Testing pregnant women in Canada for HIV
How are we doing?

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In this issue of *Canadian Family Physician*, Dr Susan MacDonald and colleagues present the results of a study of Canadian physicians' knowledge, attitudes, and practices in regard to HIV testing of pregnant women (page 2250). Testing for HIV during pregnancy has been of considerable interest from a preventive perspective since early 1994 when the AIDS Clinical Trial Group 076 trial demonstrated that antiretroviral prophylaxis could reduce HIV transmission from mother to infant by 67%, from 25% to 8%. Since then, transmission rates using more effective combination antiretroviral therapy approach 1%,[1] preventing 90% of these tragic perinatal infections.

The study by MacDonald et al indicates that disappointingly few physicians (55%) offer HIV testing to all or most pregnant women. The study, however, was carried out in 1997-1998, and as the authors point out, the situation has improved since then. Current uptake of prenatal HIV testing varies from about 55% in Ontario, 75% in Manitoba, and 80% in British Columbia to 96% in Alberta.[2] Among the five provinces for which data are available (representing about 90% of pregnancies in Canada), the weighted average is 70%.

There is little justification for the long delays in systematic implementation of this lifesaving and cost-effective measure throughout Canada. A 70% uptake for such an effective intervention is discouraging. In Ontario, epidemiologic modeling suggests that about 10 infants are infected with HIV each year; most of these infections are preventable. In fact, physicians at the Hospital for Sick Children in Toronto, Ont, have diagnosed six HIV-infected infants born since the Ontario program began 2 years ago (personal communication from S. Read, Professor, Division of Infectious Diseases, Toronto Hospital for Sick Children, August 2001). Given the long latency from HIV infection to disease onset, many more children born during this period will likely be diagnosed with HIV.

Why testing is inadequate

Clearly, the current uptake of prenatal HIV testing in Canada is inadequate. Analysis of the problem must focus on the reasons for failure to test. First, physicians providing prenatal care might not offer the HIV test for several reasons: 1) they are unaware of the rationale for testing, 2) benefits appear small in an apparently low-risk practice, 3) potential risks are perceived to be high, 4) current recommendations for pretest counseling are viewed as too time-consuming, and 5) discussing the issues surrounding HIV testing makes patients and physicians uncomfortable.

While most physicians have not diagnosed a case of HIV infection, HIV prevalence is actually higher than that of hypothyroidism or phenylketonuria (PKU). Both these conditions have well accepted newborn screening programs for which uptake approaches 100%. In Ontario, we estimate that about 40 women with undiagnosed HIV infection conceive each year, or about 1 in 3500. Congenital hypothyroidism occurs in 1 of 4000[3] and PKU in 1 of 15 000 infants.[3,4] Prenatal HIV screening is cost-effective according to studies from Canada[5-7] and elsewhere.[8] The cost of the HIV test is about $4 while the cost of treating an HIV-infected infant is more than $200 000; thus, not many HIV-infected mothers need to be identified for the program to be cost-effective. The studies of MacDonald et al and others have shown that failure to offer the test is a frequent reason for the inadequate level of testing in Canada.

A second reason for failure to test is that pregnant women themselves refuse to take the test. Women at high risk of HIV infection might be unwilling to confirm their "worst suspicions," whereas women who perceive their risk as low might consider an HIV test unnecessary. Some women experience anxiety about their partners' reaction to their testing for HIV; some might even lack the freedom to take the test without their partners' permission. Women applying for immigrant status

in Canada might fear that positive results of an HIV test could cause authorities to reject their applications. Despite these factors, at a tertiary care centre in Ottawa, Ont, of 152 pregnant women given HIV counseling, only six (3.9%) refused the test.[9]

Occasionally, HIV testing is omitted for logistic reasons, such as failure to complete a requisition or to collect a specimen. In such cases, both physician and patient believe that the test was carried out. This seems to have been the case for several recent HIV transmissions in Ontario.

