

## OBSTETRICS

# When courts intervene: public health, legal and ethical issues surrounding HIV, pregnant women, and newborn infants

Q7 Q1 Jennifer A. Tessmer-Tuck, MD; Joseph K. Poku, JD; Christopher M. Burkle, MD, JD

A 22-year-old woman (G1P0) was seen in the first trimester for prenatal care.<sup>1</sup> She informed the staff that she was not at risk for HIV and declined repeated offers of HIV testing. The patient was born in Romania and was adopted by a couple in the United States where she tested positive for HIV and began treatment with zidovudine.<sup>2,3</sup> After 2 years, her parents discontinued HIV therapy after embracing the belief that HIV does not cause AIDS and that conventional medical therapies are morbid and lethal.<sup>2,3</sup> The patient came to adopt these same beliefs.

After an otherwise uncomplicated prenatal course, the patient was in labor at 41 weeks 3 days gestation. Given her unknown HIV status, the care team recommended rapid HIV testing, which she declined. She delivered a son vaginally who required resuscitation and then admission to the neonatal intensive care unit for meconium aspiration and pneumothorax. Rapid HIV testing of her newborn infant was recommended but declined by the patient and her partner.

A review of publically available records then identified the patient's positive childhood HIV test.<sup>2,3</sup> Physicians

Ninety-three percent of pediatric AIDS cases are the result of perinatal HIV transmission, a disease that is almost entirely preventable with early intervention, which reduces the risk of perinatal HIV infection from 25% to <2%. The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics both recommend routine HIV testing of all pregnant women and at-risk newborn infants. When pregnant women decline HIV testing and/or treatment, public health, legal, and ethical dilemmas can result. Federal courts consistently uphold a woman's right to refuse medical testing and treatment, even though it may benefit her fetus/newborn infant. Federal courts also reliably respect the rights of parents to make healthcare decisions for their newborn infants, which may include declining medical testing and treatment. Confusing the issue of HIV testing and treatment, however, is the fact that there is no definitive United States Supreme Court ruling on the issue. State laws and standards vary widely and serve as guiding principles for practicing clinicians, who must be vigilant of ongoing legal challenges and changes in the states in which they practice. We present a case of an HIV-positive pregnant woman who declined treatment and then testing or treatment of her newborn infant. Ultimately, the legal system intervened. Given the rarity of such cases, we use this as a primer for the practicing clinician to highlight the public health, legal, and ethical issues surrounding prenatal and newborn infant HIV testing and treatment in the United States, including summarizing key state-to-state regulatory differences.

**Key words:** ethics, HIV testing, legal, medical, newborn infant HIV testing, prenatal HIV testing

and the hospital legal team informed her that, if she continued to decline testing, they would seek a court order mandating her newborn infant's testing and treatment. She consented to HIV testing for herself and her infant and prophylaxis for her infant while awaiting test results. Both mother and newborn infant tested HIV positive. Results and management options were discussed with both the mother and father, who declined treatment of the infant. Prophylaxis was discontinued; between days 7 and 14 of life, the infant remained off antiretroviral therapy while legal action was pursued.

During the neonatal intensive care unit course, the infant experienced poor weight gain, dysphagia, and low motor tone. Pediatric physicians thought these symptoms could be related to HIV infection and, ultimately, convinced the parents to start treatment on day 14 of life. At discharge, the parents agreed to a

plan for continued HIV treatment with the understanding that, if they failed to treat or follow up, social services would be contacted. When the mother and infant failed to show up for a scheduled appointment with pediatric infectious diseases, the infant was taken into state custody, and a legal dispute ensued.

The Mower County District Court in the State of Minnesota subsequently held that the infant had active symptoms of HIV infection that were improving with antiretroviral therapy (with minimal accompanying side-effects) and that the parents had a history of failing to attend follow-up appointments, so criteria were met for ongoing state intervention to ensure the child's well-being. The court allowed the child to remain in the parent's physical custody but under state supervision to ensure that medications were administered and that medical appointments were attended.

From the Department of Obstetrics and Gynecology, North Memorial Medical Center, Robbinsdale, MN (Dr Tessmer-Tuck); Mayo Medical School (Mr Poku) and the Department of Anesthesiology (Dr Burkle), Mayo Clinic, Rochester, MN.

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Reprints: Jennifer A. Tessmer-Tuck, MD, Department of Obstetrics and Gynecology, North Memorial Medical Center, 3300 Oakdale Ave. North, Robbinsdale, MN 55422.  
jennifer.tessmertuck@gmail.com.

