Epistemological and ethical issues in social care research

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Social Care Research Committee
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Aim & objectives of session

- **Aim**
  - To present an overview of ethical questions arising from research taking different epistemological and ontological positions

- **Objectives**
  - To review research paradigms
  - To review concepts of epistemology/ontology
  - To consider the importance of epistemology in the design and delivery of qualitative research
  - To highlight ethical issues in the construing, completing and reporting of research from different standpoints
Introductory: research questions and methodological implications
The Research Process

1. Research Question
2. Research Design
3. Data Collection
4. Present findings
The research question

- There is no best research design
- IT DEPENDS ON YOUR QUESTION
Quantitative & Qualitative approaches

- Quantitative research is concerned with counting and measuring things, producing in particular estimates of averages and differences between groups (e.g., blood pressure of patients treated with two different drugs).
- Qualitative research has its roots in social science and is more concerned with understanding why people behave as they do: their knowledge, attitudes, beliefs, fears, etc. (e.g., why do patients prefer to be involved in decision-making about their treatment?)

*(Helpsheet 9, RDSU, Peninsula Research & Development Support Unit –emphasis added)*
Epistemology, ontology and models of research
Epistemology, ontology and methodology

- Guba and Lincoln (1994:108) categorize alternative inquiry paradigms according to their stance on the following three questions:
  - The ontological question
    - What is the form and nature of reality and, therefore, what is there that can be known about it?
  - The epistemological question
    - What is the nature of the relationship between the knower or would-be knower and what can be known?
  - The methodological question
    - How can the inquirer go about finding out whatever he or she believes can be known?

- http://www.idi.ntnu.no/grupper/su/publ/html/totland/ch032.htm
Dominant paradigms in social science research

- **Positivist**
  - External world exists independently of observer and can be subject to ‘scientific’ examination which produces objective’ truth. Researcher is detached and aspires to be objective and uninvolved with the subject of the research.

- **Interpretive, hermeneutic, phenomenological, constructivist**
  - External world is always viewed via interpretations. Truth is negotiated and involves the researcher examining their epistemological standpoint and incorporating this into their research process and findings.
## Quantitative questions and underpinning assumptions

<table>
<thead>
<tr>
<th>Questions</th>
<th>Underpinning assumptions: quantitative approach</th>
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</thead>
<tbody>
<tr>
<td>How does the world work? (ontology)</td>
<td>Reality is one. By carefully dividing and studying its parts, the whole can be understood.</td>
</tr>
<tr>
<td>What is the relationship between the knower and the known? (epistemology)</td>
<td>The knower can stand outside of what is to be known. True objectivity is possible (or at least a ‘regulatory ideal’).</td>
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<tr>
<td>What role do values play in understanding the world? (ethics)</td>
<td>Values can be suspended in order to understand.</td>
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<tr>
<td>Are causal linkages possible?</td>
<td>One event comes before another event and can sometimes be said to cause that event.</td>
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<tr>
<td>What is the possibility of generalisation?</td>
<td>Explanations from one time and place can be generalised to other times and places.</td>
</tr>
<tr>
<td>What does research contribute to knowledge?</td>
<td>Generally, the positivist seeks verification or proof of propositions (post positivist aims to falsify but not prove).</td>
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</table>
## Qualitative questions and underpinning assumptions

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<th>Questions</th>
<th>Postulates of the qualitative approach</th>
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<tr>
<td>How does the world work?</td>
<td>There are multiple realities. These realities are socio-psychological constructions forming and interconnected whole. These realities can only be understood as such.</td>
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<tr>
<td>What is the relationship between the knower and the known?</td>
<td>The knower and the known are interdependent.</td>
</tr>
<tr>
<td>What role do values play in understanding the world?</td>
<td>Values mediate and shape what is understood</td>
</tr>
<tr>
<td>Are causal linkages possible?</td>
<td>Events shape each other. Multidirectional relationships can be discovered.</td>
</tr>
<tr>
<td>What is the possibility of generalisation?</td>
<td>Only tentative explanations for one time and place can be possible</td>
</tr>
<tr>
<td>What does research contribute to knowledge?</td>
<td>Generally, researcher seeks to discover or uncover propositions</td>
</tr>
</tbody>
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But there remains a question of whose voice is heard in research that seeks to understand personal experience

