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HIV Testing and Treatment with Correctional Populations: People, Not Prisoners

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Abstract

Institutional policies, practices, and norms can impede the delivery of ethical standard-of-care treatment for people with HIV in correctional settings. In this commentary, we focus on the fundamental issues that must be addressed to create an ethical environment in which best medical practices can be implemented when working with correctional populations. Thus, we consider ethical issues related to access to services, patient privacy, confidentiality, informed consent for testing and treatment, and issues related to the provision of services in an institutional setting in which maintenance of security is the primary mission. Medical providers must understand and navigate the dehumanization inherent in most correctional settings, competing life demands for incarcerated individuals, power dynamics within the correctional system, and the needs of family and significant others who remain in the community.

Keywords

Corrections; HIV; ethical treatment and care

The U.S. has the highest incarceration rate in the world and the number of people under U.S. correctional jurisdiction continues to grow. At mid-year 2008, over 2.3 million adults were

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incarcerated in the U.S.[1] and at mid-year 2007, more than 7.3 million adults were on probation or parole and under criminal justice supervision in the community.[2] The majority of people under correctional jurisdiction in the U.S. are male and members of a racial or ethnic minority.[1-2] At mid-year 2008, African American and Hispanic males were 6.6 times and 2.4 times, respectively, more likely than White males to be incarcerated.[1]

HIV infection and AIDS prevalence are higher among people who are incarcerated than among individuals in the general population, with the highest rates among women who are incarcerated and Hispanics and African Americans, regardless of gender.[3] In addition, research has documented elevated rates of hepatitis and other sexually transmitted infections (STIs) in incarcerated populations.[4-6] People entering correctional settings often report behaviors that have placed them, and their partners, at considerable risk for HIV, hepatitis, and other STIs; these risk behaviors include unprotected sex with multiple and high-risk sex partners, co-occurrence of sex and substance use, and injection drug use with needle-sharing.[7-10] Thus, identifying and treating HIV in correctional populations should be a major public health care priority in the U.S.

For incarcerated people who lack health insurance in the community, the correctional setting may be a primary point of access to HIV testing and treatment. Because of the greater prevalence of HIV and AIDS in correctional populations and the lack of access to care in the community, the delivery of HIV-treatment has placed a high cost burden on correctional health care systems. For providers who deliver HIV-treatment, information about best medical practices are readily available.[11-12] However, less attention has been given to institutional policies, practices, and norms that interfere with the delivery of treatment for HIV within the cultural context common to many correctional settings. In this commentary, we focus on the fundamental issues that must be addressed in providing HIV testing and treatment for people in the criminal justice system.

The provision of treatment to people with HIV in correctional settings encompasses special considerations related to access to services, patient privacy, confidentiality, informed consent for treatment, and the provision of services in an institutional setting whose primary mission is not health but the maintenance of security. Providers also must understand and navigate the dehumanization inherent in most correctional settings, power dynamics within the correctional system, competing life demands of incarcerated individuals, and the needs of family and significant others who remain in the community. Finally, although our discussion of providing ethical HIV testing and treatment in correctional settings does not specifically address racial and ethnic inequalities, we note that incarceration is predominantly and disproportionately experienced by racial and ethnic minorities.[1] Thus, any discussion of providing ethical medical care for incarcerated people must be sensitive to these underlying structural and sociocultural contexts of correctional settings.

Structural challenges to the conduct of ethical HIV-related programs and medical care in correctional settings

The correctional system encompasses a range of different systems, from federal penitentiaries to state prisons, jails and other short-term detention facilities, halfway houses

and other re-entry housing, and community corrections, including diversion programs, probation, parole, and electronic monitoring or house arrest. These different correctional jurisdictions greatly affect circumstances and services for individuals with HIV, and may be particularly salient for people with HIV as they move from one correctional entity or institution to another (e.g., from jail to prison to parole). These transitions have the potential to greatly disrupt HIV treatment and other programs for a given individual and present serious challenges to coordinated care, standards of care, and treatment outcomes.[13-15] In making the transition from one system (e.g., jail to prison) or one facility to another, a person with HIV who was receiving medical care in one setting may have to start all over in the new setting with new tests, diagnoses, medication, and treatment plan. This duplication of services is expensive and time-consuming and can lead to an interruption in treatment and the development of resistance to treatment medications. It is important that non-correctional personnel who provide services within a correctional setting recognize that transitions from one correctional entity to another, or from one institution to another, do not always occur seamlessly.

