Approaching research ethics in adult social care: Theories, issues and practical strategies

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Methods Review: Research ethics in social care

My objectives today

- To locate and explicate the ethics of social care research: its core features, its theoretical orientations, its principled management in research practice

- Assist with the preparation of social care research proposals and protocols that are ethically defensible
  - That attend to ethically relevant considerations in a careful way
  - That can be defended under challenge within an institutional framework of ethics review

Overview

1. The ethical tension at the heart of social care research

2. Navigating social care research ethics: Theoretical perspectives

3. Three ethical considerations for social care research

4. Thinking through practical ethical issues in social care research

1. The ethical tension at the heart of social care research

Let's first consider the ethics of social care *practice* (not research)

◦ Ethical challenges in social care practice largely centre on competing accounts of what is owed to individual service users

◦ Including, but not limited to:

- ◦ **Respecting agency**: enabling the service user to make decisions, and be free, to pursue actions that fit their personal life plan within the context of needing support

- ◦ **Maximising well-being**: enabling the service user to have a good quality of life

1. The ethical tension at the heart of social care research

Now let's consider the ethics of social care *research*

◦ Ethical challenges in social care research centre on balancing what is owed to individual research participants and what is owed to future service users who will benefit from the outcomes of the research activity

◦ We can understand this tension in the following way:

   ◦ **Wearing the 'practitioner's hat'**: Seeking to minimise the risks and respecting the choices of people recruited as participants in social care research studies

   ◦ **Wearing the 'researcher's hat'**: maximising the potential of – and overall benefits within – a piece of research ('doing good science')

1. The ethical tension at the heart of social care research

How do we square the circle, and resolve this core ethical tension in social care research?

2. Navigating research ethics: three theoretical positions

1. The 'rights-based' position

◦ Emphasises the value of research participants' autonomy and freedoms

◦ Places focus on the validity of consent

◦ If fully informed consent has been obtained, the research is ethically justified to proceed

◦ Other considerations relating to harm or overall benefit are not seen as ethically relevant

◦ If the right kinds of permissions from participants have been obtained, the research is justified to proceed (assuming sufficient people can be recruited)

2. Navigating research ethics: three theoretical positions

2. The 'duties-based' position

◦ Emphasises the duties that are owed to research participants

◦ Duties in social care research will largely track duties that exist within the broader social care practice context

◦ These duties give rise to rules that determine which proposals in research are ethically justified, irrespective of the consequences for the research going ahead

◦ One rule might require that research participants are not exposed to a more than minimal risk of harm

◦ Valid consent cannot override the fulfilment of this duty (i.e. a person could not authorise themselves being exposed to a risk of harm that would be a violating of what would otherwise be owed to that person as a social care service user)

2. Navigating research ethics: three theoretical positions

3. The 'consequences-based' position

◦ The research is justified to proceed if the overall total good that can be done through a particular research project is maximised

◦ Emphasises that the value and quality of the research is a core ethical consideration: only research with the potential to do the most good for social care in the future can be justified

◦ Requires a balancing of the benefits and harms to individual participants *and* people in the future

◦ At least in principle, non-consensual research that violates duties owed in social care practice to service users could be justified if it will lead to considerable future benefits

3. Three ethical considerations for social care research

From abstract theories to specific ethical considerations

- ◦ Typically, people gravitate towards one of these theoretical positions – at least in the abstract

- ◦ Broadly, however, we reasonably disagree about which of these basic arguments ought to 'win the day'

- ◦ Research ethics is therefore built around core ethical considerations that capture features of all three positions

- ◦ These considerations outline specific ethical features that those designing a research project ought to take into account: they shape a judgement about whether a piece of research is ethically justifiable or not

3. Three ethical considerations for social care research

1. Respect for persons

◦ This principle captures the overarching ethical requirement to treat people (research participants) in a particular kind of way, given their moral status as a human being

◦ This status accords recognition of the potential participant's unique, individual value and dignity

◦ On dominant accounts, this principle requires the potential participant to be recognised as someone whose:

   ◦ **autonomy should be respected** (respect for the person's ability to formulate a life of value to them)

   ◦ **freedom should be respected** (be enabled to pursue that life of value, or to not have it unjustifiably constrained)

   ◦ **dignity and privacy should be respected** (treated in a respectful way in the pursuit of a valuable life)

3. Three ethical considerations for social care research

1. Respect for persons

◦ In the research context, attending to these requirements means:

1. Placing central importance on obtaining valid, informed consent (in order to ensuring that the 'research offer' is aligned with the person's autonomous preferences)

2. Ensuring the 'research offer' does not disproportionately impose restrictions on the person's life

3. Managing privacy in research that involves sharing people's histories, or that impact on their private spaces, in ways that are appropriate

4. Ensuring that the researchers engage with the person in a respectful manner (not viewed merely as a 'subject')

3. Three ethical considerations for social care research

2. Maximising benefits and minimising harms

- This principle requires a positive balance to be struck between the benefits and harms that will accrue from the research to be undertaken

- Here, the concern is with maximising welfare-related considerations associated with the research taking place (not what is intrinsically owed to a participant in a research study)

3. Three ethical considerations for social care research

2. Maximising benefits and minimising harms

○ In the research context, attending to these requirements means:

1. Asking "what benefits are likely to occur from undertaking this research?"
   - Direct ('impact') benefits; indirect benefits (part of a trajectory of inquiry)
   - This is activated through methodological scrutiny: will the research, as designed, realise these bene

2. Asking "will participation in the study lead to direct benefits to the participants themselves?"
   - Direct benefits; indirect benefits (particularly in the adoption of social science methods)

3. Asking "What harms might arise through the research, and how can they be mitigated?"
   - Less significant than those in medical research – but not insignificant!

