Opt in or opt out: What is optimal for prenatal screening for HIV infection?

Sharon Walmsley

ß See related article page 679

The use of highly active antiretroviral therapy (HAART) coupled as appropriate with elective cesarean section and the use of formula feeding have decreased the risk of mother-to-child transmission of HIV from about 25% to less than 2%.[1–3] Yet despite this remarkable progress, new infant infections continue to occur, primarily among women who do not obtain prenatal care or who were not offered HIV testing during pregnancy.

As of Dec. 31, 2001, 165 cases of AIDS in children attributable to prenatal transmission had been reported to the Centre for Infectious Disease Prevention and Control, Health Canada.[4] The Canadian Perinatal HIV Surveillance Program has identified 1338 births to HIV-positive women in Canada since 1992.[5] The number of infected infants for each birth year over the last decade has decreased from 24–31 in the first few years of the program to 4 and 6 respectively in the last 2 years. This is coincident with an increased proportion of women (47%–88%) receiving antiretroviral therapy in pregnancy. Only 9 of 394 infected infants were born to women who were receiving any antiretroviral agent.[5]

Screening pregnant women for HIV infection clearly represents an important opportunity to prevent the transmission of the virus to infants. Identification of HIV infection during pregnancy allows the infected woman to make an informed decision about continuing the pregnancy and to be offered interventions to decrease the risk of mother-to-child transmission. Other benefits include the appropriate management of the infected woman and the opportunity to decrease the risk of transmission to partners or to identify infections in them. Even in populations with a low prevalence of HIV-infected pregnant women, screening is cost-effective.[6–9] Testing should be done as early in pregnancy as possible to allow for timely decisions regarding the pregnancy. Uninfected women and their partners who continue high-risk behaviour during pregnancy should be encouraged to be retested later in the pregnancy.

Targeted testing of only pregnant women considered at high risk of HIV infection is no longer recommended because it fails to identify a substantial proportion of HIV-positive pregnant women.[10] Nor is mandatory testing desirable or ethically tenable because such a program deprives women of their fundamental human rights and could cause women to avoid seeking antenatal care.[11,12]

Voluntary testing strategies are of 2 types: opt-in and opt-out. Both strategies target all pregnant women, ideally as early in the pregnancy as possible but also up to and including the time of delivery. Under the opt-in approach, HIV testing is offered by the family physician or the obstetrician and can be done only once the physician has formally obtained informed consent from the woman. Some programs require that the consent be written. Under the opt-out approach, antenatal HIV testing is part of routine screening for infections, including hepatitis B, syphilis and rubella. The physician is required to inform the woman that this testing is considered routine, but there is no requirement for formalized counselling or written informed consent. The woman, however, can opt out of testing.[13]

The opt-in approach requires that physicians be aware of the availability and the attributes of the HIV test, be willing to offer it systematically and have the time and skills required for pretest counselling. The proportion of women agreeing to undergo HIV testing through this approach has been reported to range from 36% to 86%.[14,15] Many physicians simply fail to offer the test. Testing is refused by some women because of a lack of perceived risk, previous testing or lack of endorsement by the health care provider.[16] The quality and quantity of counselling before and after testing have also been shown to be correlated with test acceptance rates and level of satisfaction.[17] The Ontario Surveillance Study showed that, under Ontario's current opt-in strategy, during the first quarter of 2001, only 52.5% of pregnant women underwent prenatal HIV testing (Dr. Robert S. Remis, University of Toronto: personal communication, 2001). A recent report suggested that 6 cases of prenatal HIV transmission in Ontario occurred in the setting where HIV testing was not offered (3 cases), not accepted (2 cases) or not done (1 case).[18]

The proportion of pregnant women undergoing testing under an opt-out approach has increased from 33%–74% to 81%–88% in several jurisdictions.[19–23] Furthermore, it has been shown that universal screening is socially acceptable and identifies a greater proportion of those infected.

