Ethical considerations in research with vulnerable older adults: The case of the Hair and Care Project

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Overview

How can we best support ethical working in research and practice?

What’s involved in making a submission for ethical approval under the current system of ethical governance in health and social care?

Our own ‘unofficial’ efforts to develop an ethical approach to research – informed by the work of sociologist Ken Plummer (2001)

Highlight the need for a debate between researchers and practitioners about ethical challenges in dementia care

Suggest a rethink to the current system for ethical governance of social research in health and social care
Background

• Series of medical scandals in the UK and abroad highlighting the vulnerability of research subjects in medical experimentation

• ‘Ethics creep’ – governance extended to cover social research in the field of health and social care

• Critics: A form of censorship and de-professionalisation through relocation of decision-making powers

• ‘Ethical absolutism’ (i.e. guidance of research according to firm principles)

• ‘Situational relativism’ (‘where ethics are produced creatively in the concrete situation to hand’ Plummer, 2001)
Research with vulnerable older adults

• Tensions between absolutist and situational approaches to ethics are amplified in the context of research involving vulnerable adults

• The process of being labelled as vulnerable can be ‘deeply silencing’ (Boden et al 2009)

• Researchers need to ‘seize the best moments’, be sensitive and adaptable and tailor their approach to the strengths of the individual (McKeown et al 2010)

• Mental Capacity Act (2005) – decision-making, consent – need to sensitively negotiate situations where a person may lack capacity to consent (e.g. Dewing 2002, 2007)
Connecting research and practice

• Everyday ethical dilemmas – arise in the context of ‘mundane, ordinary situations’ but are nevertheless a challenge and source of stress for carer and caree.

“Rules and laws have a particular but limited role to play’ (Nuffield Council on Bioethics, 2009).

An everyday ethical dilemma: For a care worker assisting a person with dementia to get dressed what is the most important consideration in this situation?

i) That the person is assisted to dress in a way that is in keeping with how they have always dressed

ii) That their comfort in getting dressed and throughout the day is the priority, or

iii) Should they be supported to dress and they wish, even when their choices may seem bizarre and likely to attract disapproval from fellow residents?
The Hair and Care Project

• An ethnographic study of appearance and the help provided to maintain it in dementia care settings

• Taking account of the perspectives of people with dementia, care-based hairdressers, care workers, family carers and managers and other stakeholders.

• Interviews, in-situ conversations in the salon, ‘appearance biographies’

• Filming – to support the participation of people with dementia in the research
Seeking ethical approval…

- Time and labour-intensive submission process including completion of 28-page online application (plus research protocol, information sheets, consent forms and draft research tools – interview schedules etc.)

- Attending the Committee
  
  - Formal and non-discursive
  - No explanation of reasoning behind decisions
  - Committee’s limited knowledge of visual methods required further explanation
  - ‘Unfavourable’ opinion – need to re-submit, loss of time for the research – repeated process of form-filling
The ‘unofficial’ approach: The Hair and Care Protocol

The Protocol – 3 sections:

• Part 1. Statement of anticipated or potential ethical challenges
• Part 2. Statement of how we intended to respond to these issues if they arose
• Part 3. Logging of unpredictable ethical dilemmas as and when they arose

• Shared with host care providers, practitioners and carers

• Part 3. Used as the basis for team discussions – using ethical dilemmas to reflect on ethical practice
Ethical stories and narrative communities

“We need stories and narratives of research ethics to help fashion our own research lives, and to see the kind of broader principle which they can then draw on” (Plummer, p.229, 2001)

- A regular slot in research team meetings for members to introduce (anonymised) ethical dilemmas from their work for discussion by the team as a whole

- Discussions revealed diverse perspectives often from different professional or clinical backgrounds
What needs to change – and why?

- Medicine has a spurious claim to exercise authority over social sciences in the field of health and social care(!)
- Any system of governance for social research should be populated by individuals who understand qualitative research and methodologies
- Accord researchers greater autonomy and hold them accountable for ethical practice *not* a series of administrative tasks
- We need to see ethical challenges as educative and create a process for learning from them
- There is a pressing need for a system that fosters discussion about ethics between researchers, practitioners and which involves people with dementia and carers too…
THANK YOU
References


• Dewing, J. (2002) From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia, *Dementia*, 1, 2, 152-171

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