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Ethical Challenges of HIV Partner Notification in Prisons

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Abstract

Partner services provide a safe and humane way for people living with HIV (PLWH) to alert their sex and/or drug-injecting partners to the possibility of HIV exposure and the need for HIV testing, yet little is known about the ethical challenges of delivering partner services in prisons. In this article, we consider 7 key ethical and methodological questions that should be considered when developing, testing, or implementing partner services in prison settings. These questions relate to the ethics of: (1) mandatory HIV testing, (2) health illiteracy, (3) level of prison staff involvement, (4) protecting confidentiality, (5) minimizing harm, (6) achieving equivalency with community standards of care, and (7) providing HIV prevention and treatment services to index patient and their partners. By assisting PLWH in prison to inform partners with whom they may have shared HIV exposure either before or during incarceration, partner services can help to identify cases of undiagnosed HIV infection for testing and linkage to medical care. The acceptability and effectiveness of a future partner services model for PLWH in prison depends critically on answering these 7 questions to assure the highest ethical standards of research and practice.

Keywords

contact tracing, criminal justice, HIV prevention, partner notification, prison, people in prison

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What Do We Already Know About This Topic?

HIV partner services are effective for notifying and testing people who have shared an exposure to the virus but raise serious ethical concerns when studied or implemented in prisons or other freedom-limiting settings.

How Does Your Research Contribute to the Field?

We discuss seven key ethical challenges to studying or implementing HIV partner notification services in prisons, emphasizing the steps required to protect the autonomy, confidentiality, safety, and well-being of people in prison.

What Are Your Research's Implications Toward Theory, Practice, or Policy?

Answers to these seven ethical questions are needed to guide the development of ethically-responsible HIV partner services research, policy, and practice models in prisons.

An estimated 389 000 people living with HIV (PLWH) are incarcerated worldwide.[1] Many of these PLWH were first diagnosed with HIV in prison and could benefit from encouragement and assistance to inform their sex and drug-injecting partners in the community of possible HIV exposure. HIV partner services are a form of contact tracing that utilizes trained health-care providers to help PLWH either to disclose their HIV-positive status or anonymously contact their partners to advise them of possible

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exposure to the virus and offer them HIV testing. Partner services are safe and highly effective[2,3] and are being implemented internationally as a public health approach to increase HIV testing.[4,5] Yet, little to no scientific research has been conducted to establish "best practice" models of ethical partner services research or practice in prisons, despite evidence that effective HIV prevention in prisons is crucial to global HIV control.[6]

Studying partner services in prisons presents important opportunities yet raises numerous ethical and methodological challenges for research and also the specific implementation models that may result from it. Not only are prisons coercive by design, they severely limit the ability to control one's privacy and physical safety. Both abilities are essential preconditions for ethical and effective partner services.[7] Moreover, people in prison are often members of economically and socially disadvantaged groups, including people who inject drugs who comprise the single largest group of people in prison globally.[8] Their participation in partner services and disease surveillance raises serious ethical concerns.[9,10] A focus on the ethical challenges of HIV partner notification in prisons is needed, therefore, to guide ethically responsible partner services research and implementation within the prison context.

In this commentary, we consider 7 key ethical questions that researchers and service providers confront when offering partner services to people in prison. Answering these questions could help to ensure that research on partner services meets the highest ethical standards in the protection of human research subjects while also providing insight and guidance regarding the key ethical components required for partner services to be effective. Informing this discussion are the 3 principles of the *Belmont Report* (ie, beneficence, justice, and respect for persons),[11] World Health Organization (WHO) guidelines for partner notification,[7] and our own experience studying and providing partner services. Here, we refer to PLWH diagnosed in prison as *index persons*, with the understanding that their partners and not the prisoner may have been the source of transmission. We discuss the ethics of HIV partner services in the context of scientific research as well as how it applies to the responsibilities of health-care administrators and providers who deliver partner services in prisons.

Question 1: What Are the Ethical Challenges to Ensuring Inmates' Voluntary Participation and Informed Consent for Partner Services?

