Ethical issues in qualitative research

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Research ethics

• Ethics as a subject
• Where are the limits
• What and why research ethics
• Ethical issues in qualitative research
• Role of ethics and other review processes
Ethics as topic

Ethics can be thought of as the study of good conduct and of the grounds for making judgements about what is good conduct (Trusted, 1987; Birch et al., 2002)
What status do ethics have?

- Objectively true?
- Relative to culture?
- Purely subjective?
Origins of ethics

• Outcome of evolution?
  – Ethics develops from mutual delousing?
Philosophical approaches to ethics

• Absolutist (Kant, Rawls)
  – Ethical values exist in themselves
  – Rules can be derived that apply to all
• Utilitarian (Mills)
  – Actions judged on the basis of their consequences for the general good
  – Allows a more relativist stance – what is good varies across cultures
• Virtue ethics (Aristotle)
  – Based on the character of the individual
  – ‘Ethical behaviour is seen as less of the application of moral principles and rules, than as the researcher internalising moral values’
• Value-based model (Cronin)
  – Ethics part of the relationships with society
  – Emphasis on care and responsibility
Limitations

• Application in the messy world
• Critiques of feminism, multi culturalism – (Doppelt, 2002)
• Different conceptions of individuals and society
• Eg Role of self reflexivity and relationship
Making moral judgements

• Role of emotion, intuition and Reason
• Neurological basis – ‘ventromedial portion of the frontal lobes’ (Phineas Cage)
• ‘To know, but not to feel’.

Singer, (2005)
The Trolley Problem

- Flick the switch?
- Push the man off the bridge?

Singer, (2005)
Ethical Principles?

- Respect for persons
- Honesty
- Benevolence
- Do no harm
- Justice

- Particular judgement on the basis of each case
- Experience and social construction of ethical choice
Research ethics - principles

‘Research is essential to the successful promotion of health and well-being’

‘The dignity, rights, safety and well-being of participants must be the primary consideration in any research study’.

Source – Department of Health Research Governance Framework
Why research ethics

• Nuremberg code
• Tuskegee Syphilis study
• Milgram conformity study
• Stanford prison experiment
Ethics and qualitative research

• Ethical considerations are more complex than quantitative
  – More personal methods
  – More intrusive – into the everyday world of the participant
  – Greater role for the researcher-participant relationship (therefore ethical interaction)

• Only ethical research is good research?
Ethical considerations of qualitative research

They are empirical and theoretical and permeate the qualitative research process. The complexities of researching private lives and placing accounts in the public arena raise multiple ethical issues for the researcher that cannot be solved solely by the application of abstract rules, principles or guidelines. Rather, there are inherent tensions in qualitative research that is characterised by fluidity and inductive uncertainty and ethical guidelines that are static and increasingly formalised (Dence et al 2004: 10)

http://www.respectproject.org/ethics/guidelines.php
Ethical decision-making
The value of ethics codes and frameworks and guidelines

• Usually combine different ethical reasoning and approaches
• A pragmatic set of ethical considerations
• A useful overarching guideline
• Help develop consistent practice
• Not a fixed set of rules
• Researchers can depart from – only after deliberation
Guidelines

Respect project
• Responsibilities to Society
• Professional expertise and standards
• Responsibilities to participants

Social Research Association
• Obligations to society
• Obligations to funders and employers
• Obligations to colleagues
• Obligations to subjects
• Ethics committees and IRB’
Responsibilities to society

• The research aims of any study should both benefit society and minimise social harm.
• Researchers should endeavour to balance professional integrity with respect for national and international law.
• Researchers should endeavour to ensure that research is commissioned and conducted with respect for, and awareness of, gender differences.
• Researchers should endeavour to ensure that research is commissioned and conducted with respect for all groups in society, regardless of race, ethnicity, religion and culture.
• Researchers should endeavour to ensure that research is commissioned and conducted with respect for under-represented social groups and that attempts are made to avoid their marginalisation or exclusion.
• Researchers should endeavour to ensure that the concerns of relevant stakeholders and user groups are addressed.

http://www.respectproject.org/ethics/guidelines.php
Professional expertise and standards

• Researchers should endeavour to ensure that an appropriate research method is selected on the basis of informed professional expertise.
• Researchers should endeavour to ensure that the research team has the necessary professional expertise and support.
• Researchers should endeavour to ensure that the research process does not involve any unwarranted material gain or loss for any participants.
• Researchers should endeavour to ensure factual accuracy and avoid falsification, fabrication, suppression or misinterpretation of data.
• Researchers should endeavour to reflect on the consequences of research engagement for all participants, and attempt to alleviate potential disadvantages to participation for any individual or category of person.
• Researchers should endeavour to ensure that reporting and dissemination are carried out in a responsible manner.

http://www.respectproject.org/ethics/guidelines.php
Professional expertise and standards

• Researchers should endeavour to ensure that methodology and findings are open for discussion and peer review.
• Researchers should endeavour to ensure that any debts to previous research as a source of knowledge, data, concepts and methodology should be fully acknowledged in all outputs.
Responsibilities to participants

• Researchers should endeavour to ensure that participation in research should be voluntary.
• Researchers should endeavour to ensure that decisions about participation in research are made from an informed position.
• Researchers should endeavour to ensure that all data are treated with appropriate confidentiality and anonymity.
• Researchers should endeavour to ensure that research participants are protected from undue intrusion, distress, indignity, physical discomfort, personal embarrassment, or psychological or other harm.
Voluntary participation

- Limitations in statutory research – eg census
- When does encouragement and persuasion become pressure?
- Role of gatekeepers
- How to manage proxy participants
The ‘Moral magic’ of consent

