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PERTIMBANGAN DLM RISET KUALITATIF

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Garis Besar Topik

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- Latar Belakang:
  - Berbagai peristiwa sejarah ttg *unethitical studies* → sejarah perkembangan peraturan & kode etik riset
  - Etik Riset
  - Sifat Riset Kualitatif
- *Invasiveness*
- *Confidentiality & Privacy*
- *Emergent Designs & the Unanticipated*
- Berbagai pertimbangan/dilema etik dlm riset kualitatif
- Informed Consent dlm studi kualitatif
- Etik dan proses penelitian

Studi yg tidak etis

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- Nuremberg/ Nazi Experiments → Nazi German ingin mempelajari kemampuan angkatan udaranya thdp serangan dingin & upaya mengatasinya dgn melakukan uji coba kpd para tahanan → Uji ketahanan thdp serangan bakteri → menilai tulang (skeleton) mll foto & membunuh pemiliknya
- Tuskegee Syphilis Study → subjects were not informed about purpose & procedures of the research
- Willowbrook Immunization Study → subjects were forced to give permission
- Jewish Chronic Disease Hospital Study

Nuremberg Trials

Nuremberg Code 1948

- Peneliti harus memberi informasi yg lengkap ttg hal yg akan dilakukan
- Penelitian hrs dimaksudkan utk kepentingan kemanusiaan → kehdpan man yg > baik
- Penelitian yg manipulasi unsur tbh man hrs memulai percobaannya pd binatang terlebih dulu
- Peneliti hrs mhindari terjadinya trauma pd man sbg subjek
- Peneliti hrs memiliki keahlian terkait dgn penelitian yg akan dilakukannya
- Subyek atau peneliti dpt menghentikan penelitian bila timbul risiko/ masalah

Declaration of Helsinki

- Based on the Nuremberg code & revised by World Medical Assembly
- Therapeutic research & Non-therapeutic research:
  - Greater care to protect subjects from harm in non-therapeutic research
  - Strong independent justification
  - The researcher must protect the life & health of the subjects

Guiding Ethical Principles

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- Respect for Human Dignity
- Respect for Free & Informed Consent
- Respect for Vulnerable Persons
- Respect for Privacy & Confidentiality
- Respect of Justice & Inclusiveness
- Balancing Harms & Benefits
- Minimizing Harm
- Maximizing Benefit

Beauchamp & Childress (1994)

The principle of respect

Qualitative Research

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- In-depth interviews
- Observation
- Focus Group Discussions

Data Collecting Methods

Dilema Etik dlm Studi Kualitatif

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- Informed Consent → data collection & analysis. Protection of participants through the informed consent process favors formalized interaction between researcher and participant.
- Influence → The major data gathering tool. Strength of qualitative research methods often lies in the informality of the communication as well as the iterative nature of the research process.
- Immersion →subjectivity of researcher
- Intervention →professional vs researcher roles. How can we reconcile these two conflicting dynamics?

Ethical Problems & Considerations for Qualitative Researcher (1)

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- Exploring the inner feelings & thoughts of the participants → have to act with sensitivity & diplomacy
- Informed consent cannot be fully informed a the very beginning → The tentative & exploratory nature of qualitative research
- The informant's anonymity might be threatened by detailed description
- The vulnerable position of participant & her/his feeling

Ethical Problems & Considerations for Qualitative Researcher (2)

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- Conflicting role expectations as investigator & professional
- Participants do not always comprehend the health professionals & see them primarily as carer
- Clients or participant may become fearful & distressed during interviews
- Over-involvement & empathy →assumption & inaccuracies
- Ethics committees do not fully understand the character of qualitative research

Potential Risks: Invasiveness

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- Establishing Rapport
- In-depth Interviewing
- Sensitive Research
- Vulnerable Participants/Subjects

Establishing Rapport?

- Many scholars "feel that most of traditional in-depth interviewing is unethical, whether wittingly or unwittingly. The techniques and tactics of interviewing, they say, are really ways of manipulating the respondents."