Voluntary participation in partner services typically begins with HIV testing. Unfortunately, HIV testing in some prison jurisdictions is compulsory and prisoners lack the right to refuse. Although this practice typically reflects decisions made at the policy level, it is opposed by most international public health agencies[12,13] and runs counter to the basic ethical principle that participation in research and medical treatment should be voluntary and with the person's full informed consent. Those who provide partner services to people in prison are bound by similar principled commitments.[7] Moreover, at the service level, mandatory HIV testing and inadequate post-test counseling may reduce the willingness of index patients to name or refer their partners for HIV testing.

With opt-out testing, a person is informed that HIV screening will be done, and consent is inferred unless specifically declined.[14] Opt-out approaches are effective and comply with international guidelines. Yet, they also raise serious concerns about whether or not people are adequately informed about the risks of HIV testing or receive their HIV test results and appropriate posttest counseling.[15,16] If HIV testing is to be offered as part of partner services, steps must be taken to assure that individuals understand their right to accept or refuse HIV testing without incurring reward or penalty. Following these steps also provides an opportunity to teach patients about the importance and voluntary nature of partner services.

Question 2: What Information Do Incarcerated People Need to Make an Informed Decision about Whether or Not to Participate in Partner Services?

Health illiteracy is a major barrier to health promotion among people in prison[17] and also of great concern to researchers in conducting ethical research involving prisoners. Also, prisoners often are members of marginalized or ethnic populations with their own cultural and linguistic conventions. Consequently, informed consent for partner services should be provided both orally and also in a written form at a language level consistent with the individual's ability to read and write.

Research suggests that PLWH who understand the seriousness of HIV infection and the benefits of early treatment may be more willing to notify their partners and motivate them to be tested.[18] Therefore, in addition to high-quality posttest counseling, index patients should receive basic education about HIV for their own health and also for communicating with their partners about exposure. Peer educators have been shown to be especially effective in delivering such information to other inmates.[19] Decisional aides in the form of brochures, fact-sheets, videos, and decision tables can also be used to explain the advantages and disadvantages of available partner notification options and to assist PLWH to decide whether and how to notify their partners.[20] Index patients who choose to notify partners themselves may need coaching to anticipate and handle their partner's reactions and guide them toward HIV testing.

Question 3: Who Is Best Suited Institutionally or Occupationally to Recruit Prison Inmates for Partner Services Research or to Assist Them in Identifying and Notifying Their At-Risk Partners?

The ethics of collaborative responsibility dictate that input should be obtained from prisoners and other stakeholders on the design and conduct of research protocols or studies

involving prisoners.[21] Yet the boundaries between the responsibilities of prison staff and those of researchers and partner service providers must be strictly drawn and agreed upon in advance of action. Although correctional officers can help to ensure that inmates receive timely access to health services,[22] their occupational role in enforcing prison regulations, which can involve punishments and loss of privileges, renders them unacceptable candidates for counseling inmates about partner services. Also, because of their law enforcement duties, correctional officers should never be given the responsibility to contact partners, some of whom may be engaged in illegal activities.[7]

In contrast to custodial staff, prison medical providers are bound by the norms of professional independence that mandates placing the needs of patients first and the freedom to exercise professional judgment in their care and treatment without undue influence by institutional or other interests.[23] Maintaining this independence is a critical component of high-quality medical care and an essential principle of health-care professionalism.[11] This principle is especially important in prison settings where the relationship between medical providers and patients is based on assignment rather than choice.[7] Prison medical providers potentially can play an important role in assisting index patients to identify partners with at least 2 caveats. First, people in prison depend entirely on prison medical staff for their health care. Consequently, it is essential that prisoners do not feel threatened or obligated to refer partners because of this reliance. Second, despite a professional code that dictates medical independence, providers can feel caught between a primary duty to care for their patients and secondary duty to follow the rules of prison management.[24] Clear definition of responsibilities that uncompromisingly separate those of medical providers from correctional staff and professional oversight by an outside body of professionals may help to keep the patient's needs first.

