An HIV Testing Conundrum: Balancing the Health and Privacy Considerations of Multiple Stakeholders

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ABSTRACT
Legal standards for HIV testing are evolving in an attempt to achieve an ethical equilibrium between the privacy rights of infected or potentially infected individuals and public health considerations that seek to limit the spread and severity of the disease through early recognition and treatment. Although guided by US Centers for Disease Control and Prevention recommendations, these standards are determined by state law. In this case, an ethical dilemma is presented and discussed in which the privacy interests of an HIV-infected individual come into conflict with the health considerations of an inadvertently exposed neurology resident and her unborn child, a conundrum amplified by the restricted HIV testing laws of the state in which the incident took place.

Case
Note: This is a hypothetical case.
A 35-year-old woman had a witnessed seizure at a mall in Massachusetts and was brought to the emergency department of the nearest hospital, where she did not normally receive her care. Her MRI suggested multiple small abscesses. A pregnant neurology resident received an inadvertent needlestick while attempting to draw blood from the patient when she was agitated during a portion of the postictal period.

The patient was hospitalized. On the following day when the patient’s sensorium had cleared, the neurology attending physician asked her for permission to test for potentially transmissible diseases, in accordance with the hospital’s needlestick policy. The patient was HIV-positive but had kept her disease secret from her family and her partner, and was concerned that testing results would come to the attention of her cousin, who worked in the medical records department of the medical center. Aware that in Massachusetts HIV testing cannot be legally obtained without her permission, she disclosed none of this information to the attending physician and simply responded that she would not give permission for the testing.

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DISCUSSION

Most ethics consultations focus on the potential benefits and harms to individual patients. In this case, however, the ethical deliberation is more complex, involving the health and well-being of three individuals, as well as consideration of the public health. In addition, this deliberation must consider the law.

When it comes to the patient, potential harms from disclosure of her HIV status arise from at least two sources: (1) damage to relationships with important people in her life, and (2) social, vocational, or residential discrimination.\(^1,2\) However, potential benefits to the patient also exist. Because her disease may result in future health problems that bring her back to the same medical center, knowledge of her HIV status could result in more rapid and effective treatment—and the avoidance of unnecessary testing and intervention. Consider, for example, that the patient’s CNS disease renders her comatose. In states such as Massachusetts, where no legal provision for emergency testing without consent (in adults) exists, health care professionals would have to use a less satisfactory empiric therapeutic strategy to treat the potential causes of her coma.\(^3\)

From the perspective of the neurology resident and her unborn child, there are no apparent benefits to respecting the patient’s legal right to refuse HIV testing. There are, however, obvious harms. If the patient’s HIV status is unknown, the resident will have to decide whether to receive postexposure prophylaxis (PEP). If the patient’s HIV status were negative, the drugs would offer only the risk of harm and offer no benefit. Alternatively, the resident could defer her decision to receive PEP until she is certain of her seroconversion status, but the delay could add to the anxiety she may already be experiencing.

Because the health care team is unaware of the patient’s actual HIV status, the public’s stake in this analysis would be considered in an ethics consultation. An estimated 25% of Americans infected with HIV are unaware of their status.\(^2\) Reducing this percentage results both in earlier treatment for the individual patient and in reduced rates of HIV transmission. It is well established that once they become aware of their HIV status, many people will alter their behavior in a manner that reduces transmission risk.\(^4-6\) In 2009, it was estimated that 600,000 life-years could be saved in the US population if all states adopted the Centers for Disease Control and Prevention’s (CDC’s) “opt-out” screening recommendations for routine HIV testing in health-care settings.\(^7\) The CDC’s opt-out standard allows HIV testing to proceed unless a patient informed of the risks and benefits of HIV testing refuses, rather than an opt-in standard that requires actual permission.\(^2,6,8\)

Other stakeholders’ perspectives should be considered. For the neurology resident, this includes the risk of maternal and fetal infection with HIV following needle-stick injury, the latency for maternal seroconversion, the likelihood and latency of fetal infection, and the magnitude of risk reduction of infection for both mother and fetus with PEP related to the timing of its administration.
The risk of HIV transmission from a needlestick is low, estimated at 0.33%, although studies suggest that the volume of blood injected and viral load matter.\textsuperscript{9,10} The median time to seroconversion following HIV exposure with historical testing algorithms is 63 days.\textsuperscript{11} Even with fourth-generation immunoassays, a minimum latency of 10 days exists before infection can be detected.\textsuperscript{12} Data regarding the effectiveness of PEP in reducing risk of infection following occupational exposure are limited. PEP with zidovudine is estimated to reduce the infection rate by 81% in needlestick recipients.\textsuperscript{10} It is unclear whether delay in administration of PEP following exposure increases infection risk.