(Fontana & Frey, 2000, p. 662)

Clinical vs Research Relationships

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- **Clinical Relationships**

  Primarily focused on the needs of the patient/client
- **Research Relationships**

  Primarily focused on the need of the researcher to collect data

Safeguards

- Self-reflection
- Informed consent
- Clarity!

Invasiveness: In-depth Interviewing

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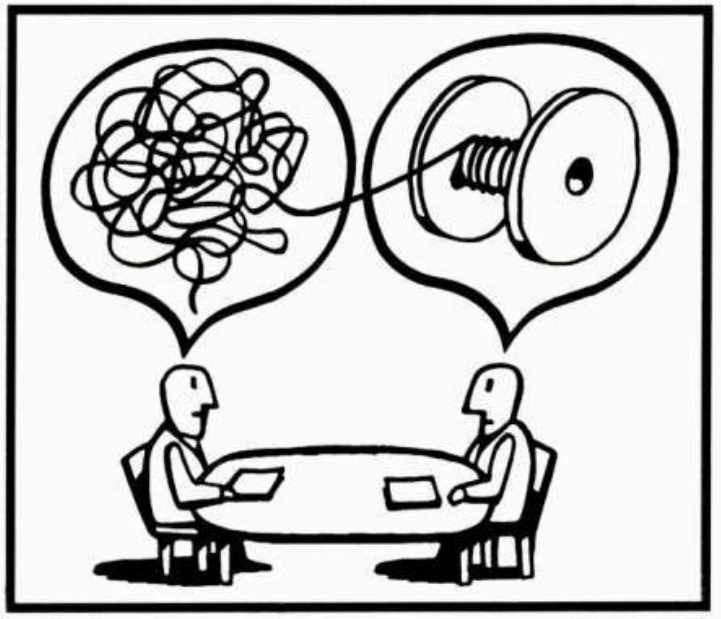
- Can be intrusive psychologically, socially & politically
- Re-traumatization possible
- Cultural variations in response
- Emotional reactions in interviewer possible also

Safeguards

- Interviewer expertise
- Available follow-up
- Timing & length of interviews
- Emotional stability of participants
- Nature of interview question
- Opportunity to end interview



Benefits

- An opportunity to help others & to express emotions
- Overall benefits—exploration of uncharted area, potential to develop understanding & interventions

Sensitive Research

- "A sensitive topic is one which potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding, and/or dissemination of research data."

  (Lee & Renzetti, 1990, p. 512)

Types of Sensitive Research

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- Delves into some deeply personal experience
- Is concerned with deviance or social control
- Impinges on the vested interests of powerful persons or the exercise of coercion or domination
- Deals with things sacred to those being studied which they do not wish profaned

(Lee & Renzetti, p.6)

Safeguards

- Questioning of the social & scientific value of the research: Should the research be conducted?
- Expertise of the researcher
- Knowledge of the sensitive subject

Vulnerable Participants

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*Vulnerable participants may or may not be those involved in the research of sensitive topics

- Members of oppressed groups, e.g. people with mental illnesses, prisoners, homeless people
- Those traumatized, in pain, very ill
- Children (< 12-year-old)
- Mentally or emotionally disabled people
- Physically disabled people (need alternative procedure for documenting Inf Consent)
- Institutionalized people (the voluntary nature of participation)
- Pregnant women

Safeguards

- Consent by a surrogate decision maker if necessary
- Questioning choice of participant population: Could a less vulnerable group be used? Does the research have social value? Will the group benefit from the results?
- Timing of research
- Research evidence

Confidentiality & Privacy

- Naturalistic Observation
- Focus Groups
- Report Writing

Privacy: Naturalistic Observation

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- "Naturalistic observation is used to study behavior in a natural environment. Because knowledge of the research can be expected to influence behavior, naturalistic observation generally implies that the subjects do not know that they are being observed, and hence can not have given their free and informed consent. Due to the need for respect for privacy, even in public places, naturalistic observation raises concerns of the privacy and dignity of those being observed."

