Introduction

In 2008, over 2.3 million individuals were detained in state or federal prisons and local jails (West & Sabol, 2009). Individuals living with HIV/AIDS are disproportionately represented in the U.S. incarcerated population, with the rate of confirmed AIDS over 2 times higher in prisons than in the general population (Muraczek, 2008). Due to ethical challenges presented by the correctional environment, incarcerated individuals who participate in research are considered to be a vulnerable population (DHHS, 2009). Incarcerated individuals lack autonomy (the foundation for providing voluntary consent), privacy, and interact with correctional staff who may have agendas or concerns of increased vulnerability (Leavie et al., 2004; Mobley et al., 2007). Correctional settings are an important venue for the conduct of HIV/AIDS research because of the high rate of HIV/AIDS among incarcerated individuals and because of public health concerns following their release from prison (Brewer-Smyth, 2008; Spaulding, et al., 2002).

One recommendation used to evaluate the ethical conduct of research is the assessment of potential risks and benefits for participants (National Commission for the Protection of Human Subjects, 1978). There is a little research related to an assessment of these ethical issues with vulnerable populations, especially HIV/AIDS research with correctional populations (Institute of Medicine, 2004). To fill this gap, the current study examines the potential risks and benefits for participants in HIV/AIDS research in correctional settings.

Method

Participants

A nationwide sample of 92 key informants (15 prison administrators, 16 IRB chairs or members, 16 IRB prisoner representatives, 15 research ethicists, and 30 researchers) with experience in and/or knowledge of the conduct of HIV/AIDS research in correctional settings were interviewed for this study.

Interview Protocol

A semi-structured interview guide was developed that consisted of 18 questions related to HIV/AIDS research within correctional settings. Questions were related to the correctional setting, application of ethical principles, regulatory oversight, vulnerable populations, and recommendations for researchers and IRB members involved in the conduct or oversight of HIV/AIDS correctional research.

Procedure

Potential interviewees were identified through literature reviews, internet searches, and snowball sampling. Semi-structured telephone interviews lasting approximately one hour were conducted with participants, who were compensated $100 for their time. Interviews were audio-recorded, transcribed, and imported into NVivo 8 for qualitative data analyses.

Data Analyses

Qualitative interview data was coded using NVivo 8 with procedures designed to ensure thoroughness and reliability. A sub-sample of five interviews was selected to develop an initial set of free nodes transcribed, and imported into NVivo 8 for qualitative data analyses.

Findings: Potential Risks for Harm

Violation of Ethical Principles

- Confidentiality & Privacy
- Disclosure of HIV/AIDS status
- Undue Influence & Informed Consent

Findings: Potential Benefits

- Access to a “standard of care” or enhanced medical care
- Increased attention from medical staff
- Opportunity to communicate with and receive social support from individuals outside of the correctional setting
- Opportunity to learn about and receive social support from individuals within the correctional setting
- Opportunity to share knowledge of prevention and intervention strategies within the correctional setting

Discussion

Findings revealed a range of potential risks for harm and potential benefits associated with participation in HIV/AIDS research in correctional settings. The major risks of participation were related to breaches of confidentiality and privacy, the potential for coercion from correctional staff, and potential psychosocial distress. The major benefits of participation were related to the access of otherwise unavailable services, contact with research staff outside of the correctional setting, and HIV/AIDS/STI education.

This qualitative study investigated the perspectives of prison administrators, IRB chairs and members, IRB prisoner representatives, research ethicists, and researchers familiar with the challenges in conducting HIV/AIDS research in correctional settings. Findings offer researchers and IRB members insights into the potential risks and benefits of participation in HIV/AIDS correctional research. These insights may be helpful in the development of training for HIV/AIDS correctional researchers.

Future research might systematically explore the risks and benefits of different types of HIV/AIDS correctional research (e.g., the risks and benefits of participation in biomedical research versus behavioral intervention research). Additionally, the current study did not examine risks and benefits from the perspective of individuals who are incarcerated. Future research could directly examine the perspectives of potential participants in correctional HIV/AIDS research.

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For more information

Center for Behavioral Health Research and Services: http://cfhs.uaa.alaska.edu
Research Ethics Projects Website: http://www.uaa.alaska.edu/researchethics

References


