SP_ IRS: Research in Inclusive and Special Education

Lecture: Research Ethics.

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Lecturer Education



Presentation Outline



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Ethics



- What are ethics?
- What are common ethical issues that seem to surface in research?
- When should ethical issues be considered?

Ethics

- Ethics: principles for guiding decision making and reconciling conflicting values
 - People may disagree on 'ethics' because it is based on people's personal value systems
 - What one person considers to be good or right may be considered bad or wrong by another person

Major approaches to ethics

Deontological Approach

This approach states that we should identify and use a Universal code when making ethical decisions. An action is either ethical or not ethical, without exception.

Ethical skepticism

 This is the relativist viewpoint, stating that ethical standards are not universal but are relative to one's particular culture and time.

<u>Utilitarianism</u>

This is a very practical viewpoint, stating that decisions about the ethics of a study should depend on the balance of the consequences and benefits for the research participants and the larger society.

- The utilitarian approach is used by most people in academia (such as Institutional Review Boards).
- "Do the potential benefits outweigh the risks associated with this research?"

Ethical Guidelines for Research with Humans

 One set of guidelines specifically developed to guide research conducted by educational researchers is the <u>AERA Guidelines</u>.

 The AERA is the largest professional association in the field of education, and is also known as the American Educational Research Association.

- Research involving human subjects in the Medical, Social and Behavioral Sciences poses complex ethical issues.
- It requires careful thought and consideration on the part of both researchers and research participants.
- Prospective participants must be given adequate information on both the possible risks and the potential benefits of their involvement to allow them to make informed decisions



Ethical Issues

Justification for the research

 Access to participants/Privacy

Informed consent

Potential harm



- With research involving human subjects the risks and costs must be balanced against the potential benefits
- Trivial or repetitive research is may be unethical where the subjects are at risk



After years of experimentation the scientist proved that children become addicted to nicotine

Informed Consent

- This is the process of providing the research participants with information enables them to make an informed decision as to whether they want to participate in the research study.
- State the purpose of the research and describe the procedures to be followed.
- Describe any potential risks or discomforts the participant may encounter.
- Describe any potential benefits from participation.
- Describe extant to which results will be kept confidential.
- Give a list of names the participants may contact with any questions they have.
- State that participant is voluntary and that they are free to withdraw from the study at any time.

Informed Consent with Minors as Research Participants

- Consent must be obtained from parents or guardians.
- consent must also be obtained from minors who are old enough or have enough intellectual capacity to say they are willing to participate.

The process of obtaining consent

- 1. Identify participant population
- 2. Produce information sheet and consent document
- 3. Obtain permission from school's ethics committee
- 4. Present research information to participant and discuss its contents indicating that withdrawal at any time is possible
- 5. Answer participants questions
- 6. Give a copy of the consent document
- 7. Allow the participant time to consider
- 8. Meet participant and discuss documents, to answer any more questions and assess participants understan
- 9. Obtain appropriate signed consent
- 10. Start research

Deception

- Providing false information to the participant about the nature and/or purpose of the study
 - It is discouraged by the AERA, but not disallowed in all cases.
 - Sometimes deception is required in order to conduct a valid research study. The researcher must justify the use of deception.
- If deception is used the following are very important:
 - Debriefing is an interview with the research participant providing an opportunity for the experimenter to reveal deceptive aspects of the study and for the participant to have any questions about the study answered.
 - Dehoaxing: informing the participant about deceptive aspects of the research study
 - Desensitizing: eliminating any stress or other undesirable feelings the study may have created

Freedom to Withdraw

- Participants must be informed that they are free to withdraw from the study at any time without penalty.
- If you have a power relationship with the participants you must be extra careful to make sure that they really do feel free to withdraw.

Protection from Mental and Physical Harm

- This is the most fundamental ethical issue confronting the researcher.
- Educational research generally poses minimal risk to participants.

