GIVING VOICE VERSUS GATE-KEEPING: NEGOTIATING COMPLEXITIES IN RESEARCH COLLABORATIONS

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or…

Rapport with participants, rapport with gate-keepers

ABSTRACT

This paper interrogates the potential for conflict within collaborations with particular regard to the ethical principle of respect (as described in the Belmont Report): that *individuals should be treated as autonomous agents yet those with diminished autonomy must be protected*. As a social psychologist interested in risk and resilience in young women, much of my research has been on sensitive topics including self-harm and sexual abuse. Conducting research with these young women entails a number of *challenges, including access, recruitment, the development of trust and managing potential vulnerability*. At the same time, participants frequently report benefits from participation, even when distress is experienced. Although collaborating with service providers with which potential research participants engage may reduce some of these difficulties, other tensions frequently arise. Further, research on sensitive topics and/or with vulnerable people poses specific ethical difficulties. These include tensions between researcher and participant needs, such as conveying the possibility of distress while not discouraging participation and staying within the confines of the research topic (as described to ethics review boards and funders) versus allowing participants to influence the agenda. *Service providers ‘are often cognisant of some of these possible issues, and may take on a gate-keeper role through a desire to protect their clients. In so doing the autonomy of potential participants is diminished*. Thus the development of trust on the part of both collaborating services and participants is key to the opening of research spaces. The challenges of complex and competing needs in research collaborations will be examined.

BELMONT REPORT

- Increased scrutiny for vulnerable individuals is based on the basic premises of the Belmont Report – respect for persons, beneficence and justice.
- Respect for persons: two basic ethical convictions:

1. individuals should be treated as autonomous agents,
2. persons with diminished autonomy are entitled to protection

BENEFICENCE

- Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by *making efforts to secure their well-being*.
- In the Belmont Report, beneficence is understood as an obligation.

1. do not harm and
2. maximize possible benefits and minimize possible harms.

JUSTICE

- Why / how is the sample selected
- Will resulting benefits accrue to that sample?

- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

WHAT ARE VULNERABLE POPULATIONS?

- The disadvantaged sub-segment of the community requiring utmost care, specific ancillary considerations and augmented protections in research (Shivayogi, 2013).
- Any individual that due to conditions, either acute or chronic, who has his/her ability to make fully informed decisions for him/herself diminished can be considered vulnerable
- Any population that due to circumstances, may be vulnerable to coercion or undue influence to participate in research projects.

RESEARCH ON SENSITIVE TOPICS / WITH VULNERABLE PEOPLE

- E.g., self-harm and sexual abuse.
  - access,
  - recruitment,
  - the development of trust
  - managing potential vulnerability

RESEARCHER SAFETY

- Distress protocols
- Blurring boundaries

ETHICS IN RESEARCH ON SENSITIVE TOPICS / WITH VULNERABLE PEOPLE

- Tensions between researcher and participant needs:
  - conveying the possibility of distress

  BUT

  - not discouraging participation;

  - staying within the confines of the research topic

  VERSUS

  - allowing participants to influence the agenda.

COLLABORATORS AS GATE-KEEPERS

- Desire to protect
- Distrust of researchers
  - ‘heart’ vs ‘head’
- Lack of resources
- Potential participants cast as lacking in agency or ability to assert or attend to own needs

BENEFITS TO PARTICIPANTS

- Return to Beneficence and Justice…
- Participants frequently report benefits from participation, *even when distress is experienced* (e.g. Decker et al., 2011).
- What constitutes ‘harm’?

- Grief, anger and fear in response to discussing trauma is understandable and not necessarily harmful. - Becker-Blease & Freyd, 2006.

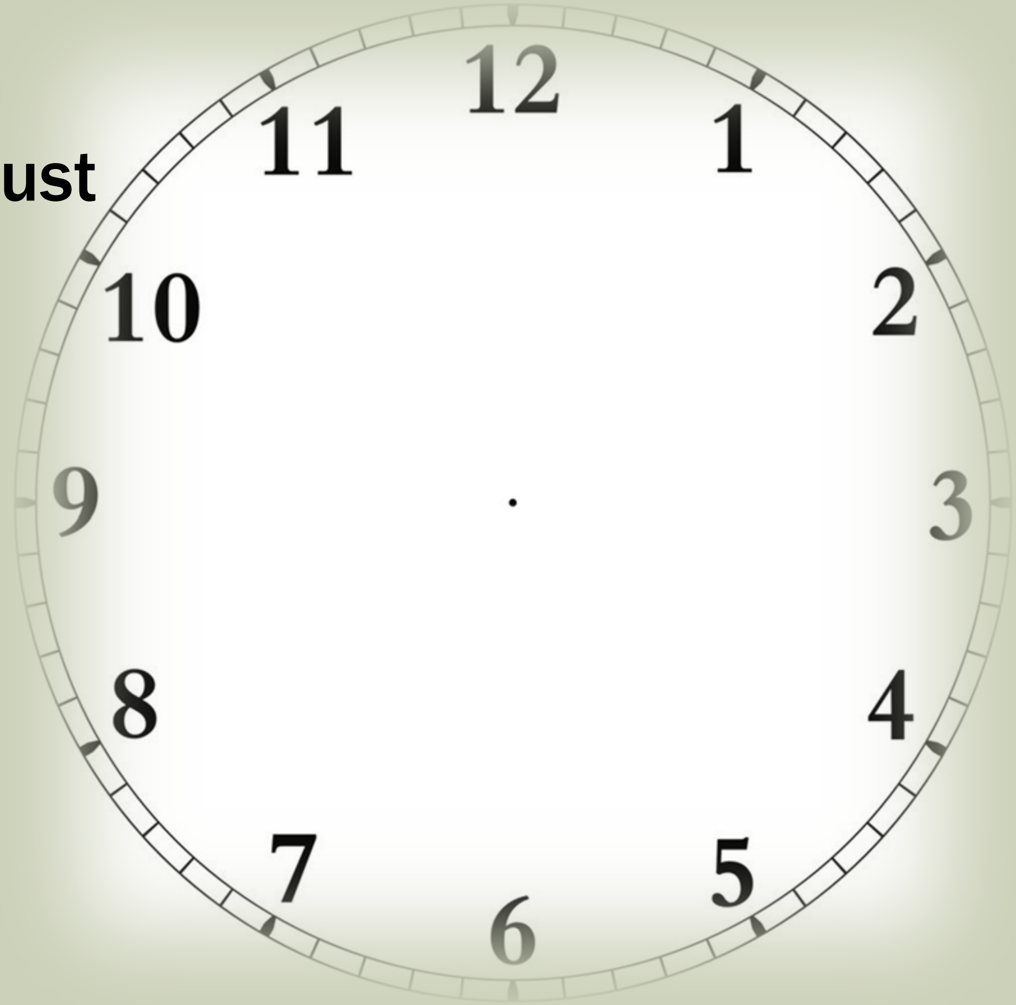
- Cognisance of strength and resilience.

PARTICIPANTS

- The ethics of age and informed consent
- Interviewing, not counselling
  - “How did you feel about that?”
  - Staying on track vs ‘being heard’
- Preconceived ideas:
  - ‘I haven’t been raped’;
    ‘I’m not suicidal’

SOLUTIONS?

Building trust and rapport



MITIGATING HARM, MAXIMISING BENEFITS

- Assessing potential harm
  - E.g. - screening interviews
- Distress protocols
- Participant benefits (e.g. Newman, Walker, Gefland, 1999)

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