

Should patients be compelled to undergo HIV testing after a needlestick injury involving a health care worker?

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A person may cause evil to others not only by his actions but by his inaction, and in either case he is justly accountable to them for the injury. The latter case, it is true, requires a much more cautious exercise of compulsion than the former.

—John Stuart Mill, On Liberty

nurse, Janet, suffers a high-risk needlestick injury while caring for Bob, an HIV-infected patient with chronic renal failure on hemodialysis. Bob is believed to be poorly compliant with antiretroviral therapy. However, he refuses to discuss his HIV status despite conversations with sympathetic physicians, will not consent to the release of old medical records, and refuses blood draws for HIV viral load testing, CD4 cell counts, or HIV genotypic analysis. While prescribing postexposure prophylaxis for Janet, it is assumed that Bob may be harboring drug-resistant HIV, and the regimen is modified accordingly. Although Janet remains

HIV-negative, her outcome is otherwise poor. She is depressed, and has intrusive thoughts and recurrent nightmares relating to her needlestick injury. Trying to return to work precipitates panic attacks. Janet feels abandoned by the health care system, and she is outraged that laws forbid disclosing protected health information or performing HIV-related blood tests without Bob's consent, even if these might have improved the medical management of her needlestick exposure.

This true story vividly illustrates an unusual ethical dilemma, pitting a patient's right to privacy against a health care provider's right to optimal medical care. This conflict is not easily resolved, as both parties have valid and competing interests.

Privacy rights and HIV exceptionalism

Throughout history, efforts to contain communicable diseases have brought civil liberties and public health into conflict. In the 1980s, the HIV crisis was a perfect storm for public policymakers. Fear of coercion and discrimination drove AIDS activists to mount a vigorous assault on the venerable pillars of public health practice: routine testing, reporting, and contact tracing. A climate of paranoia and prejudice, and a perception of therapeutic impotence, made stringent constraints on screening tests, name reporting, and partner notification seem reasonable and beneficial. (There is a historical precedent for this reasoning. In nineteenth-century Britain, the failure of the repressive Contagious Disease Acts showed that coercive measures tended to backfire by driving venereal disease underground.¹)

Instead, anonymous testing and reporting were emphasized. Skeptics dubbed this radical departure "HIV exceptionalism." ² These measures strengthened informed consent and patient confidentiality, but HIV exceptionalism may have discouraged active attempts to diagnose, treat, and prevent HIV infection. ³ Social and medical advances have since weakened the rationale for HIV exceptionalism. The stigma of HIV is receding, and the workplace and privacy rights of HIV patients are now protected by legislation. Therapeutic nihilism has waned with the advent of highly active antiretroviral therapy. With HIV infection increasingly a chronic manageable disease, HIV positive patients have become candidates for costly and rationed treatment, including hemodialysis, cardiac surgery, cancer chemotherapy, and even organ transplantation, developments unthinkable even a few years ago.

HIV privacy rights are not absolute

There are serious ethical problems with HIV exceptionalism. Making patient privacy an inviolable and absolute right may result in harm to others, such as sexual partners who may be unwittingly infected if their partners do not inform them of their HIV status. HIV infected persons have a moral duty to disclose their infection to prospective partners and to take precautions against exposing them, especially when their partners have no grounds to assume that HIV infection is likely.⁴ Successful

criminal prosecutions for HIV transmission by consensual intercourse have been brought in Canada, Britain, and the United States.⁵ In addition to the right-to-know of sexual contacts of HIV patients, it has been argued that physicians have a duty to warn their patient's partners if the HIV patient is unwilling or unlikely to do so himself. This is similar to the Tarasoff standard imposed on therapists, requiring them to breach confidentiality when their patients pose a serious risk to a third party.⁶ Recently, two Australian physicians were successfully sued for failing to ensure that a man informed his wife of his positive HIV test result. She subsequently contracted HIV.⁷

Needlestick injuries and compulsory HIV testing

Another challenge to patient confidentiality may occur when a health care worker suffers a needlestick injury or other body fluid exposure. Most source patients freely cooperate with HIV testing to prevent harm to caregivers, but a minority of 0.1 to 6 percent refuse.⁸ An estimated 380,000 needlestick injuries occur yearly in U.S. hospitals⁹; thus the HIV status of up to 20,000 patients involved in needlestick injuries in the United States each year may be unknown. When patients refuse HIV testing, an ethical dilemma results, pitting the competing rights of patient privacy, autonomy, and bodily integrity against avoidance of harm to health care workers.