In the Canadian provinces and territories that have adopted the opt-in approach (Yukon Territory, British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick and Prince Edward Island), testing rates have ranged from 50% to 60%.[4] Rates of testing are higher in the provinces and territories that have adopted the opt-out approach (Northwest Territories, Nunavut, Alberta, Nova Scotia, and Newfoundland and Labrador). In Newfoundland and Labrador, it is estimated that almost all pregnant women

were tested in 2000.[4] In this issue (see page 679) Gayatri Jayaraman and colleagues[24] report that, in Alberta, only 4.7% of eligible pregnant women declined testing in the first 4 months after the province adopted the opt-out approach in 1998, 3.3% declined testing in 1999, and 1.7% declined testing in 2000. These results are similar to those of a cohort study in Alabama, which showed that the rate of HIV testing in pregnancy increased from 75% to 88% after a change in policy from an opt-in to an opt-out approach.[22] The US Institute of Medicine has recommended a national policy of universal HIV testing using opt-out testing.[13] These guidelines are supported by the American College of Obstetrics and Gynecology and the American Academy of Pediatrics.[25]

Although the opt-out approach can increase testing rates and will certainly decrease the incidence of mother-to-child transmission of HIV, there are important psychosocial and ethical issues to consider.[19] Without traditional informed consent, a woman who receives a positive HIV test result may be faced with issues of discrimination and stigmatization associated with the diagnosis. This could result in rejection or violence by her partner or her community. The isolation, guilt, shame and depression associated with such a diagnosis must also be considered. Therefore, for optimal use of an opt-out approach, physicians must be certain that the objectives, risks and benefits of the strategy are explained to their patients and that the women understand their right to refusal. Women with a positive test result and those who refuse testing should not be denied prenatal or obstetric care or be discriminated against in other ways. It is perhaps these women to whom thorough and informed pretest counselling should be offered.

Should fathers also be tested? In 2 recent cases of mother-to-child transmission of HIV in Ontario, the women were screened in pregnancy and had a negative test result (Dr. Susan M. King, Hospital for Sick Children, Toronto: personal communication, 2002). Through the pregnancy, they continued to have unprotected intercourse with their stable partners, and seroconversion occurred unknowingly during the pregnancy from their HIV-positive partners. In light of this observation, consideration must also be given to counselling and testing of the paternal partners, with or without repeat testing during pregnancy.

In conclusion, rates of testing for HIV infection appear to be markedly increased in jurisdictions that have adopted an opt-out strategy. Given that mother-to-child transmission of HIV infection continues to occur but may be preventable, the opt-in strategy is just not good enough. As has been shown in Alberta by Jayaraman and colleagues, testing rates improve with the opt-out approach. This approach should be adopted in the remaining jurisdictions with opt-in strategies, where testing rates remain suboptimal and HIV-infected children continue to be born. Policies should also be modified to consider screening the paternal partner as well.

Dr. Walmsley is Associate Professor of Medicine, University of Toronto, and Assistant Director, Immunodeficiency Clinic, Toronto Hospital, Toronto, Ont.

Competing interests: None declared.

