregnant women
- Disabled people
- People with mental illness
- People with terminal illness
- Embryo and fetuses
- The unconscious
- Minority communities, however defined

For all of these groups, the key issue is related to the capacity to give informed consent, when the ability to do so is compromised for different reasons, including power differentials.

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Importance of care for the researcher

- Research doesn't happen in a vacuum
- To maintain ethical standards, have to take care of yourself during the research process
- Make sure you have people to talk to, as part of your ethical approvals

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Research is essential for a profession – just make sure it's ethical!

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