A patchwork of legislation in the United States and Canada allows compulsory HIV testing after occupational body fluid exposures to health care workers and first responders. Laws providing for court-ordered HIV testing in accidental or deliberate exposure of a health care worker, first responder, or police officer have been passed in 16 states: Arkansas, California, Kentucky, Maine, Michigan, New York, North Dakota, Ohio, Oregon, South Dakota, Tennessee, Utah, Virginia, Washington, Wisconsin, and Wyoming. 10

In Canada, laws providing for mandatory HIV testing after body fluid exposures suffered by emergency personnel, good Samaritans, and health care workers have been enacted in Ontario and Alberta, despite the opposition of the Canadian Medical Association on grounds of patient privacy.¹¹

There is increased interest in this issue in Europe, after Dutch courts recently ruled that patients could be ordered to submit to HIV testing after occupational blood exposure by health care workers. The issue became an emotional one for Dutch physicians, who felt that discussions of patient's rights neglected the rights of doctors in certain situations.¹²

Do patients have ethical obligations to health care workers?

The physician-patient relationship is traditionally construed as a one-way street, with obligations flowing from the physician to the weaker party in the relationship, the patient. Doctors and other health care workers voluntarily accept risk of contagion in the performance of their duties, and this is one of the reasons that medicine has traditionally been viewed as a noble

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profession. Fearsome pathogens such as smallpox, Ebola, and SARS have exacted a disproportionately high death toll among health care workers. While health care workers implicitly accept this risk, patients are under no particular obligation to cooperate in the event of an accidental needlestick injury or other body fluid exposure. However, it has been argued that patients have the same ethical obligation to prevent harm to health care workers as they do to other persons, and society has a reciprocal obligation to health care workers to provide maximal workplace safety, counseling and compensation for injury, and public recognition. Such reciprocity may extend to compulsory HIV testing to optimize care of exposed health care workers.

Consequences of needlestick injuries are not limited to HIV infection

Mandatory HIV testing may help prevent HIV infection, alleviate the anxiety and psychological disturbances associated with needlestick injuries, and avoid the dangers of antiretroviral therapy. Prospective studies suggest that the risk of HIV transmission is approximately 0.3 percent after percutaneous exposure to HIV infected blood. As of December 2001, the CDC had received voluntary reports of 57 documented and 138 possible cases of HIV seroconversion associated with occupational exposure to HIV in U.S. health care workers.⁹

Even without HIV seroconversion, occupational HIV exposure may be psychologically devastating and disabling. An Australian study found that 82 percent of HIV exposed health care workers recalled severe distress. 15 In another retrospective study, 55 percent of exposed health care professionals experienced severe acute distress, 25 percent persistent sexual dysfunction, and 30 percent quit their jobs as a direct result. 16 Occupational HIV exposure may precipitate post-traumatic stress disorder (PTSD). 17 Exposed health care workers find it unfair that patients may refuse HIV testing or conceal their HIV positive status. These perceptions of abandonment by the health care system and loss of control may increase the risk of PTSD and depression.

The anxiety of health care workers is amplified by the possibility that postexposure prophylaxis (PEP) may fail. Although postexposure zidovudine is associated with an 81 percent reduction in HIV infection, at least 21 cases of HIV seroconversion have occurred in health care personnel despite their receiving PEP.9 With heavily treated HIV patients surviving longer, antiretroviral drug resistance raises the risk of PEP failure. In one study of hospital needlestick injuries, 50 of 64 (78 percent) source patients had detectable HIV in blood. Of these 50 patients, 38 percent had HIV strains resistant to nucleoside reverse transcriptase inhibitors or protease inhibitors, the usual classes of medications used for PEP. Resistant HIV strains have been transmitted to health care workers despite their receipt of PEP with combination drug regimens. If source patients are treatment-experienced, the treatment

history and the genotypic resistance profile become important in the choice of an optimal PEP regimen.²⁰ However, this information may not be available due to patient reluctance, confidentiality restrictions, or both.

Practical arguments for and against compulsory HIV testing

It has been argued that forced HIV testing is of little practical value, as it does not obviate the need to emergently initiate antiretroviral therapy after exposure. If obtained rapidly, HIV testing and genotypic analysis may facilitate construction of a PEP regimen tailored to the source patient's HIV strain. Although PEP is most efficacious when started within 24 to 36 hours, it may be beneficial started as late as seven days after high-risk exposures.²⁰ Rapid HIV testing is now widely available. Although the next generation of HIV genotypic and phenotypic resistance tests provide results with 1 to 2 days, most facilities currently would have difficulty obtaining the results of HIV resistance testing within seven days. Furthermore, if the source patient's HIV test is negative, exposed persons may stop PEP early, avoiding the generally minor, but sometimes life-threatening drug toxicities. A negative test from the source patient should also alleviate anxiety and prevent psychiatric sequelae in those exposed. In analogous settings of imminent or potential harm, patient information relevant to the management of persons at risk is not regarded as privileged. For example, the contacts of patients having multidrug resistant tuberculosis require specific prophylactic regimens. Public health officials do not need patient permission to use tuberculosis sensitivity data in treating exposed persons.

