THE (UN)CARING LOGIC OF FIELDWORK: THE LIMITS OF WITNESSING IN HEALTH RESEARCH

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Introduction

• ‘Care’ as a category for the (self)reflection on the activities of researchers in healthcare settings
• Can researchers’ activities be considered as caring / demonstrating care or contributing to / facilitating care?
• Question both methodological / epistemological and ethical / moral
• Still problematic despite the ‘reflexive turn’ in social sciences, feminist and action research
Background

- Qualitative (ethnographic) research into communication between urological cancer patients and healthcare professionals
- 13 patients diagnosed with prostate and bladder cancer followed over the period of 12 months
- Observation of formal appointments with doctors and nurses and informal interactions with nurses
- Semi-structured interviews with patients and healthcare professionals
- Experienced emotional strain: tensions between the expected role of an observer and an obligation to act to alleviate the suffering of patients
Emotions in research

• Emotional experiences of the researcher still rarely recognised
• Most often perceived as a threat to the research not to the researcher (i.e. loss of objectivity)
• Reflexive turn in social science: emotions as part of the research experience
• Researcher’s work as ‘emotion work’ (i.e. transfer of feelings from the research participants, emotions evoked by the process of data collection)
• Emotions as a source of knowledge (Dickson-Swift et al, 2009; Hubbard et al, 2001)
Story 1 – Interrupted service

• Frank (67) has just been given a diagnosis of possible bladder cancer in an out-patient diagnostic clinic.
• He should be seen by a nurse from an in-patient ward for information and reassurance.
• He is under the care of Jenny, a student nurse on the placement, clearly not aware of this procedure.
• I ask Jenny if a nurse from the inpatient ward should be called to see Frank. She shrugs off my question.
• I speak to Anne, one of the staff nurses.
• Anne intercepts Frank at the exit, but he chooses to leave. He still looks shaken and I worry about him. I also worry that I ‘contaminated’ my research field.
Story 2 – Misinformation

• Allan (84) has just been given a diagnosis of prostate cancer in an out-patient diagnostic clinic.
• His daughter, Rose, is with him in the clinic.
• Bill, a urology nurse, explains the details of hormonal treatment that Allan will receive.
• He mentions that hormonal injections may cause a ‘flare’ effect. Rose doesn’t understand what it means and asks if Allan’s cancer will get worse.
• Bill doesn’t answer her question.
• I know that the ‘flare’ effect of the injections is counteracted by the tablets that Allan will also receive.
• After some hesitation I decide to speak out formulating my words as a question to Bill.
• Rose seems to relax. However, I feel that I have overstepped my responsibility.
Conflicting roles

- The boundary nature of participant/observation
- Tendencies for inclusion: fieldworker as person, resource, or member (Emerson and Pollner, 2001)
- Formed personal relations with patients and healthcare professionals
- Called to provide information or practical help
- In healthcare settings no credible role for the researcher as a participant (Wind, 2008)
- BUT, in certain spaces and situations treated as a team member
- Conflicting fields: actively caring medical field, supposedly detached academic field
Methodological question

• Conflicting paradigms of empiricism and reflexivity
• Traditional vision of the researcher as a detached and uninvolved observer
• Concerns about the (undue) influence of the researcher on the reality (observer’s effect; researcher’s bias; ‘going native’)
• Reflexive vision of the researcher as a participant in social interaction
• Recognition that the researcher’s influence is unavoidable (researcher as a tool; situated knowledge)
• Principles of feminist / action research – researcher as an advocate for the underprivileged
• Involvement as moral rather than methodological choice? (Anspach and Mizrachi, 2006)
Ethical question

• Research in healthcare settings strictly regulated (professional codes of conduct, ethics and management approvals)
• Responsibility for the well-being of the research participants directly in relation to the research interaction (principle of non-maleficence)
• In a narrowly regulated sense: any involvement out-with the professional capacity can be judged as unethical
• Is a researcher responsible for the well-being of the research participant outside of the immediate research context?
• In a broader sense: lack of involvement on behalf of the research participants can be judged as unethical (principle of non-beneficence)
'Witnessing’ in research

• Ethnographer as a witness of social actions (watching, describing, analysing)
• But also as a witness FOR research participants (establishing or ratifying a moral community) (Bosk, 2008)
• Witnessing suffering as a call for an existential commitment ('empathic witnessing' (Kleinman, 1988))
• But also as a call for engagement, advocacy and direct action (Smith and Kleinman, 2010)
• As witnesses researchers ‘responsible both for reframing meanings of equity and care and for acting upon those meanings through their acts of witnessing’ (Ropers-Huilman, 1999)
Logic of care

- Contrasting logics of choice and care in modern healthcare (Mol, 2008)
- Logic of choice: based on fixed dichotomies (active/passive, mind/body, thinking/action); assuming autonomy, rationality and control
- Logic of care: no fixed variables, the possibility for fluid adaptation; concerned with actively improving life; accepting the unavoidability of failure
- Care as ‘tinkering’:
  ‘As control is illusory, as all elements involved (bodies, technologies, food, colleagues, what have you) are capricious, the task is that of attuning everything to everything else, one way or another’ (Mol, 2009)
- Translating the logic of care to other spheres
Conclusion: research and care

- Mol’s notion of care useful for academic (self)reflection
- Logic of choice in academia: ethical issues limited to informed consent; research practice as rational, objective and controlled
- Logic of care in academia: conflicting moral obligations; research practice as (also) emotional, subjective and negotiated
- Important reflection on care and witnessing in research, and on their limits
References


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