References

1. Watts DH. Management of human immunodeficiency virus infection in pregnancy. *N Engl J Med* 2002;346:1879-91.
2. US Department of Health and Human Services. *Public Health Services Task Force recommendation for use of antiretroviral drugs in pregnant HIV-1 infected women for maternal health and interventions to reduce perinatal HIV-1 transmission in the United States*. Rockville (MD): HIV/AIDS Treatment Information Service; 2002. Available: www.aidsinfo.nih.gov/guidelines/perinatal/perinatal-083002.html (accessed 2003 Feb 12).
3. Newell ML, Rogers M. Pregnancy and HIV infection: a European consensus on management. *AIDS* 2002;16:S1-18.
4. Division of HIV/AIDS Epidemiology and Surveillance, Centre for Infectious Disease Prevention and Control, Health Canada. *Perinatal transmission of HIV*. HIV/AIDS Epi Update series. Ottawa: Health Canada; 2002. p. 24-9. Available: www.hc-sc.gc.ca/pphb-dgspsp/publicat/epiu-aepi/hiv-vih/peri_e.html (accessed 2003 Feb 12).
5. King SM, Lapointe N, Forbes J, Samson L, Vaudry W, Singer J, et al, and the Canadian Pediatric AIDS Research Group. Are we close to elimination of prenatal HIV infection in Canada? [abstract]. *Can J Infect Dis* 2002;13:52A.
6. Postma MJ, Beck EJ, Mandalia S, Sherr L, Walters MD, Houweling H, et al. Universal HIV screening of pregnant women in England: cost effectiveness analysis. *BMJ* 1999;318:1656-60.
7. Ades AE, Gupta R, Gibb DM, Duong T, Nicoll A, Goldberg D, et al. Selective versus universal antenatal HIV testing: epidemiological and implementational factors in policy choice. *AIDS* 1999;13:271-8.
8. Postma MJ, Beck EJ, Hankins CA, Mandalia S, Jager JC, de Jong-van den Berg LT, et al. Cost effectiveness of expanded antenatal HIV testing in London. *AIDS* 2000;14:2383-9.
9. Patrick DM, Money DM, Forbes J, Dobson SR, Rekart ML, Cook DA, et al. Routine prenatal screening for HIV in a low-prevalence setting. *CMAJ* 1998; 159(8):942-7.
10. Samson L, King S. Evidence-based guidelines for universal counselling and offering of HIV testing in pregnancy in Canada. *CMAJ* 1998;158(11):1449-57.
11. Nakchbandi IA, Longenecker JC, Ricksecker MA, Latta RA, Healton C, Smith DG, et al. A decision analysis of mandatory compared with voluntary HIV testing in pregnant women. *Ann Intern Med* 1998;128:760-7.
12. Peckham CS, Newell ML. Controversy in mandatory HIV screening of pregnant women. *Curr Opin Infect Dis* 1997;10:18-21.
13. Committee on Perinatal Transmission of HIV and Commission on Behavioral and Social Sciences and Education, Institute of Medicine. *Reducing the odds: preventing perinatal transmission of HIV in the United States*. Washington: National Academy Press; 1999.
14. Simpson WM, Johnstone FD, Boyd FM, Goldberg DJ, Hart GJ, Prescott RJ. Uptake and acceptability of antenatal HIV testing: randomised controlled trial of different methods of offering the test. *BMJ* 1998;316:262-7.
15. Fernandez MI, Wilson TE, Ethier KA, Walter EB, Gay CL, Moore J, for the Perinatal Guidelines Evaluation Project. Acceptance of HIV testing during prenatal care. *Public Health Rep* 2000;115:460-8.
16. Carusi D, Learman LA, Posner SF. Human immunodeficiency virus test refusal in pregnancy: a challenge to voluntary testing. *Obstet Gynecol* 1998;91:540-5.
17. Kiarie J, Nduati R, Koigi K, Musia J, John G. HIV-1 testing in pregnancy: acceptability and correlates of return for test results. *AIDS* 2000;14:1468-70.
18. Bitnun A, King SM, Arneson C, Read SE. Failure to prevent perinatal HIV infection [letter]. *CMAJ* 2002;166(7):904-5.
19. Lo B, Wolf L, Sengupta S. Ethical issues in early detection of HIV infection to reduce vertical transmission. *J Acquir Immune Defic Syndr Hum Retrovirol* 2000;25:S136-43.
20. Simpson WM, Johnstone FD, Goldberg DJ, Gormley SM, Hart GJ. Antenatal HIV testing: assessment of a routine voluntary approach. *BMJ* 1999;318:1660-1.
21. Blott M, Yearwood J, Gerval M, Welch J, Zuckerman M. Routine antenatal HIV testing is acceptable to woman. *BMJ* 1999;319:1069-70.
22. Stringer EM, Stringer JS, Cliver SP, Goldenberg RL, Goepfert AR. Evaluation of a new testing policy for human immunodeficiency virus to improve screening rates. *Obstet Gynecol* 2001;98:1104-8.
23. Stringer E, Stringer J, Cliver S, Goldenberg R, Goepfert A. Active refusal increases human immunodeficiency virus screening in an urban prenatal clinic system. *Obstet Gynecol* 2001;97:S58.
24. Jayaraman GC, Preiksaitis JK, Larke B. Mandatory reporting of HIV infection and opt-out prenatal screening for HIV infection: effect on testing rates. *CMAJ* 2003;168(6):679-82.
25. Human immunodeficiency virus screening. Joint statement of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. *Pediatrics* 1999;104(1 pt 1):128.

Correspondence to: *Dr. Sharon Walmsley, University Health Network, Toronto General Site, Rm. EG219, 200 Elizabeth St., Toronto ON M5G 2C4; fax 416 595-5826; sharon.walmsley@uhn.on.ca*