

Qualitative Research Example for Institute Presentation

# Do Drug Abuse Researchers have a “Duty to Protect” Third Parties from HIV Transmission? Moral Perspectives of Street Drug Users

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# HIV Research Ethics Question(s)

- Do ethnographic researchers working over long periods with marginalized drug users and their partners have a moral duty to warn the HIV negative participant if they are unaware that the partner with whom s/he is having unprotected sex is HIV positive?
- How can prospective participants' views on investigator responsibilities in such situations inform confidentiality and disclosure policies?

# Background/Rationale

- Ethnographers are often involved in long term professional relationships with HIV seropositive active drug users who may discuss with the researcher sexual or needle sharing practices with other research participants known by the investigator to be HIV negative.
- In such situations investigators often struggle with the “scientist-citizen dilemma”: Their ethical obligation to protect participant confidentiality and their responsibility to protect third parties from harm.
- Appelbaum and Rosenbaum (1989) argued that Tarasoff type duty-to-warn responsibilities could apply to researchers who had a special relationship the a participant, could predict harm, and knew the identity of the third party in harms way.
- Participant perspectives can inform ethical decisions regarding if and when investigator’s confidentiality obligations are superceded by their responsibility to intervene in HIV transmission.

# Specific Aims

- Aim 1: To explore the attitudes and moral reasoning of drug users to investigator obligations to maintain or disclose confidential information when an HIV positive participant is deceptively engaging in unsafe sex with an HIV negative participant
- AIM 2: To examine how different informed consent policies influence drug users' attitudes to an investigators "duty to warn."

# Hypotheses or Anticipated Themes

## Anticipated Themes

- “Respect” Researchers have an obligation to keep all information private
- “Beneficence” Saving someone’s life is more important than keeping a confidentiality promise
- “Professional Duty” Researchers have to abide by whatever confidentiality or disclosure policy was communicated in informed consent
- “Professional Competence” Researchers should not expect drug using participants to understand or remember confidentiality policies described during informed consent
- “Social Responsibility” The HIV positive participant has a moral obligation to tell his/her partner
- “Personal Responsibility” The HIV negative participant is responsible for his/her own HIV risk practices

# Study Population

- 100 HIV positive and HIV negative homeless or marginalized active drug users
- 11 focus groups homogenous with respect to gender, ethnicity (African American, Lantino/a, non-Hispanic white), language (English v. Spanish) and sexual orientation (self-identified MSM)

# Research Design

- 8 – 10 participants in each focus group
- Discussion begins with participant's previous experiences with research
- Video using professional actors speaking in English or Spanish starts with 30 second introduction asking viewers to think about ethical issues followed by a naturalistic vignette depicting an ethnographic interview
- Following open-ended comments, scripted probes to elicit discussion on investigator and participant rights and obligations

# Measures/Methods

4 minute video depicts a street setting meeting between an ethnographer and participant and includes all 3 Tarasoff criteria:

- 1 Investigator has a “special relationship” (symbolized by the gift of food and obvious familiarity)
- 2 Risk of HIV transmission is “foreseeable” when participant who is known to be HIV+ tells ethnographer s/he has lied to his/her HIV-partner about his/her HIV status and is having unprotected sex
- 3 Since the HIV- partner is also a participant, the potential “victim” is “identifiable” and locatable.

The participant rejects Investigators suggestions to tell partner and investigator reminds participant that the limits of confidentiality had been explicitly mentioned during informed consent.



# Procedures

- Video and focus group script modified following CAB review
- Recruitment will use street outreach and announcements in service agencies serving homeless, drug using, and HIV +
- Focus groups conducted in agency meeting rooms
- Informed consent obtained by 3<sup>rd</sup> party in waiting room
- Participants assigned “color names” to protect identity on tape recordings
- Video presented
- Focus group script guided participant discussions
- \$25 compensation + pizza and snacks

# Analytic Strategies

- 2 independent coders read the transcripts and code responses in terms of emergent themes and themes reflecting Belmont principles and other bioethics constructs where appropriate.
- An integrated codebook is generated
- Inter-rater agreement assessed by coding of 2 additional independent coders
- A final set of codes catalogued in a software program (Atlas.ti) and salience of different themes compared across focus groups

# Community Consultation/Dissemination Plan

- CAB review and modifications to video script and focus group probes
- CAB review of content analysis and interpretation
- Disseminate “newsletters” thanking participants and summarizing results to service agencies from which participants were recruited

# Project Challenges

Following initial discussion of the vignette would it be helpful to prompt for reactions to the problem within different contexts?

- *What if the investigator learned the HIV+ participant was having unprotected sex with a minor?*
- *What if this was the first time the participant was meeting with the investigator?*
- *Would the informed consent issues be different in the participant was not a drug user?*

Grouping focus group members with respect to HIV+ or HIV- status would potentially violate their privacy. Is it a problem that each focus group would have a mixture of HIV+ and negative participants?