

## Law and Ethics in Medicine

### HIV Testing in Pregnant Women: Ethical Considerations

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The global HIV/AIDS pandemic is continuing unabated and the number of people living with HIV/AIDS worldwide has tripled in the last decade. Most of the estimated thirty-five million people infected with HIV live in developing countries. In North America the number of new HIV infections in women is now growing at a faster rate than that of men. Canadian epidemiological data shows that women comprised 21.5% of HIV-positive test results in 1996, more than double the number between 1985-1994.<sup>1</sup> AIDS is now one of the leading causes of death in all women aged 25 to 44 years in the United States.<sup>2</sup> The virus has a long latency period and thus most of these women were infected during adolescence or in their early twenties. In Canada women make up less than 10% of the total number of AIDS cases, but the majority of these cases are in women of reproductive age (15-44).<sup>3</sup> Much of the recent attention given to HIV infection in women has focused on maternal to child (vertical) transmission. This article discusses some of the historical, ethical, and legal considerations of HIV testing during pregnancy in Canada.

Reported rates of vertical transmission in the absence of preventative measures range from 15-40%.<sup>4</sup> Transmission can occur *in utero*, during labour and delivery, or through breast milk. Interventions to reduce vertical transmission were first demonstrated in the AIDS Clinical Trial Group Study 076. This study compared vertical transmission rates between HIV positive women receiving zidovudine or placebo. This study was interrupted in 1994 when it revealed a significantly lower transmission rate in the treatment group and it was felt to be unethical to continue giving HIV positive women placebo. The final results were vertical transmission rates of 8.3% in the zidovudine group versus 25.5% in the placebo group.<sup>5</sup> Subsequent studies have demonstrated that vertical transmission rates can be even further reduced when zidovudine is combined with HAART

(highly active antiretroviral therapy), the current standard of care in treatment of HIV infection.<sup>6</sup> The potential long-term effects of exposure to these drugs during pregnancy are unknown and there can be significant limitations in adhering to antiretroviral therapy.<sup>7</sup> The guidelines regarding treatment of HIV/AIDS and interventions to reduce vertical transmission are continually being reevaluated and updated.

The goal of counselling about and testing for HIV infection in pregnant women should be to provide infected women with support, access to appropriate treatment, and information to decrease the risk of HIV transmission to their children and sexual partners. Samson and King state that, "early diagnosis of HIV infection in a pregnant woman optimizes her medical and psychosocial care, decreases the incidence of mother-to-child transmission and decreases the risk of horizontal transmission to sexual partners."<sup>8</sup> Counselling is also seen as an important component of primary prevention, as it is an opportunity to provide uninfected women with information that may help them remain HIV negative.

Since HIV testing became available in the 1980s there has been agreement among health care providers and policy makers that people should be tested only with their informed, voluntary, and specific consent. The main reason for this approach is that there is significant stigmatization of and discrimination against people living with HIV/AIDS.<sup>9</sup> Counselling is required both before and after HIV testing and is a part of informed decision making.<sup>10</sup> Specific consent means, for example, that the blanket consent to testing and treatment forms that patients sign when admitted to hospital do not include HIV testing. Before a testing policy is implemented, models of care for HIV positive individuals and families should already be in place.

There are several possible types of prenatal HIV testing programs: mandatory, voluntary, targeted, and universal. HIV testing is not currently mandatory under any circumstance in Canada, although it is required in a few specific circumstances such as if a person chooses to donate blood or organs.<sup>11</sup> A theoretical benefit to a mandatory prenatal testing program would be that it would have the potential to identify all HIV positive women who present for prenatal care. However, most studies have concluded that the harms of mandatory testing outweigh the benefits. Mandatory programs that would force women to undergo an HIV test as a prerequisite to obtaining medical care could have detrimental effects on both maternal and child health. Some women would be discouraged from seeking any prenatal care.<sup>12</sup> This would counter the ethical principle of beneficence, as it would do more harm than good. Coercive testing without voluntary informed consent also contradicts the principle of autonomy. The principle of autonomy is central to any discussion of medical ethics, since it means that competent individuals have a near absolute right to make their own health care decisions.<sup>13</sup>

Mandatory HIV testing is difficult to defend legally as well as ethically. Canadian case law enshrines the right of patients to give or refuse consent to medical testing and treatment. The Supreme Court has ruled that the right of a woman to give or refuse informed consent is not restricted by pregnancy.<sup>14</sup> Finally, any legislation that allowed the government to force a pregnant woman to undergo an HIV test would likely contravene the *Canadian Charter of Rights and Freedoms*. In contrast, voluntary testing respects both the ethical principle of autonomy and the legal rights of women.

Initial HIV testing programs for pregnant women specifically sought to test only women with identifiable risk factors (targeted testing). The problem with this approach was that many women were unaware of or unwilling to disclose their own or their partners risk behavior. Physicians also failed to identify many women at risk.<sup>15</sup> Women who were infected through sexual contact with men or who had no identifiable risk factors comprise the majority of AIDS cases in Canadian women.<sup>16</sup> Thus, there has been an increasing shift to universal testing policies, which advocate offering HIV testing to all pregnant women. Universal and voluntary programs ensure that HIV counselling is provided to all pregnant women and all of these women are then offered an HIV test. The voluntary component means that after receiving counselling, a woman has the right to refuse to consent to an HIV test. Well-designed and implemented universal and voluntary strategies can be effective in increasing the uptake rates of prenatal HIV testing.<sup>17</sup> However, some urban centres with universal and voluntary programs have had less success, especially where women felt that services were lacking confidentiality and cultural sensitivity.<sup>18,19</sup> Lower levels of uptake may also result from the fact that not all physicians counsel pregnant women about HIV. Women may also choose to have an HIV test at an anonymous test site and not disclose this to their physician. In order to increase the effectiveness of prenatal HIV testing policies, women themselves need to have greater input into their development and evaluation.<sup>20</sup>

The wording of the official policy of the Ontario Ministry of Health has recently been changed from "HIV testing *should be*

*discussed* with all pregnant women and all women considering pregnancy" to "HIV testing *must be offered* to all pregnant women and all women considering pregnancy."<sup>21</sup> This new universal prenatal counselling and voluntary HIV testing policy explicitly states that informed consent, as well as pre- and post-test counselling is required. Inherent in the provision of counselling is the fact that women have the right to refuse HIV testing and even to refuse recommended treatment. The ethical principles of justice and beneficence dictate that quality of care should not be affected by a woman's decisions regarding testing.<sup>22</sup>

Physicians who fail to inform women about the risks of HIV during pregnancy and who fail to offer HIV testing to pregnant women would be vulnerable to a civil suit by the woman and to professional misconduct charges by the College of Physicians and Surgeons. Conversely, a physician who performed an HIV test on a woman without meeting the requirements of informed consent could also face significant legal consequences.<sup>23</sup>

In conclusion, physicians have a legal and an ethical obligation to provide counselling on HIV related concerns to all pregnant women, and ideally to all women. Women have the right to receive linguistically and culturally appropriate HIV counselling. They have the right to have access to voluntary HIV testing, treatment, and appropriate HIV care. Hopefully, the medical care of all women will one day meet these standards.

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