• Giving consent confers rights on others
• Withholding or withdrawing consent withholding or removes those rights
• Consent is a state of mind
  – Always refers to an object – consenting to x, y, z and ‘intentional state’ (Hurd 1996: 125)
  – therefore is changeable
• Consent is not
  – ‘negligent ignorance’ likelihood of something happening
  – Just foreknowledge of the occurrence of an action
  – just desiring an action
• Consent involves a conscious choice to confer the right to do x y or z.
• Consent requires
  – Capacity to withhold consent (ie no duress)
  – Capacity to understand what is being consented to (MCA)

Hurd, 1996
More on consent

- People usually consent to a description of the object not the object itself
- Therefore – an inaccurate description of the object can mean that there is no consent
- Consent is a choice to act or deliberately not prevent, allow or facilitate the act of another – it is not intending actions of the other
- Also consent needs to be freely made – no duress and with capacity – autonomous person
- There is an open question as to how much someone needs to know about what they are consenting to
- The theory is that in order to consent you need the similar levels of autonomy as needed to commit the acts to which one consents

Hurd, 1996
Confidentiality

• Why maintain confidentiality?
• A standard promise for researchers
• Anonymity / Confidentiality
• Disclosures of harm to others
• Participants who want to be named
• Presenting findings
Protect participants from harm

• What constitutes undue intrusion, distress or harm
• What causes the harm – how to address the reactions of different participants
• Are harm and intrusion ever justified?
Ethical issues in qualitative research

• Research design
• Researcher/Participant relationships
• Interpretation of data
• Predicting the impact of different methods on particular participants
  – Eg potential source of distress
• Balance benefits with potential harm
• Consider legal requirements in terms of disclosure of harms

Orb et al 2000
Making decisions in qualitative research

- Consider how to balance the moral and ethical codes of different actors
- Balancing conflicting principles/moral impulses
- Question the primacy of privacy – relate to different cultures
- How to respond where the moral codes of the researcher or the sponsoring organisation are challenged
Researcher/Participant relationships

• Increased impact on participants
• Importance of power relationships
• Participation of people in natural environments
• Deception?
Research practice

• Where the purpose is to understand differing perspectives – how does this affect a duty of confidentiality?

• Huge value of understanding both sides of a relationship – adds to the strength of the research

• Raises ethical challenges
Example – Research Dyads

Researcher interviewed a married couple, Andy and Bella, about their care relationship (Andy cares for Bella). She met with them both twice, speaking first to Andy and then to Bella. While speaking to Andy, Bella “made herself scarce,” and Andy did likewise when it was his wife’s turn to talk. Andy and Bella were experiencing difficulties in their care relationship, and it seemed possible that there was violence between the couple.

During the first interview with Andy, he mentioned one very tense episode regarding his care for Bella. The event seemed really important as a transitional moment in their caring exchanges, and when the researcher met with Bella, she was keen to hear the other side to the story.

Forbat and Henderson 2003
‘Stuck in the middle’? Ethical questions from dyad research

• To what extent would it be ethical to ask her directly about this episode?
• If Bella speaks spontaneously of the event, what are the ethics of then publishing accounts from husband and wife alongside each other?
• What are the ethical protocols for confidentiality between research participants?

Forbat and Henderson (2003)
Ethical challenges from dyad research

• Conflict of interest
  – Between researcher and the participants
  – Between the participants

• Imbalance
  – In relationship between researcher and participants
  – In terms of ethical and ideological concerns

• Taking sides
  – Explicit strategies re confidentiality and neutrality and sharing transcripts

• Intrusion
  – Affecting the relationships
  – Allow for withdrawal, but consider how to explain to other party

Forbat and Henderson (2003)
More ethical challenges from dyad research

• Inclusion
  – How to make sure both parties consent and allow equal opportunity not to take part or to withdraw

• Influence
  – How should issues raised by one party be raised in interviews with the other – if they do not come up spontaneously?

• Disseminating results
  – Double the information – double the chance of breaking confidentiality
  – Partners recognising their own contribution also recognise their partners – share transcripts?
Questions to ask in planning

• What prior discussions about confidentiality will you have with participants?
• How will you maintain confidentiality within the process of interviewing?
• How will you handle potential difficulties within the interview, such as questions about the other participant, or issues of interest raised by the other participant?
• How will you deal with the transcription and transcription return process?

Forbat and Henderson (2003)
Examples of dilemmas (discussion)

• Covert Research
• Breaking confidentiality
• Offering incentives
• Distressing topics
Sources of ethics review

- National Research Ethics Service (www.nres.nhs.uk)
- Social Care Research Ethics Committee (www.screc.org.uk)
- University Research Ethics Committees http://www.arec.org.uk/
Principles of Research Ethics Review

- Reciprocity
- Avoidance of ‘double-handling
- Proportionality
- Independence
- Researcher-led

‘At Last! An ethics committee that will listen to reason’

Other approvals needed

- Research Governance Framework - five domains
  - Ethics;
  - Science;
  - Information;
  - Health, safety and employment;
  - Finance and intellectual property.

- Approvals required from local authority Research Governance for research involving adult social care

- For research involving NHS patients and staff, Research and Development approval required from each NHS Trust involved (Research Passports)
Other issues around approvals

• Mental Capacity Act (2005) – placed legal duties on researchers
• Academy of Medical Sciences (2011) – proposals to streamline clinical research
Resources

• The Respect Project
  – www.respectproject.org/ethics

• The Social Research Association
  – www.the-sra.org.uk

• KCL Research Ethics
  – www.kcl.ac.uk/innovation/research/support/ethics/index.aspx

• Department of Health Research Governance Framework
  – www.dh.gov.uk