3. Three ethical considerations for social care research

3. Fair conduct in research

◦ This principle is concerned with meeting justice requirements within the research endeavour

◦ For social care research, justice can be understood in a number of ways here:

1. Attending to whose social care needs are being foregrounded in making research priority decisions
    1. Have certain sub-groups of service users been arbitrarily excluded from the sample frame?
    2. Have a particular sub-set of problems been neglected in deciding which research objectives ought to be prioritised?
2. Attending to issues of distributive justice: are the risks, burdens, and potential benefits likely to accrue in the research process fairly distributed?
    1. Are there 'pathways to benefit' available to those who are bearing most of the burdens?
    2. Are some participants being unfair taken advantage of ('exploited') or disadvantaged in how the research is designed?

3. Three ethical considerations for social care research

Interpreting and balancing considerations

◦ The three considerations ought to be attended to thoughtfully and carefully in the development of a social care research protocol

◦ They will not function as an algorithm for the production of ethically justifiable research, nor as a 'tick box exercise' that ensures the considerations have been taken into account in a linear and definitive way

◦ Two questions:

1. How should these ethical considerations be applied to the specific research activities that are planned (and should they be modified accordingly)?

2. How should any conflict between these considerations, as presented through the proposed design, be thought through and addressed? Trade-offs will be required as there are no *a priori* right answers to how these considerations should be balanced

4. Thinking through practical ethical issues in social care research

1. Paying participants (beyond reimbursing expenses)

A social care researcher is proposing to pay service users with dementia £10 to participate in a 1-hour interview about their experiences using a fall detector

- **Does payment invalidate consent?**
  - Coercive? Should we inform participants beforehand about the payment they will receive? Would a non-cash payment benefit be more appropriate?

- **Will payment benefit participants, or cause them harm?**
  - Unintended impacts on social security? An extra, direct benefit of participating in research?

- **Is the payment crucial to obtaining the benefits that the research has the potential to bring about?**
  - Will the research team struggle to recruit sufficient participants without paying them?

- **Is the payment fair?**
  - Reasonable recompense for taking time out of their day to support the research? Are there arbitrary exclusions of people who might otherwise receive the payment (those not speaking English as a first language?)

4. Thinking through practical ethical issues in social care research

2. Covert ethnographic research in a care home

A social care researcher is interested in examining concerns raised in a recent report by the regulator that contact between care staff and residents in care homes is not supportive of a person-centred approach to realising good care outcomes, being too rigidly focused on the completion of a minimal set of personal care tasks.

The researcher intends to examine how care assistant-resident interactions take place in the home, and the explanatory factors that might underpin these interactions. She intends to seek employment in the care home and conduct covert, participatory observation research during her shifts. She does intend to inform the care provider, the manager, the care staff, or the residents that she will be conducting observational research on the grounds that this will bias her data.

4. Thinking through practical ethical issues in social care research

2. Covert ethnographic research in a care home

◦ Here, the 'research offer' being proposed looks like it encapsulates a striking tension between two considerations: **respect for persons** and **maximising benefits and minimising harms**

◦ Are the benefits appropriate?

◦ Does the proposed research design enable the beneficial insights to be obtained?

◦ Would it be really be impossible to obtain these beneficial insights if consent for research participation was obtained? Would that lead to other harms?

◦ Are there other ways in which the participants could be respected in the research?

   ◦ Fully informed 'after the event'? De-briefing sessions and a clear rationale provided?

   ◦ Or, does the researcher maintain the view that the participants ought to remain in ignorance – so as not to cause residual negative ripple effects for those living and working in the setting?

Conclusion: From ethical considerations to research ethics governance

'Reasonable disagreement': The rationale for pre-emptive, external ethics review

- Importantly, we can (and frequently do!) genuinely and reasonably disagree about how trade-offs between these ethical considerations should be made in cases like this

- External, pre-emptive ethical oversight of social care research by Research Ethics Committees has been subject to significant critique – why not simply equip researchers to make these judgements for themselves?

- Its justification lies in two main observations:
  1. **Social accountability**: Society has a 'stake' in overseeing research because research inquiry has implications for human social life: we are all invested in the activities of research
  2. **Contestability**: In practice, a committee approach to ethical decision-making is a well-established mechanism for handling the requirement to make a judgment, in a fair procedural manner, when reasonable disagreement of precisely this kind exists

Conclusion: From ethical considerations to research ethics governance

Facing the research ethics committee

◦ Uncertainty, fear and (sometimes) frustration are common feelings experienced by social care researchers submitting their proposals for ethical review

◦ A well-functioning ethics review process should provide an important opportunity for researchers to explain and defend various aspects of their proposal:

   ◦ To clarify how the ethical considerations are being attended to
   ◦ To explain, justify, and defend how trade-offs are made when these considerations are in conflict

◦ There are justifiable concerns expressed about how the institutionalisation and proceduralisation of ethics review can 'de-centre' careful and responsive ethical reasoning: we all need to fight against this!

Thank you

I look forward to your questions and thoughts

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