Utilizing community health workers to provide partner services offers a possible solution in separating the responsibilities of disease notifiers from the competing duties of prison medical staff. For example, WHO guidelines emphasize that collaboration with community-based organizations to provide health services can assist greatly in promoting health and well-being in prisons.[25] Community-based organizations tend to have considerable capacity and expertise in providing HIV testing, counseling, and referral services.[26,27] Because staff members employed by community organizations tend to know the culture, social cliques, and layouts of specific neighborhoods, they may also be better equipped than prison medical providers to locate partners in the community and connect them with HIV testing and treatment services. Irrespective of who provides partner services, it is essential that providers receive ethics training to reinforce respect for the index person's human rights to autonomy and confidentialty.[28] Written policies and protocols for delivering partner services will help to further codify these ethical standards.[21]

Question 4: How Can Prison Inmates' Participation in Partner Services Be Kept Confidential from Other Prisoners, Correctional Staff, and Partners Who Are Named?

Breaches of confidentiality can occur unintentionally in any setting and at any stage of partner notification unless rigorous procedures are in place to protect the confidentiality of index patients and their partners. Due to the confined and often overcrowded living conditions in many correctional facilities, PLWH are especially vulnerable to unwanted disclosure of their HIV status or use of HIV-related services. As a consequence, they may refuse to participate in partner services to protect their confidentiality and avoid possible stigmatization.

To avoid unintentionally revealing the index person's identity to third parties without a legitimate reason to know, elicitation of their partners' contact information could be conducted during HIV posttest counseling that all prisoners receive or alternatively during a patient's regularly scheduled clinic visit. In either case, partner elicitation should occur in a private setting away from other prisoners or prison staff. These methods avoid individuals being singled out overtly as needing partner services. Records pertaining to partner services should be kept separately from a patient's medical record, secured safely, and with access limited to those who provide partner services.

A strong case can be made that service providers who assist index patients in identifying their partners should not be the same people who contact and notify their partners. Separating these duties would help to ensure that the index patient's name is not revealed unintendedly to partners. Utilizing community service providers who do not know the index patient in prison also could help to reduce this risk of unintended disclosure. No information about the index patient should be revealed to partners, including that the person who named them is incarcerated. Such information alone may be sufficient to identify the index patient. In addition, providers should only notify partners who the index person has agreed to notify. The "duty to warn" should not be extended to unnamed persons in the index patient's network even if contact with them during the notification process suggests that they also might be at risk.

Question 5: What Policies Are Needed in Prisons to Protect the Safety and Welfare of PLWH Who Participate in Partner Services?

Policies and ethical procedures for the protection of prisoners as research subjects and as patients in a prison setting have been codified through a number of globally accepted documents.[29] The core principles that these agreements represent are further reinforced by prison and institutional review boards in fulfilling their oversight mission. Nonetheless, partner services in prisons are at a nascent stage, and specific guidelines to

protect the safety and well-being of prisoners who participate are still being developed.

Harms attributable to partner notification appear from the scientific literature to be exceedingly rare.[7] Yet most existing data on their safety are derived from studies with couples in community settings and have excluded persons at risk for intimate partner violence (IPV).[3] This targeted sampling possibly masks the extent to which IPV occurs outside of an experimental environment. Because prisons are characterized by levels of conflict not usually found in community settings, findings in the literature reporting on retaliatory physical violence may not be fully applicable to people in prison.

Notifying a partner is not without social risk for the index patient and possible emotional and social consequences for the partner who now confronts the likelihood of HIV exposure. For these reasons, index patients should be counseled as to their partners' possible reactions to being notified. Upon learning of exposure or that they are HIV positive, partners may choose to make substantial life changes including severing HIV risky relationships, even when the index patient's identity is unknown. For HIV-diagnosed prisoners, a change in their relationships with partners could entail the loss of much valued social support during incarceration and later upon release.[30] Prisoners who experience dissolution of a partnership may benefit from counseling and referral to community services and peer support after their sentence has ended. They also may profit emotionally from counseling that helps them to cope with their own responses if they believe that their own infection was due to transmission from their partner.