0002-9378/free

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## Relevance of perinatal HIV in the United States

As of year-end 2010, there were an estimated 10,798 persons living in the United States who contracted HIV perinatally.<sup>4</sup> In 2011 (the most recent year for which data are available), 53 new cases of perinatal HIV infection were diagnosed, which is consistent with the average from 2008-2011 of 50-100 cases of perinatal HIV annually.<sup>4</sup> Mother-to-child transmission occurs by 1 of 3 routes: in utero, during delivery, or through breastfeeding; HIV transmission during pregnancy or delivery accounts for approximately 65% of these cases.<sup>5</sup> Left untreated, 20% of infants who are born with HIV will die before age 6 months, and >50% will die by age 2 years.<sup>5</sup> Early intervention can reduce the risk of mother-to-child transmission from 25-30%<sup>6</sup> to <2%.<sup>7</sup> Because of early identification of cases, antiretroviral treatment of HIV-infected mothers, the avoidance of breastfeeding, and cesarean delivery when indicated, the number of US children who acquired HIV perinatally peaked in 1991 at 1650 cases.<sup>8</sup>

In 2006, the Centers for Disease Control and Prevention (CDC) revised recommendations for HIV testing and endorsed routine HIV testing of all pregnant women in the United States, unless the woman declines, which is called an "opt-out" approach.<sup>9,10</sup> (Opt-in testing refers to the process of offering HIV testing but requires active permission from the patient to test<sup>10</sup>). Women who decline HIV testing early in pregnancy should be counseled to test later. A repeat HIV test during the third trimester is recommended for women with  $\geq 1$  risk factors that include (1) living in communities with a high rate of HIV infection, (2) receiving care at facilities with a high rate of HIV infection, (3) participating in high-risk behaviors such as intravenous drug use, or (4) experiencing HIV-like symptoms. Any pregnant woman with undocumented HIV status who is in labor should have rapid HIV testing and, if the results are positive, be treated. If the mother's HIV status is unknown at birth,

newborn infants should have rapid HIV testing.

Although practicing clinicians often follow the CDC's recommendations, the CDC has no legal bearing on the testing and treatment of women; to date, the Supreme Court has not weighed in on the issue. This leaves states to develop their own regulations, which vary widely. The burden then falls on clinicians to maintain competence regarding their states' regulations (Table). Unfortunately, a study of American College of Obstetricians and Gynecologists (ACOG) Fellows found that many practicing obstetrics/gynecology physicians did not know their own states' laws pertaining to HIV testing for pregnant women and that their recommendations to patients therefore were not consistent with their own states mandates.<sup>11</sup> In states that had specific prenatal HIV testing recommendations, only 57% of clinicians followed the recommended approach. In states that did not have regulations for testing of pregnant women, clinicians tended to choose either the opt-in (51%) or opt-out (49%) approach, although they should have defaulted to following general HIV testing laws for adults, which (at the time) required informed consent and opting-in. Many clinicians (28.7%) also failed to retest in the second or third trimester if a patient had declined initial testing, and 18.2% of clinicians reported that they would not do rapid HIV testing on a patient who arrived on labor and delivery with an unknown HIV status. The authors concluded that additional education of practicing obstetricians/gynecologists on ACOG and CDC recommendations and the variations in state regulations was important to ongoing public health attempts to decrease perinatal HIV transmission.

### Informed consent and HIV testing

Many states have adopted legislation that requires opt-out HIV testing of pregnant women (Table). Separate, informed consent for HIV testing is not recommended by the CDC<sup>9</sup>; however, at the time of the CDC's 2006 recommendations, 20 states still required separate informed consent for HIV testing. By

2008, 11 states had removed this barrier.<sup>12</sup> Some states require neither opting-out nor informed consent. Arkansas allows providers to test patients without their consent<sup>13</sup>; North Carolina requires providers to test pregnant women with unknown HIV status at the time of labor, regardless of consent<sup>14</sup> (Table).

Nevertheless, concerns remain about the impact that forced HIV testing may have on pregnant women. Positive HIV results may lead to psychologic stress, partner relationship strains, and social stigmatism, to name a few. Providers fear that pregnant women could forego prenatal care under an HIV-testing mandate. Many also believe that mandatory testing violates a woman's privacy and equal protection rights.

### Maternal vs fetal rights and HIV

The Supreme Court has held that an adult has the right to refuse medical testing and treatment.<sup>15</sup> When a woman becomes pregnant, however, declining testing and/or treatment for HIV is ethically more complex, because most obstetrics providers want to provide the best care for both the woman and her fetus.

Discussions surrounding rights of the fetus date back as early as the middle 1880s. In *Dietrich v Inhabitants of Northampton* (1884),<sup>16</sup> a fetus died after a pregnant woman's fall from a defective bridge. The woman herself experienced no other injury, so the court ruled that the construction company was *not* liable for the fetus' death. This was ultimately termed the *single entity rule*, because a pregnant woman and her fetus were legally considered a single entity. In 1949, however, the case of *Verkennes v Corniea*<sup>17</sup> changed legal and ethical thinking. In this case, a woman and her term infant died after a uterine rupture and hemorrhage. The court found the hospital and physician liable for the negligent care of the viable fetus, regardless of what happened to the mother. This case was the first to legally separate care of the fetus from care of the pregnant woman.

Despite this legal separation of the woman and the fetus, US law

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