(TCPS 2.5)

Privacy & Naturalistic Observation

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- Private settings: homes, sometimes hospitals & workplaces,
- Sacred settings: places of worship

*Have all occupants provided consent?

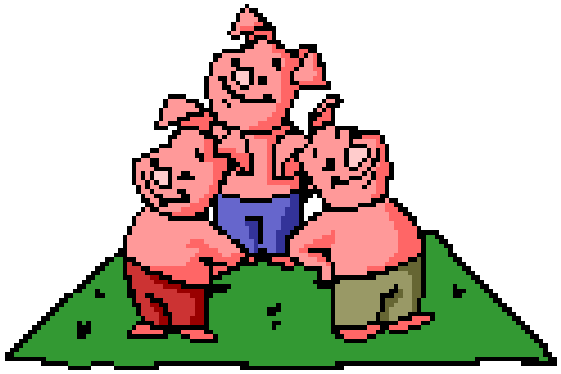
*Have cultural differences been considered?

Safeguards

- Consents of all observed individuals when potential for an infringement of privacy is high or a mechanism to avoid observation of non-participants
- Understanding of cultural differences

Confidentiality: Focus Groups

- There can be no guarantee of confidentiality in focus groups
- A breach in confidentiality could have serious consequences for a research participants



Safeguards

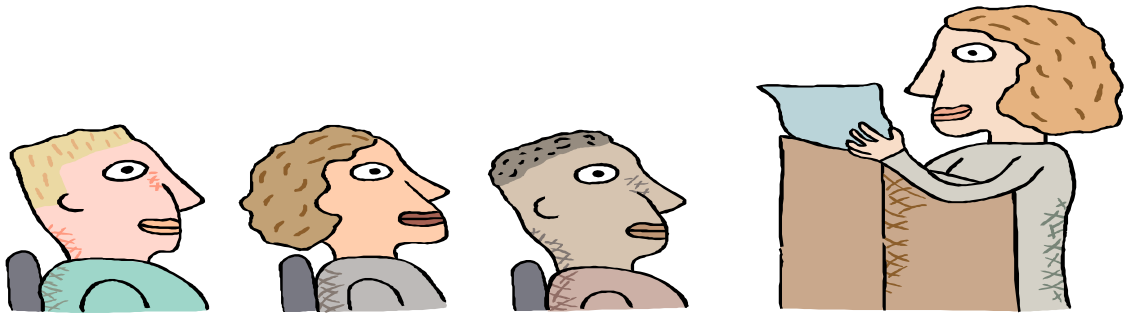
- Reconsider the use of focus group when researching a sensitive topic
- Encourage confidentiality
- Inform participants of limits to confidentiality

Confidentiality: Report Writing

- Rich data—revealing unique characteristics of individuals through words & pictures
- Small samples
- Unique samples

Safeguards

- Unique identifying information should be removed or not gathered at all
- Increase sample & number of sites
- Consider implications personal, social, & political: moral imagination
- Should all data be published?



Emergent Designs & The Unanticipated

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- Predicting Harms
- Research Ethics Review

Memprediksi Bahaya Potential

What could participants reveal?

- Suicidal/homicidal intentions
- Abuse to children
- Criminal Activity

"The doctor will see you now."

*Research data can be subpoenaed

*Responsibilities of health professionals

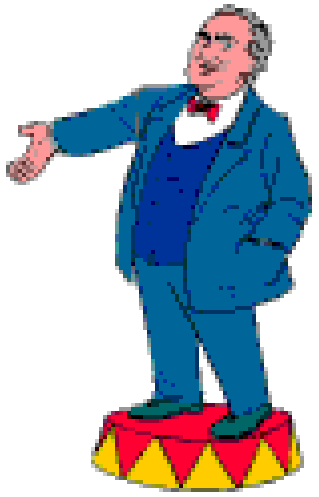
Safeguards

- Understanding & disclosure of foreseeable harms
- Moral imagination
- Legal advice

Emergent Designs: Research Ethics Review

- Ethical approval of research not yet designed?
- Participant consent to research not yet designed?
- Predicting harms & benefits