Available evidence suggests that consensual and nonconsensual sexual activities in prison are rare[31-33] but frequent enough to warrant careful attention before implementing partner services. Moreover, unsafe drug injection occurs with some frequency in prisons.[34] Partner services, therefore, may lead to naming of partners who are also incarcerated or employed within the index person's same prison facility. Such naming might, in turn, result in some form of retaliatory violence or punishments. One strategy to militate against such possible outcomes is to routinely offer HIV testing to all inmates and prison staff since this approach does not require informing a specific partner of exposure.[13] Postponing notification until the index patient is released or transferred to another facility is another option but could delay HIV testing for the partner and treatment if needed.

Question 6: Which Adaptations Are Needed to Assure that Partner Services Offered in Prison Are Substantially Equivalent to Those Offered in the Community?

The United Nations Standard Minimum Rules for the Treatment of Prisoners adopted in 1955 and later revised as the "Nelson Mandela Rules" advise that the human rights of prisoners include access to the medical services needed to evaluate, promote, protect, and improve their physical and mental health.[35] Distributed justice for prisoners demands that these services be equal to those available to nonincarcerated persons. The WHO recommends offering multiple partner referral methods, including direct referral by the index patient (ie, patient referral or "self-tell"), anonymous notification by a health-care provider (ie, provider referral), or some combination of these 2 approaches (ie, dual referral and contract referral). The choice of referral method is based on the index person's individual preferences and consideration of factors such as the patient's ability to contact partners and desire for anonymity.

Although patient referral is an option for some prisoners, incarceration often results in estrangement from a partner, and index patients have limited ability to search for or contact their partners while they are incarcerated. Moreover, prison settings provide little privacy for PLWH to disclose their HIV-positive status to partners. For this reason, the service option of provider referral can serve as an acceptable alternative to relieve the burden or difficulties of informing a partner and also offer anonymity to PLWH who wish to remain anonymous. Yet, no single referral method is universally preferred, and index persons may wish to use different strategies with different partners. To address different needs and preferences, researchers and providers should work with prison administrators to make reasonable accommodations for PLWH who need assistance to contact partners or to arrange a private setting within prison in which to disclose their HIV status.

Question 7: What Health Services Should Be Provided to Index Persons in Prison and to Their Partners Who Are Notified?

Although the rights of people in prison to medical and preventive health care are preserved in human rights law,[36] health services in many prisons often are inadequate to address the extraordinarily high burden of illness among inmates.[34,37] Furthermore, studies suggest that diseases that disproportionally affect people in prison also are highly prevalent among their partners in the community.[38]

From an ethical standpoint and also from the perspective of good medical and public health practice, it is essential that partner services are implemented as part of a comprehensive package of HIV prevention and treatment services.[7] These include the provision of antiretroviral therapy (ART), substance use treatment if needed, and other essential medical care to treat comorbid conditions.[12] In previous studies where ART was unavailable or underutilized, researchers have worked with prison authorities to expand HIV treatment services in prison during the implementation of research studies.[39] The provision of essential medical care in prisons is not only an ethical requirement but, insofar as it improves the health of PLWH, is likely also to motivate patients to see that their partners receive these same types of services.

As part of their ethical obligation, researchers and providers should carefully consider how partners who are contacted will be linked to HIV testing and treatment. Available evidence suggests that people with an incarcerated partner are often themselves members of socially or economically disadvantaged groups that may require assistance to access HIV testing and treatment.[38] One approach to increase HIV testing among partners is to offer immediate point-of-care testing and treatment referral for those with an initial reactive test.[40] Also, by working with community agencies to ensure that ART is accessible and affordable for partners who test positive for the virus, researchers and service providers are likely to generate higher levels of interest and acceptance for partner services in the community.

In sum, partner services offer a compassionate and effective way to refer high-risk individuals for HIV testing and should be offered to PLWH in prison. Although numerous practical and ethical challenges must be considered and successfully met if partner services are to succeed within prison settings, these challenges are similar in most respects to those encountered when studying or implementing partner services in community settings. Potential risks can be mitigated, and the benefits of HIV partner services made substantially greater, by examining and developing ethical answers to the 7 questions that are posed. Partner services as a personal and public health strategy in prison is worth the investment given its potential impact in reducing HIV transmission and allowing people whose infection is undiagnosed into testing, treatment, and care.

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