The arguments against compulsory HIV testing involve the patient rights of autonomy, bodily integrity, and confidentiality. The principle of individual self-determination is deeply rooted in common law, the U.S. Constitution, and the American psyche. The right of competent patients to refuse potentially beneficial medical diagnosis and treatment has been repeatedly upheld by the U.S. Supreme Court.⁶ However, HIV testing could be performed on source patients without revealing the results to them, if they did not wish to know, and they certainly would not be compelled to accept antiretroviral therapy if tested positive. Compulsory HIV testing may violate the Fourth Amendment right of citizens "to be secure in their persons . . . against unreasonable searches and seizures." However, U.S. courts have historically ruled that the violation of bodily integrity of blood drawing is not unduly burdensome, if there is an overwhelming public health interest.⁶

Patient privacy might be at risk with compulsory HIV testing if confidentiality lapses occur that expose individuals to the stigma of being HIV positive. However, it should be feasible to divulge the results of compelled HIV testing only to those with a need to know, namely, the exposed health care worker or first responder, the treating physician, and the source patient, if he or she wishes to be informed of the test results.

Recommendations

If patients refuse to undergo HIV testing, the care of exposed health care workers could be optimized with several measures short of forcible testing. Patient consent could be waived to obtain the release of records from other facilities and physicians, or previously drawn blood samples could be tested without patient permission. Twelve states currently have legislation providing for this contingency: California, Connecticut, Florida, Iowa, Louisiana, Montana, Nebraska, North Dakota, Pennsylvania, Rhode Island, Virginia, and Wyoming.¹⁰

In HIV patients undergoing costly and rationed medical treatment, such as hemodialysis or organ transplantation, perhaps a social contract should be made explicit: in exchange for the long-term public expenditure involved, patients should agree in advance to cooperate in the event of a body fluid exposure.

Finally, we believe that in the last resort compulsory HIV testing is intellectually justifiable on utilitarian grounds. The potential benefit to health care providers, such as avoiding medications if source patients are HIV negative and optimizing postexposure prophylaxis if it is necessary, outweigh the loss of autonomy and privacy by patients. It is likely that most patients would not physically resist HIV testing if forced on them by the courts and legal system. However, the worst-case scenario of a sedated patient in restraints being forcibly phlebotomized would give most health care workers second thoughts about the wisdom and justice of compulsory HIV testing.

Conclusion

Dialogue and persuasion are preferable to compulsion and confrontation. The overwhelming majority of patients agree to postexposure blood tests if the case is presented in a sensitive manner and adequate support is offered for possible positive test results. Minimizing the stigma of HIV disease and making the benefits of antiretroviral therapy as widely accessible as possible can reduce the barriers to disclosure of HIV status by patients. If necessary, we believe that patient consent should be waived to make relevant medical records available, or to perform testing on stored blood samples. As a last resort, compulsory HIV testing, including resistance testing, is intellectually justifiable but obnoxious, and perhaps incompatible with the notion of medicine as a compassionate profession.

Embedded in this conflict between the rights to harm avoidance of health care workers and the privacy rights of patients is another, deeper paradox. This more fundamental clash is between dueling conceptions of the role of physicians and other health care workers. Are doctors simply employees, fulfilling a contractual obligation to patients on a contingent, limited, financial basis, with patients having reciprocal obligations and duties to physicians? Is medicine a job like any other, or is it a noble calling and a vocation, with supererogatory duties and obligations to our patients, carrying out difficult and dangerous work with no necessary expectation of repayment? In the real

world, for most of us, the answer is a mix of both. How to best balance these opposed and competing priorities in our own lives and practices is perhaps the central dilemma of modern medicine.

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Morning Rounds

"Good morning," I said.
"Come closer," she asked.
I did not, could not,
and stood in the doorway.
"Do you need anything?"
"Come closer," she said.
I am close, I thought.
The room was small, filled by her bed.
"I mean near the bed—next to me—
so I can see you."
I moved closer, foreseeing her death,
which I could not prevent.

"I like it when you are close."
I moved even closer,
reaching for her hand.
"That's what I needed,
to touch your hand and to thank you."
She smiled, her face aglow,
and I wept silently
as I moved even closer
to kiss her cheek
to thank her
for asking me to come closer
when I thought I could not.

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