There are three ways, and three ways only, to encourage participation ethically (Senese 1997):

- **Anonymity:** Promise and keep your promises of anonymity. After identifying your sampling frame, try to forget about taking names or any other unique identifiers. Reassure people that you won't go to the media. Fill them in on what journal outlet you have planned.
- **Confidentiality:** This is what you should promise if you can't keep anonymity. In other words, *use confidentiality if you can't guarantee anonymity*. It requires that you guarantee that no one will be individually identifiable in any way by you, that all your tables, reports, and publications will only discuss findings in the aggregate.
- **Informed Consent:** Be honest and fair with your subjects. Tell them everything they want to know about your research. Be aware of any hidden power differentials that might be pressuring them to participate.

Confidentiality

- Confidentiality of electronically stored participant information.
- Appropriate selection and use of tools for analysis of the primary data
- Who has access to the data
- Data protection act





Autonomy

- The ethical principle of autonomy means that each person should be given the respect, time, and opportunity necessary to make his or her own decisions.
- Prospective participants must be given the information they will need to decide to enter a study or not to participate.
- There should not be pressure to participate.



The participants

- The participants may not have the experience or educational background in order to fully understand the implications of the research
- They may be swayed because of their respect of and trust in the researcher who stands as an authority figure
- If they are being paid for their participation they may be swayed by economic considerations from a free judgement of the risks



Vulnerable participants

- Potentially vulnerable participants such as children, the elderly, the mentally ill may be incapable of understanding information that would enable them to make an informed decision about study participation.
- Consequently, careful consideration of their situation and needs is required, and extra care must be taken to protect them.
- For example, how will you assess the diminished capacity of an elderly individual, who will be the guardian, and how and when will you involve another individual as guardian in the process?



Voluntary informed consent is the agreement given by a well-informed person who:

- □ Has received the necessary information expressed in spoken words and in writing;
- □ Has adequately understood the information; and
- ☐ Has made the choice to participate (or not participate) without coercion.

Essential Elements for Informed Consent

- Research description (what is being studied, what is the procedure, who is sponsoring the study?);
- Risks of participating;
- Benefits of participating;
- Alternatives to participation, such as other studies or services in the area;
- Assurance that information will be kept confidential;
- Compensation for time, travel or possible harm;
- Contacts (whom to contact with questions/concerns); and
- Voluntary participation and withdrawal.

Informed Consent, Cont'd

- Adequate understanding includes the difference between *research* and *health care*
 - related concept: "therapeutic misconception"
- ☐ After thinking seriously about the information, the person can arrive at a decision without being forced, threatened or offered something so valuable that free choice is impossible
 - related concepts: "coercion" and "undue inducement"

Informed Consent is a Process

- Informed consent is a process of collaborative communication and decision making, not the signing of a form
- Informed consent requires that prospective participants:
 - Be appropriately informed about the nature of the research
 - Adequately understand this information and its implications
 - □ Voluntarily decide to participate, without coercion
 - Explicitly consent to participate, orally or in writing

Contact Information

Give the names of people who can answer questions about the research; include the principal investigator.

If the researcher is a student, include the names and phone numbers of the principal investigator and, where applicable, the chair of the school ethical committee for questions.

Furnish the contact name of a neutral third party who can explain the rights of research participants if the participant has any questions.



"Personally, I wouldn't have signed it."

Withdrawal

- Always stress the fact that participation
 is voluntary and that the participant
 can withdraw at any time
- State that refusing to participate will involve no penalty or decrease in benefits to which the participant is otherwise entitled.
- Emphasize that the individual may discontinue participation at any time without penalty or loss of benefits.
- If there are limitations or risks involved in withdrawal, such as a danger to the participant's well being, these must also be clearly explained.



Conclusion

- Ethical consideration is a very important aspect in educational research
- And the following should be looked into from day 1
- Anonymity
- Confidentiality
- Informed Consent
- Vulnerable participants

Tutorial and workshop

- Design a letter to school, head teacher, MOE and parents for getting consent of your research participants.
- Discuss in groups and do group presentation
 About ethics in research.