Correctional systems operate within a hierarchical chain of command that often is unfamiliar to care providers from outside the correctional system and that can interfere with the ability of providers to offer community standards of care within a correctional system. Providers from outside the correctional system must learn how to work within the constraints of a correctional system.[16] For example, providers from outside the system may assume that correctional staff members who give formal approval for programs or treatment are the same staff members who control access to the movement of people within an incarceration facility. However, having formal permission to provide treatment or services does not necessarily translate into ready access to the people who require those services. Similarly, personnel who conduct HIV testing in a correctional setting are often different from those who provide HIV treatment or transitional planning services for people with HIV,[17] creating openings for miscommunication and failure to coordinate services. To work effectively within a correctional system, providers from outside the system must learn how the system operates, both formally and informally, and cultivate a flexible attitude that can adapt to institutional “lockdowns,” movement constraints, and other environmental disturbances that are daily occurrences in correctional settings. A provider’s patience and willingness to work within the system greatly enhances his/her ability to provide community standards of care and create sustainable programs. Providers must consider whether their goal is to change the system within which they deliver services or to help incarcerated people navigate and manage their lives and improve their health within that system.

Ethical challenges related to informed consent, confidentiality, and privacy

There has been considerable ethical and public health debate about whether HIV testing should be mandatory in correctional settings.[17-18] Currently, HIV testing practices in correctional settings may be broadly grouped into (1) voluntary or by request only, (2) voluntary but routine, and (3) mandated.[17-18] Recent guidelines[19] advocate voluntary but routine testing in all correctional settings. These guidelines further suggest that voluntary testing be enacted through opt-out rather than opt-in procedures. Whichever way it is administered, each of these testing practices raises questions about informed consent,

confidentiality, and privacy. When HIV-testing is voluntary, providers must ensure that the people who are incarcerated have the freedom and the capacity to give or withhold consent for testing. In correctional settings in which HIV testing is "voluntary but routine," people who are incarcerated may not know that they are being tested or may not understand their right to give or withhold consent.[17]

Before consenting to HIV-testing, people who are incarcerated must understand the potential consequences of a positive HIV test, both structural consequences (e.g., loss of privacy or confidentiality, stigmatization, state-mandated reporting, being required to move to a new housing unit or different institution, access to treatment and care, and potential for loss of educational or training opportunities) and personal and emotional consequences (e.g., the strain of coping emotionally with a positive HIV-diagnosis and/or exacerbation of mental health or psychiatric problems faced by many incarcerated individuals). Before asking a person who is incarcerated to provide consent for testing, providers must ensure that the person comprehends information about testing to ensure that consent is truly informed. Comprehension capacity among incarcerated populations is often diminished due to low literacy, mental illness, substance abuse, and other factors.[20] When HIV testing is mandatory, treatment providers and correctional administrators have an ethical obligation to provide information about the test process, test results, and the implications of a positive test result to the person being tested.

Providers must ensure that participation in HIV-related programs, services, or research is free from coercion. The potential for undue influence in correctional settings is pervasive and subtle. In a setting where deprivation of key resources is the norm, the overwhelming advantages of participation in HIV-related programs, services, or research may impair an individual's ability to make a free choice to participate or not participate. Compared with people in the free world, people who are incarcerated may be more likely to volunteer to participate in programs, services, or research for the opportunity to interact with different staff, to break up the boredom of daily institutional life, or to get access to better medical services, investigational drugs, or care and services that are otherwise not available.[20-21] Consent to participate in HIV-related research may be particularly problematic, in that compensation for participation (e.g., toiletries or small amounts of money) that seems modest in the free world may be so enticing in correctional settings that people feel that they cannot refuse to participate, even though they might otherwise refuse. In response to these threats to freely given informed consent, correctional populations are often denied the opportunity to participate in behavioral or biomedical research (e.g., HIV-related clinical trials) and denied an opportunity available to people outside the correctional system, thereby adding another layer of deprivation to the experience of incarceration.[20]

