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Is It Time to Revisit Prenatal HIV Testing Laws?

Daniel Zank, MS

Of the many unfortunate situations brought on by the HIV/AIDS epidemic, few evoke the same sympathetic and visceral response as the image of a child born HIV-positive. Legislators must consider far more than this image, however, if they are to create ethical and responsible policies for prenatal and perinatal HIV testing. Lawmakers must carefully weigh issues of maternal privacy, stigmatization, and informed consent in addition to the potential benefit to the infant. The dynamic nature of the risks against which these policies protect also necessitates periodic review to determine whether the appropriate protections are provided to both mother and child.

Because HIV testing is not mandatory for pregnant women, the exact number of infants born to seropositive mothers is not known. In 1998, an estimated 6,000 to 7,000 infants were born to HIV-positive mothers in the U.S., a number that had remained stable for five years [1]. The Centers for Disease Control and Prevention (CDC) estimates that in 2002 only 144-236 children were born HIV-positive [2]. This was the smallest number of perinatally infected infants since the HIV/AIDS epidemic took hold in the early 1980s. Many of these cases of transmission could have been prevented by better prenatal management of maternal HIV infection, but prevention is complicated by the fact that many HIV-positive pregnant women are asymptomatic, unaware of their serostatus, or fail to seek prenatal care.

As HIV/AIDS treatments have evolved, so too has the rationale for testing. Initially, there were no treatment options to prevent vertical transmission, and 25-30 percent of infants born to HIV-positive mothers contracted the disease during pregnancy, parturition, or breastfeeding [2]. The turning point came in 1994, when researchers demonstrated a reduction in perinatal transmission rates to less than 2 percent as a result of (1) antepartum maternal treatment and postpartum neonatal treatment with the antiretroviral (ARV) drug zidovudine, (2) use of elective cesarean delivery when appropriate, and (3) avoidance of breastfeeding [3, 4]. Due to increasing patterns of resistance, the Public Health Service Task Force and the CDC now recommend combination ARV therapy in place of zidovudine monotherapy [5]. Implementation of this prophylactic regimen is contingent upon determining maternal serostatus.

Current State Laws

In the interest of preventing perinatal transmission of HIV, 21 states have adopted statutes that specifically address antepartum testing. These statutes can be classified

into two groups. Thirteen states have adopted “opt-in” testing statutes, which dictate that an HIV test must be offered to every pregnant woman at the time she presents for her first prenatal care visit and that the woman must consent to the test before it can be performed [6]. Eight states have adopted “opt-out” statutes, which require that every pregnant woman be informed that she will be tested for HIV as part of a battery of routine screening tests at the time she presents for her first prenatal care visit. In such states, the test will be performed unless the woman refuses either orally or in writing [6]. Both types of statutes generally include provisions for pretest counseling concerning the risks and benefits of prenatal HIV screening so that consent may be considered “informed.” The CDC, the American College of Obstetricians and Gynecologists, and the American Academy of Pediatrics have issued statements in support of the opt-out method of prenatal screening, citing evidence that this method improves testing rates among pregnant women [7, 8].

The remaining 29 states do not specifically address prenatal testing for HIV, and in these jurisdictions screening of pregnant women is performed on a voluntary basis subject to the same informed consent laws that govern nonpregnant individuals.

Only two states have adopted statutes that address postpartum HIV testing of newborns without the consent of the mother [9, 10]: New York, which has implemented mandatory HIV screening of all newborns, and Indiana, which permits testing of newborns without consent if the attending physician deems the screening test medically necessary based upon maternal risk factors for HIV. Mandatory newborn testing has the potential to benefit both infant and mother. It expedites treatment of exposed infants to reduce the risk of perinatal HIV infection and confirmation of maternal seropositivity, which allows maternal treatment and the opportunity for behavior modification to prevent spread of infection.

Balancing Health Benefits and Ethical Harms

Nevertheless, these epidemiologic benefits must be balanced with nontrivial ethical harms. A woman’s positive test result may precipitate anxiety and depression, compounded by the social stigmatization of being labeled “HIV-positive.” Relationships with family, friends, neighbors, and partners may be irreparably altered, sometimes leading to domestic or intimate partner violence. Individuals may be burdened with fears concerning employability and insurability if serostatus is revealed. Although false positives are fewer than 1 in 250,000 with standard screening and confirmatory tests, such results may unnecessarily disrupt the mother’s life and cause the infant to undergo unnecessary treatment [11].