- Notion of dominant voice (… the researcher)
- Raises questions of how the voices of vulnerable populations are heard
- NB ‘does he take sugar in his tea?’
  - Dangers of research duplicating patronising and dismissive attitudes
  - Thus (re)producing a version of the world that is unrecognisable to service user and carer groups
- Power and knowledge very important
- Focus of research on subjective experience
- Importance of methodological choices
A theoretical (de)tour: power & knowledge

- Structuralist, post-structuralist and postmodern
- Foucault (1979 etc)
  - ‘discourse’ and dominant discourse – example of sex offending
- Feminist epistemologists (Harding, Code, Hill Collins et al)
  - ...fails to grasp that modern science has been constructed by and within power relations in society, not apart from them. The issue is not how one scientist or another used or abused social power in doing his (sic) science but rather where the sciences and their agendas, concepts, and consequences have been located within particular currents of politics. How have their ideas and practices advanced some groups at the expense of others? (Harding, 1991, p. 81).
- Post-colonial (Said, Fanon & Spivak et al) – knowledge culturally created
- Queer theorists (Butler, Rich et al) – dominant forms of knowledge ignore or denigrate the experience of LGBT people
Implications for conduct of research(ers)

- Researcher standpoint important (e.g. feminist research)
- Researcher as joint producer of research findings
- Research with human subjects ‘dialogical’
Group discussion

- Case study one (fictional but with some basis in reality!)
- Research question: How do ex-armed-service personnel manage their lives following disability caused ‘in action’?
- Research aim:
  - to explore the impact on ex-service personnel of being disabled during armed combat
- Methodological options:
  1. Literature review
  2. Survey designed on basis of literature review and previous ‘measures’
  3. Interviews: structured, semi-structured, unstructured
  4. Focus groups
- Which options (combination) of options is (a) most convenient for the researcher? (b) most likely to facilitate the expression of research participants’ experiences
- What are the ethical issues that the committee should consider?
Ethical issues: an epistemological conundrum?
Main approaches to ethical thinking

• Principle-based
  • Kantian - categorical imperative (means not ends)
  • Utilitarian - greatest benefit for greatest number
• Character-relationship-based (Banks, 2006)
  • Virtue - good, honourable conduct descriptors, equity
  • Care (relational) (Noddings, 1984, 2002)
Ethical issues: construing the project

- Involves reflection on
  - How the researcher understands/constructs the issue to be explored
  - The origins of the researcher’s understandings/ constructions
  - Other ways of viewing the issue
  - Implications of pursuing one particular way of understanding the issue
  - Power & knowledge – whose knowledge whose power? (NB contribution of service-user/patient perspectives)
  - The potential contribution of the research
  - How can potential research participants be involved in designing and monitoring the project?
Researching sensitive topics

- A simple definition of sensitive research would therefore be ‘research which potentially poses a substantial threat to those who are or have been involved in it. (Lee 1993; p.4)

- Areas of Threat
  - Intrusive
  - Incriminating or stigmatising (confidentiality)
  - Political
    - Lee (1993; pp. 4-11)
  - NB there is a current literature which has built on the work of Lee
Sensitive topics: some issues to consider

- Relationship of researcher and research participant
- Importance of research question
- Possible distress caused focus of research
- Emphasis on process balanced with need to respect dignity
- Power in process and protocol – how is this ameliorated?
Ethical Issues: doing the research

- Consent (especially problematic with children and people lacking mental capacity)
- Harm
  - To research participants
  - To other people
  - To researcher
  - NB harm can be physical, psychological, emotional and (in some cases) financial
  - Establishing whether an approach might be harmful is not always straightforward
- Confidentiality
- Data protection – during collection, and archiving
- Presentation of data
Consent

- Underpinned by Kantian & character-relationship approaches
- ‘Informed’ (‘no surprises’)
- Mental capacity & vulnerable populations
- Iterative; some qualitative interviews last over many sessions – consent as an ongoing process (reaffirmed at each session)
- For large scale surveys or the use of standardised tools, participants need to be forewarned about the overall aim and possibly distressing questions
- Whether and how to follow-up those at risk in the case of anonymous surveys
Confidentiality & new knowledge