Ensuring that consent for testing, treatment, or research is freely given is difficult in correctional institutions which are, by nature, coercive environments that constrain the freedom of people who are incarcerated. There are few opportunities for people who are incarcerated to refuse participation in correctional programs; most commonly, refusing to participate in required programs results in disciplinary actions. Thus, people who are incarcerated may feel coerced to participate in technically voluntary programs because they have no experience in refusing participation without negative consequences. Giving people

who are incarcerated the capacity to make a decision to participate or not participate in HIV-related testing, treatment, and/or research programs can be an empowering experience for people confined within a system that suppresses individual autonomy by design.[20]

Protecting confidentiality and privacy in correctional settings are major challenges that involve adequate protection for medical records, personal disclosures in group settings, and reports of behavior that violate security rules or threaten safety and security. In many correctional settings, it is virtually impossible to protect privacy and confidentiality without complex safeguards. Even when the confidentiality of medical or program records are adequately secured, a person who is incarcerated can face disclosure and stigmatization by virtue of the public nature of programs and services in correctional settings. In some correctional systems, people with HIV are housed separately, relocated for treatment, or have to wait in public *pill-lines* (also called *med-lines*) for medications. Unwanted disclosure of participation in HIV-related programs or research can open an individual to discrimination and the threat of violence from prison staff and other incarcerated individuals due to homophobic fears, stigma about HIV, and misconceptions about HIV-transmission. In addition to protection for their privacy and confidentiality of their medical and program records, people who are incarcerated who are identified as being infected with HIV may require additional social support and protection from assault and discrimination.

Interpersonal challenges to providing ethical care

Providers who deliver HIV-related services in correctional settings may face an additional challenge in providing services in a cultural context and environment that is designed to objectify and dehumanize the individual. A practical approach to resisting this view of people who are incarcerated is to avoid labels and derogatory terms that stigmatize, objectify, or dehumanize, including terms such as *inmates*, *convicts*, *prisoners*, *felons*, *parolees*, *predators*, *offenders*, and *perpetrators*. Rather, providers should use labels that humanize people who are incarcerated while describing their current life situation, including phrases such as *people in prison*, *people recently released from prison*, *people on probation or parole*, *people with a criminal conviction*, or *people with an incarceration history*. These terms denote that incarceration is a current life situation and not an inherent characteristic of the person being receiving testing, treatment or other services. Dehumanizing and objectifying people who are incarcerated can foster a belief that they don’t deserve access to ethical care and treatment and a belief that people who are incarcerated are the all the same, obscuring important differences in treatment needs and resources.

Discussion of the ethical provision of HIV-related care must be embedded in the multiple life challenges that make it difficult for people who are incarcerated to prioritize distal life goals, such as HIV-treatment and prevention, when faced with immediate and pressing concerns.[22-23] These challenges, which may particularly affect people immediately after their release from prison or jail, include social barriers (e.g., limited education and occupational skills and poverty), personal barriers (e.g., history of poor family and personal relationships, alcohol and drug abuse, and mental health problems), and structural barriers (e.g., racism, disparate arrest rates and sentencing policies, limited access to social services and health care, lack of health insurance, and policies that prevent residency in publicly

funded housing). For people with HIV who have been recently released from a correctional setting, questions that might help in identifying priorities focus on: (1) Resource priorities: Do I spend money on medication or food? (2) Criminal justice priorities: Do I worry about medication adherence or parole adherence? and (3) Time priorities: Do I seek medical care or look for a job? Choices and decisions that appear incomprehensible to providers often reflect the realities of competing priorities for people who are incarcerated or have recently been released.

Finally, when providing HIV-related care or programs for incarcerated people, the needs and resources of family members and friends who remain in the community should be considered. Incarceration is a social problem that indirectly affects millions of people in the U.S. Nearly 1.5 million children under the age of 18 have a parent in federal or state prison[24] and there are millions of adults—parents, spouses, partners, and friends—who are affected by familial incarceration. Fortunately, there is a growing awareness of the social impact of incarceration on individual, family, and community health.[25] Family members and friends in the community can be significant resources for people who are incarcerated or who have been recently released from a correctional setting, especially for individuals with HIV. Indeed, strong family and social support is a key predictor of successful community reintegration among people after release from prison.[22]