Suggestion: Staged approval process



Elemen Informed Consent

- Identitas peneliti
- Proses penetapan responden
- Tujuan penelitian
- Prosedur penelitian
- Potensial risiko yg mungkin terjadi
- Potensial manfaat yg diperoleh
- Kompensasi yg diberikan
- Prosedur alternatif (bila ada)
- Upaya menjaga kerahasiaan/confidentiality
- Hak utk menolak tanpa dikenakan sangsi
- Kesediaan utk menjawab pertanyaan
- Cara memperoleh hasil penelitian

ETIK & PROSES PENELITIAN

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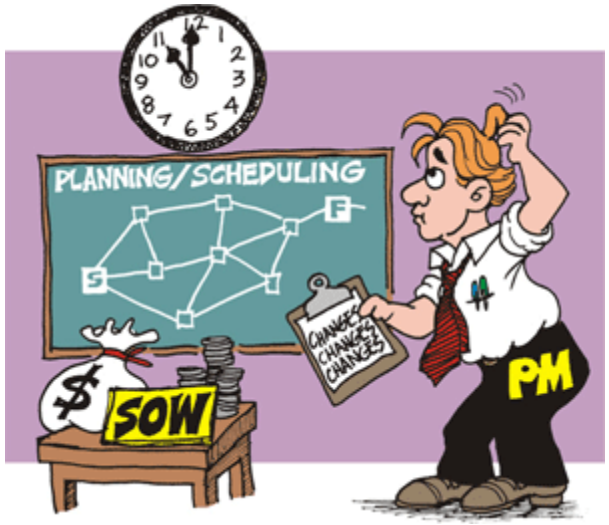
- Tahap persiapan
- Tahap pengumpulan data
- Tahap pengolahan data
- Tahap penulisan & publikasi



Tahap Persiapan

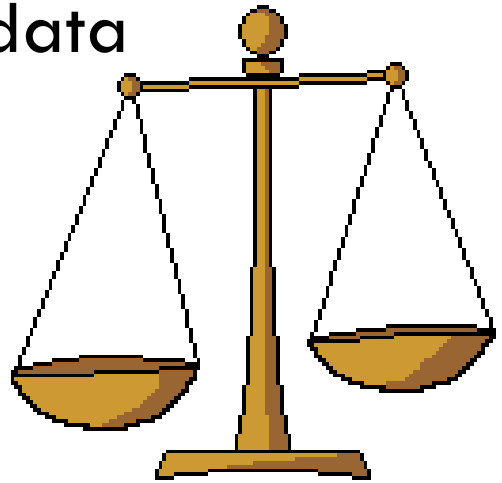
- Kewajiban meneliti dlm tri dharma PT
- Persetujuan etik dari komite yang kompeten
- Kewajiban kpd sumber
  - Sikap jujur
  - Hindari '*scientific bandits*' → ijin menggunakan data

Tahap Pengumpulan Data

- Percobaan pd manusia → kesukarelaan & memperoleh informed consent
- Memperhatikan kondisi psikologis partisipan
- Jujur & obyektif → hindari pengumpulan data berdasarkan rekaan & subyektifitas

Tahap Pengolahan Data

- Obyektif & jujur
- Berdiri di tengah, tdk berat sebelah
- Cegah kecenderungan memanipulasi data shg hasil sesuai dgn hipotesis
- Hindari 'penciptaan & penyulapan' data



Tahap Penulisan & Publikasi

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- Penulisan: penulisan sumber; perijinan utk menampilkan data/foto yg sifatnya pribadi
- Kejujuran: akui keterbatasan penelitian & tdk mengesampingkan berbagai pendapat yg berbeda
- Publikasi: penulisan nama indv/ kelompok & tdk mempublikasikan > dari 1 terbitan

Pustaka

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- Creswell, J. W. (2003). Qualitative inquiry & research design: Choosing among five traditions. Thousand Oaks: SAGE Publication.
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- Iphofen, R. (2005). Ethical issues in qualitative health research. In I. Holloway (Ed.), Qualitative research in health care. Berkshire: Open University Press.