- Pure utilitarian perspective
  - Fullest information enhances the greater good
  - Total confidentiality (cf early sociological research)
- Kantian perspective
  - Respectful relationship (categorical imperative)
  - So act as to treat humanity, whether in your own person or that of any other, never solely as a means but always also as an end (Kant 1964:32)
  - Could incorporate total or partial confidentiality as long as the nature and parameters were explicit, in advance, to the research participant(s)
- Character-relationship approaches
  - Virtue & Care
    - Limited confidentiality (NB notions of good/care extend to victims)
Confidentiality & public protection

- Protecting confidentiality can involve serious legal problems, such as in cases when a researcher – through a promise of confidentiality and the trust of the relationship – has obtained knowledge of mistreatment, malpractice, child abuse, the use of drugs, or other criminal behaviour by the interviewee or others (Kvale 1996; p. 115).
  - NB Tarasoff ruling(s)
Confidentiality: (BSC, 2006)

• Research participants should be informed about how far they will be afforded anonymity and confidentiality. Para 4 (iii)

• Researchers should not breach the 'duty of confidentiality' and not pass on identifiable data to third parties without participants' consent. Para 4 (iv)
  • [http://www.britsocc crim.org/codeofethics.htm](http://www.britsocc crim.org/codeofethics.htm)
Confidentiality - BPS

• Restrict breaches of confidentiality to those exceptional circumstances under which there appears sufficient evidence to raise serious concern about: (a) the safety of clients; (b) the safety of other persons who may be endangered by the client’s behaviour; or (c) the health, welfare or safety of children or vulnerable adults.

Ethical management of distress: epistemologies, principles and relationship

• How researchers react to distress is both an ethical and an epistemological concern.

• Aspirations to ‘scientific’ objectivity may prompt researchers to act in a respectful if uninvolved manner during the research interview.

• Character-relationship ethics offer alternative insights into what might be ethical conduct in these circumstances.

• Research not involving face to face interactions with participants can still cause distress – this needs to be managed in advance through careful choice of questions and offering potential lines of support

• Researchers and research participants may become distressed

• Researchers may also feel threatened by research participants

• Recognition of potential harms to researchers can be responded to through organisation lone worker policies.

• Balance the importance of the topic, the skill level of the researcher, the possible value of discussing distressing topics for the service user
Case study

• Research aim:
  To identify the daily living support needs of physically disabled undergraduate students

• Research question:
  Do physically disabled students require help to complete successfully a course of undergraduate study?

• Methodological options:
  1. Literature review
  2. Survey designed on basis of literature review and previous ‘measures’
  3. Interviews with disabled students: structured, semi-structured, unstructured
  4. Interviews with disabled students' support workers
  5. Focus groups of students, and or workers

• Which options (combination) of options is (a) most convenient for the researcher? (b) most likely to facilitate the expression of research participants’ experiences

• What are the ethical issues that the committee should consider?
Disseminating research

• Qualitative research can co-create graphic descriptions of unpleasant and offensive thoughts and behaviours; such descriptions both provide information and cause affect.

• [A] major ethical issue for researchers to resolve is what data to include in papers and presentations. In many ways this is an ethical choice involving consideration of:
  • (a) a Utilitarian perspective that suggests the greater knowledge available is for the greater good;
  • (b) a Kantian perspective may consider that presenting stark details of violence is disrespectful to victims; and
  • (c) an ethic of care perspective that would consider the emotional impact of research data on people who read, hear or see the data presented.

• For example, does the detailed presentation of sensitive material enhance general understanding or (re)offend and (re)harm particular groups? The answer to this question is, probably, ‘both’.

• Moreover, to present graphic detail of sensitive issues without adequate explanation and justification may be experienced as offensive or distressing. (NB researching (child) pornography)

• Acknowledging the potential distress caused by questions and commenting on possible implications can be seen as a minimum in reporting quantitative research

• Cowburn, M. (2013)
Ethical issues: a summary

• Construing the project – issues of contesting knowledges and definitional choices
• Informed (ongoing) consent
• Safety of research participant
• Safety of researcher
• Problem of confidentiality & disclosure (strongly highlights Utilitarian vs. Kantian perspectives)
• Power relations in interview & ability to express freely (risk of distress);
• On-going ethical scrutiny
• Data protection
• Dissemination – presentation of data
Group discussion – final section of day

- Questions?
- Implications for committee practice?
- Role in determining kinds of dissemination
- Committee responses to researchers with particular ‘agendas’ in relation to epistemologies
- Committee’s role in promote user voice in all kinds of research?
- How to ameliorate the power in the protocol and process
- Further training needs?