More specific to HIV/STI transmission risk, incarceration can have a significant and detrimental effect on sexual partnerships.[22-23,26-29] Sexual and romantic partners in the community may develop new sexual relationships during their significant other's incarceration, and incarcerated partners may incur HIV/STIs during incarceration. Further, stressors associated with community reintegration can interfere with reestablishing relationships following release from prison, thereby increasing risk for transmission of infectious. Work conducted by our research group showed that 24% of young men engaged in behavior that increased their own and their partner's risk for HIV/STI exposure within three months after release from prison.[30] In a second study we conducted, approximately one-fourth of young men tested positive for hepatitis or another STI six months after release from prison.[6]

In sum, HIV treatment systems are likely to be enhanced when they address a person's broader interpersonal and psychosocial needs, including the needs of family members and significant others in the community.[22-23] HIV-related programs conducted in the vulnerable transitional period immediately before and after release from prison can facilitate discussion between sexual partners about the risks of infection and opportunities for treatment and risk reduction.[22,30] These transitional programs might be successful in overcoming denial about the potential for risk behavior when one partner is incarcerated and the other partner remains in the community. Transitional interventions also have the potential to promote stable and healthy intimate relationships which may support efforts to reduce infectious disease transmission risk and promote successful community reintegration.

Recommendations for HIV prevention, care, and treatment in correctional settings

Delivering HIV prevention, care, and treatment in correctional settings is not a question of simply determining the best medical practices for the treatment of HIV among incarcerated people. Rather, ethical care encompasses the creation of an environment and an approach in which best preventive and medical practices can be delivered safely and respectfully within the culture of a correctional setting. Ethical HIV prevention, care, and treatment in correctional settings requires that people who are infected with HIV or at risk for HIV infection (a) have safe access to medical, testing, and preventive services; (b) understand their treatment options and the potential benefits or side effects of testing and treatment; (c) have the information and capacity to freely consent to or refuse testing and treatment; and (d) have reasonable assurance that the confidentiality of their medical records and the privacy of their medical treatment will be protected.

An ethical environment of care also ensures that people with HIV who are incarcerated receive treatment (a) in a medical system designed to provide optimal care in a private and confidential setting; (b) from a provider who views them as autonomous individuals, rather than as prisoners without rights or individuality; (c) that addresses their interpersonal and psychosocial needs; and (d) that includes continuity of treatment support and care as they move from one correctional setting or institution into another or into the community after release. The provision of ethical HIV-treatment and prevention services in a correctional setting may be further enhanced when provided by individuals who are familiar with (a) structural challenges inherent in correctional settings; (b) the hierarchical nature of correctional settings; (c) constraints on voluntary informed consent to participate or not participate in HIV-related testing, treatment and research; and (d) the needs of individual incarcerated people and their partners, family members, and friends in the community.

We also support the guidelines recommended by Zack[31] who advocated that HIV prevention and treatment should be available to all people who are incarcerated and, when possible, be integrated into existing educational programs throughout a person’s incarceration (i.e., upon entry, in association with all institutional transfers, during the course of their incarceration). Zack further advocated that HIV prevention and treatment be integrated with correctional substance abuse and mental health treatment programs. Finally, Zack highlighted the importance of providing comprehensive pre-post release transitional support for HIV prevention and treatment as people re-enter the community, including (1) continuity of current HIV treatment; (2) support with housing, employment, and education; (3) family and social support; (4) facilitated links to community programs and providers; (5) and working collaboratively with community law enforcement (e.g., parole and/or probation) to ensure that referrals and programs are consistent with a person’s conditions of release.

Finally, structural changes are needed within correctional settings to support these recommendations. At an operating level, technological advances in electronic medical record storage and health information systems could be used to improve continuity of care both within the correctional setting and during transition from incarceration to the community. For example, with the permission of people who are living with HIV, effective

use of health information systems could facilitate improved transition of care within the correctional setting as people move from one facility to another. Similarly, these systems could provide medical providers in the community easy access to a person's treatment records while incarcerated, improving continuity of care. In conjunction with these systemic improvements, increased attention to education and training of staff across the correctional setting about effective HIV prevention, care, and treatment is warranted.[17,31] Such training could address strategies for integrating HIV care and treatment into other correctional programs (e.g., substance abuse), and increase awareness of the ethical issues raised in this manuscript.

In closing, the ethical provision of HIV prevention, care, and treatment within correctional settings is essential. Adherence to the recommendations described above will greatly enhance the capacity of health care providers to deliver medical services ethically to people with HIV who are incarcerated.

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Notes

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