Do Researchers have a Duty to Warn Third Parties at Risk for HIV Transmission?

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Why Study Ethical Issues in Research Involving Street Drug Users?

- Belmont principles: Respect, Beneficence, Justice
- Not all study populations are the same
- To meet the highest standards of human subjects protections requires fitting ethical procedures to the study population
What are Drug Users Research Ethics Vulnerabilities?

Informed, Rational and Voluntary Consent (Respect)
- Cognitive impairments, cravings & withdrawal,
- Co-morbid mental health disorders
- Poverty, Health disparities

Informational Harms (Beneficence/Nonmaleficence)
- Illegal behaviors, dangerous social networks,
- Social stigma, economic discrimination

Under or Over Representation in Research (Justice)
- Minority status
- Public Priorities
Goodness-of Fit Ethics
Research Vulnerability is...

• *The joint product* of participant characteristics and the research context.

• The extent to which participants’ rights and welfare are jeopardized or protected by investigator actions within a specific experimental context.
GFE Questions


• What special life circumstances may render participants more or less susceptible to research ethics vulnerability (REV)?

• Which aspects of the research design may create or exacerbate REV?

• What procedures can be implemented to reduce REV?
Relational Ethics


- The translation of Belmont principals into best fitted ethical practices cannot be achieved simply through the moral reflections of scientists and IRBs.

- Moral discourse between scientist and participants is an essential means of fitting these principles to participant characteristics and research methods.
Drug Users as Moral Agents

- Drug users have the ability and willingness to grapple with complex dimensions of morality

- They share with investigators an appreciation for foundational moral principles guiding research

- Their application of these principles are contextually sensitive


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Minimizing Research Vulnerability Through Co-Learning

**INVESTIGATOR**
- Knowledge base
- Scientific method
- Testable hypotheses
- Ethical procedures available to protect participant rights and welfare

**PARTICIPANT**
- Health priorities
- Cultural values
- Fears and hopes about the general or specific scientific enterprise
- The real world context in which hypotheses will be studied

Methodology of Co-Learning

• Ensure that participants are familiar with the research methods and context for which their opinions are sought

• Avoid procedures that discourage non-contemplative responses

• Encourage an “opinions in progress” deliberation of the ethical issues (Fisher & Wallace, 2000)
An Example of GFE Research:
Confidentiality & Disclosure in Ethnographic Drug Use & HIV Research

Key Ethical Questions
When Principles of Respect and Beneficence Conflict

• When, if ever, does an ethnographer’s responsibility to intervene in HIV transmission supersede obligations to protect participant confidentiality?

• Do researchers have a moral obligation to 3rd parties under conditions that meeting Tarasoff Duty to Warn criteria?

• How are the answers to these question influenced by initial informed consent?
100 Participants: 11 Focus Groups

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Ethnicity</th>
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<tbody>
<tr>
<td>• 68% Male</td>
<td>• African American (33%)</td>
</tr>
<tr>
<td>• 76% Heterosexual</td>
<td>• Hispanic (37%; majority Puerto Rican)</td>
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<tr>
<td>• 22 - 70 years, M = 43</td>
<td>• non-Hispanic White (22%)</td>
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<tr>
<td>• 39% HIV+</td>
<td>• Other Latino or mixed Hispanic Caribbean/West Indian (8%)</td>
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<td>• 61% unemployed</td>
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<td>• 46% lived at a shelter, community housing, boarding home or with a family member</td>
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<td>• 79% ≤ high school education</td>
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<td>• 75% previous research experience</td>
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<td></td>
<td>Commonly used drugs</td>
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<tr>
<td></td>
<td>• powder cocaine (45%)</td>
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<tr>
<td></td>
<td>• heroin (44%)</td>
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<tr>
<td></td>
<td>• crack (32%)</td>
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<tr>
<td></td>
<td>• marijuana (29%)</td>
</tr>
<tr>
<td></td>
<td>• illicit methadone (18%)</td>
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<tr>
<td></td>
<td>• speedball (heroin + cocaine) (13%)</td>
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</table>
Co-Learning Methodology

Video Cases

• Video scripts created with CAB prior to filming

• Case enactments using actors representing an investigator and a participant

• Narrator encourages focus group members to think about case-specific ethical issues

• Videos in English & Spanish

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Co-Learning Methodology

Focus Group Composition
• Homogenous for gender, language, sexual orientation
• Video participant gender matched to group gender

Focus Group Introduction
“We’ve asked you here today to get your advice on how to improve the way research is conducted when it involves persons who use drugs and are at risk of HIV”
Field Research/Ethnography
The Researcher as Moral Agent
“There is some obligation to say something”

- **Agency**: “If you know who they are, then I would think that there is an obligation to tell those people that they’re at risk”

- **Conscience** “[the researcher] is going to think that he should have told, …if he doesn’t say it, how is the researcher going to feel later on?”

- **Professionalism** “[the researcher] needs to tell; She needs to be a professional and do her job. ” “It’s in his job description”
Responsibility to Community

• “She is messing with her credibility in the neighborhood....if she knows that he’s putting someone at risk to be hurt then she has to disclose.”

• “Because if [Chris] doesn’t know, he can infect the next person, and the next person. [Steve] is endangering a lot of lives…”

• “There are going to be other people that are going to be glad that you told because they won’t mess around with that person either.”
The Participant as Moral Agent

“Taking your responsibility”

• “If you knew that you are positive and you don’t tell nobody it should be a crime because your killing them”

• People are dying who have nothing to do with what you did sexually, and... that overrides all that other stuff about I don’t want to tell because I’m gonna lose them.

• “It's fair [for the researcher] to tell], you know why? Cause he [Steve] lied.”
“People are responsible for themselves”

• “If you’re HIV positive and you’re involved in a relationship… it’s the person’s obligation, who is positive, to tell.

• I don’t think [the researcher] should tell. Everyone knows about AIDS. If you don’t have a rubber on… you’re taking you’re chances and it’s as simple as that.
Contractual Obligations

“She should enforce the rules on him”

**Researcher**

“I think [the researcher] should tell [Chris] because she already explained to him the rules and regulations at the beginning.”

“It is illegal to reveal any information that you don’t sign a paper telling that you want to release information.

**Participant**

They sign consent forms at the beginning of the interview. They should follow whatever the consent forms say

I don't care if you're high. Always read things before you sign it.
Pragmatic Implications & Recommendations

• "He could have killed her for that!"

Alternatives

• "She is not gonna have to convince him but she can say to him that the three of them can talk together"

• What she could tell her is that, you know what, when was the last time you got tested? *Don't you think it's time you got tested for HIV? Since your boyfriend is getting high, whatever.*"
Implications
Research on Research Ethics

• There are no cookies cutter solutions to fitting confidentiality/disclosure policies to all populations and all research designs.

• Empirical studies drawing upon stakeholder perspectives are an essential means of achieving policies ethically fitted to the research context and participant vulnerabilities and values.

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Implications for Goodness-of-Fit Confidentiality & Disclosure Policies

• Street drug users view both investigators and participants as moral agents

• Investigators & participants are responsible for actions that place others or themselves in jeopardy

• Both are responsible for commitments made during informed consent

• Policies need to reflect these dual obligations from both participant and investigator perspectives
What Policy Would You Recommend?
References

References


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