The primary legal challenge to mandatory prenatal and perinatal HIV testing has been in defense of maternal rights to privacy and personal autonomy collectively guaranteed by the First, Third, Fourth, and Ninth Amendments. Infringement upon these rights must be justified by a legitimate and compelling state interest and must use the least restrictive means necessary to secure that interest. In *Roe v. Wade* the Supreme Court found that the state has a compelling interest in potential human life, but that interest begins only during the third trimester of pregnancy [12]. *Planned*

Parenthood v. Casey subsequently reaffirmed the central holdings of *Roe*, but extended the state's interest to the cusp of viability, which, due to advancements in neonatal care, is now thought to be during the second trimester [13].

In the case of perinatal HIV infection, the state's compelling interest extends beyond protection of a potential life, since the state may provide financial support for HIV-infected infants in the form of state-sponsored health insurance and social services. While observational data show that the opt-out testing approach may increase testing rates to as high as 85 percent, mandatory prenatal testing could boost HIV screening rates to nearly 100 percent [8]. But is mandatory testing the most narrowly tailored means of achieving prevention?

Other arguments against mandatory testing are rooted in HIV exceptionalism rather than protections of personal autonomy. Early in the epidemic, legislators created HIV treatment and testing policies that increased privacy protections, required a rigorous process of pretest counseling and informed consent, and exempted HIV from many public health interventions. The basis for HIV exceptionalism was the desire to protect individuals from discrimination and marginalization at a time when the virus was closely associated with homosexuality and intravenous (IV) drug use. While men who have sex with men and IV drug users are still among the highest risk groups for HIV infection, the explosion of the disease among the heterosexual population and the development of effective treatments have served to diminish the social stigma associated with it. This normalization may justify assuming a more traditional public health perspective about mandatory prenatal screening.

The precedent for a more utilitarian, public health approach has been established by mandatory prenatal and newborn screening for other diseases and disorders. Syphilis is a curable sexually transmitted disease, although it can be disabling or life-threatening to an infant when passed from mother to child during pregnancy. As a result of the implementation of state mandates requiring serologic assays for syphilis during pregnancy, the rate of congenital syphilis decreased by an average of 14.1 percent per year from 1996-2005 [14]. This reduction demonstrates the enormous public health utility of mandated screening for a preventable disorder.

Phenylketonuria (PKU) is a rare genetic metabolic disorder that results in progressive mental retardation in the absence of dietary restrictions during early childhood development. In 2002 all states required testing for PKU in their newborn screening battery. Interestingly, screening mandates for these disorders remain unchallenged [15, 16].

Medical professional organizations, including the American Medical Association, have decried mandatory HIV testing as a threat to patient autonomy and to the patient-doctor relationship. Mandatory testing has the potential to lead to an informalization of the consent and notification process, which increases the likelihood that a patient may be tested without his or her knowledge, thus undermining the public's trust of physicians. Professional organizations have also

expressed concerns that mandatory HIV testing may discourage some pregnant women from seeking medical care [17].

The CDC has recently called for an end to HIV exceptionalism and the requirement for specific informed consent for HIV screening. Consent for HIV testing would come with the blanket consent to receive medical care. CDC recommendations also support opt-out testing of all pregnant women early in pregnancy and again during the third trimester [18]. Ostensibly, the CDC has determined that the risks associated with stigmatization have diminished to the point that they are now offset by the personal benefits of early treatment and the public health benefit of preventing transmission of the virus to others through treatment and behavior change.

How these recommendations will affect state laws regarding prenatal HIV testing remains to be seen. It now falls to legislators to determine whether the current social climate is one in which seropositive individuals no longer reasonably need to fear discrimination and thus no longer require the protections provided by HIV exceptionalism.

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Daniel Zank, MS, is a second-year medical student at Loyola University Chicago Stritch School of Medicine and interned during the summer of 2007 with the American Medical Association's Council on Ethical and Judicial Affairs in Chicago.

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