HIV can be transferred from a mother to the fetus at any time during pregnancy and to the infant during breastfeeding. However, this risk is substantially reduced prenatally from 20% without treatment to 10.4% with zidovudine monotherapy and further reduced to 1.2% with highly active antiretroviral therapy (HAART).\textsuperscript{13} The CDC recommends three-drug therapy in HIV-infected pregnant women for purposes of improving the mother’s health and reducing the risk of HIV transmission to the fetus.\textsuperscript{6,15} The earlier in pregnancy that antiviral prophylaxis is initiated, the more effective the treatment. It is estimated that each additional week of three-drug therapy exposure antepartum reduces the risk of in utero transmission by 10%.\textsuperscript{14}

In American culture, considerable emphasis is placed on the rights of the individual, as evidenced by the principles of self-determination and privacy. These principles are manifested in the Health Information Portability and Accountability Act (HIPAA) Privacy Rule, which protects the privacy of an individual’s health care information.\textsuperscript{15} Individual autonomy, however, is not absolute. For example, autonomy is the justification for a patient with capacity to refuse recommended treatment, or in this case testing, but it does not provide an individual with the right to demand treatment or testing that is not medically indicated.\textsuperscript{16}

Many instances exist in which public health considerations are felt to supersede individual liberty. For example, every state has laws intended to protect public safety by limiting the driving privileges of patients with uncontrolled epilepsy.\textsuperscript{17} Quarantine, or social distancing, as implemented in the severe acute respiratory syndrome (SARS) epidemic is another, albeit controversial, application of this principle.\textsuperscript{18–20}

Society has historically provided HIV testing unique status when it comes to determining the balance between personal and public good. Some say this status reflects the principle of exceptionalism, that is, a public health policy that allows HIV testing a privileged and exceptional status in comparison to testing for other disease conditions. This exceptional status was originally justified by the absence of effective HIV treatment and the potential harm inflicted by stigmatizing the limited populations at risk in the 1980s and early 1990s.\textsuperscript{2} It should be recognized, however, that both the ability to improve the natural history of the disease with effective treatment and the demographics of at-risk populations have changed from the time that HIV testing laws were first written, reducing the justification for this exceptional status. As a result, many but not all states have adapted their laws over time to reflect the benefits accrued from the early recognition and treatment of HIV.\textsuperscript{20}

There is no consensus on where the fulcrum lies in balancing the rights of the individual and considerations of public health. Much depends on context. In the setting of a public health emergency, some argue that a physician’s responsibility shifts from the individual patient to the public.\textsuperscript{21} Two important and potentially conflicting principles should be considered in this case. One is that individuals’ liberties should only be restricted when justified by a proven public health benefit.
of sufficient magnitude.\textsuperscript{19} A second is that knowingly placing others at risk is a justification for legally mandated intervention in support of the potential victim.\textsuperscript{19}

**CONCLUSION**

Wherein lies the resolution for this dilemma? Numerous stakeholders and their relative authorities make the deliberation complex. The goals of HIV detection are clear and uncontested: to improve the health of the individual patient and to minimize disease transmission. As noted above, the CDC’s 2006 HIV testing recommendations support these goals by advocating for an opt-out testing strategy to improve HIV surveillance.\textsuperscript{6} This approach is consistent with existing testing paradigms in the majority of states.\textsuperscript{5} A poll conducted in 2006 suggested that 65% of Americans supported this approach.\textsuperscript{6}

If the public and the infected patient were the only stakeholders in this case, there would be a limited ethical conflict if CDC recommendations were followed. Presumably, the patient would be offered HIV testing by her physicians in response to the MRI findings, and the patient would refuse. The physicians might feel thwarted in their ability to care for the patient but would need to respect the patient’s autonomy and her legal right to refuse testing.

In this hypothetical case, the neurology resident and her fetus are also stakeholders. The fetus is particularly vulnerable and is a member of a population that deserves unique protection in the minds of most ethics scholars.\textsuperscript{1} The balance of benefits and harms from disclosing the patient’s HIV status and treating the resident and her fetus would outweigh the balance of benefits and harms from not disclosing the patient’s HIV status. Thus, the CDC’s recommendations may not be sufficient in this case—ethical considerations suggest that mandatory testing may be necessary.

State laws pertaining to HIV testing are disparate.\textsuperscript{3} HIV-testing laws in the majority of states are consistent with current CDC recommendations. Five states, including Massachusetts, however, have laws that are incompatible with these recommendations.\textsuperscript{20} Thirty-four states have a statute for mandatory source testing with inadvertent health care worker exposure.\textsuperscript{3,21} Even in states where mandatory testing in specific circumstances is legal, there are no provisions for forcing the patient to provide a blood sample except with judicial intervention.\textsuperscript{21} In the case described, either attempting to take a blood sample without the patient’s permission or performing HIV testing without the patient’s permission could result in civil and criminal penalties.\textsuperscript{22}

The most expeditious means to address the problem would be to have a skilled HIV counselor meet with the patient.\textsuperscript{6} The goals would be to explore and hopefully resolve the patient’s testing reluctance, which could stem from a number of sources, including concerns of intimate partner violence, stigmatization, and discrimination.\textsuperscript{6} Additionally, appealing to the patient’s conscience by making her aware of the implications of the neurology resident’s plight may serve as an effective strategy. Ideally, this strategy would lead to the patient’s willingness to disclose her HIV status, if only on a limited basis. Agreement might allow this to occur between the patient and the neurology resident, thus allowing the resident to make more informed decisions regarding PEP. If the patient were to remain resolute in her unwillingness to be tested, the resident would have no recourse other than to receive PEP empirically or await potential seroconversion.

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REFERENCES