Finally, a few pregnant women receive no prenatal care and therefore have no opportunity for HIV testing. Some of these women are visitors or recent immigrants, and some are from countries with high prevalence of HIV. Though regimens administered only at delivery and to newborns are less effective than full regimens, many of these HIV transmissions could be prevented.

A change in policy

What can be done to improve the current situation? First, provincial and territorial governments should reconsider their HIV testing policies. In Alberta and Newfoundland, high levels of testing are achieved through routinely testing pregnant women using an "opt out" strategy. Women are tested unless they specifically refuse. All women are supposed to be informed about HIV testing, but in reality this might not always be the case. Other provinces where testing is performed only if women "opt in" have achieved rates varying from approximately 55% to 80%. (In fact, the true measure of success is not the proportion of pregnant women tested but rather the proportion of HIV-infected pregnant women detected; unfortunately, such data are difficult to obtain.)

Here we are faced with a dilemma. The opt out approach assures a high level of testing and prevents almost all HIV transmissions at the possible cost of conducting some tests without full informed consent. The opt in approach results in a lower level of uptake and many unnecessary transmissions. The approximately 20 infections in babies born each year in Canada are entirely preventable; they result in enormous emotional and financial costs.

Physician-patient interaction is important in making decisions. Canadian guidelines recommend comprehensive counseling about risks and benefits and verbal consent before testing.[10] Many issues raised in the guidelines are complex and could be difficult for patients to comprehend, while others are rapidly changing. Some providers will choose to convey the information briefly and concisely, while others will discuss issues in greater depth. The effect of different counseling approaches on whether patients comprehend and agree to testing is not well understood.[11-15] Presenting extensive and complex information about HIV transmission and testing could lead to confusion and fear, and cause patients to refuse testing. Such an approach also belies the "routine" nature of the test. Giving only a brief explanation could mean more patients agree to testing, albeit with a less comprehensive understanding of relevant issues.

Although women must never be tested without their knowledge, counseling requirements must also be feasible and realistic. It might be useful to distinguish counseling for testing during pregnancy from counseling for HIV testing requested by patients or recommended by physicians due to high risk. For most pregnant patients, the likelihood of positive test results is remote.

Patients often look to physicians for guidance. Providers should not be afraid to express a favourable opinion about the desirability of the test. In any case, given the progressive nature of HIV infection, HIV screening during pregnancy is not determining *whether* HIV-infected women will be diagnosed but *when*. Physicians should point out that the earlier this information is available, the more can be done to improve the prognosis of women, their babies, and their sexual partners. Expressing a guiding opinion about testing is appropriate; coercion is not.

Counseling for prenatal HIV testing for most women can be straightforward. Neither physicians nor patients should focus on HIV risk factors; this stigmatizes HIV testing and will fail to identify HIV-infected women unaware of their partners' risky activities.[16,17] Counseling should focus on the risks and benefits of the test, including the benefits of reducing mother-to-infant transmission, of access to therapy for women, and of reducing HIV transmission to sexual partners.

For most women, the risk of HIV testing is extremely low, as is the potential for benefit, so the decision should be to test. In those few cases where the risk of HIV is perceived as substantial, providers could refer patients to more specialized services, such as anonymous testing centres.

Physicians who fail to offer HIV testing to women who subsequently infect their infants might be held legally liable. We hope that legal action against physicians is not necessary to increase awareness and improve HIV testing.

Recommendations

To ensure that as many infected pregnant women as possible know their HIV status and to reduce mother-infant transmission in Canada, we offer the following recommendations.

1. Because of the many implications of HIV testing and diagnosis, pregnant women should not be tested for HIV without their knowledge and agreement.
2. The process of obtaining informed consent for HIV testing during pregnancy must be simplified.
3. Testing for HIV during pregnancy, with appropriate consent, has become the standard of obstetric practice in Canada. Provincial medical licensing bodies should formally adopt this standard, where this has not already been done.
4. For the few women with no prenatal care before delivery, hospitals should make rapid HIV testing available when women arrive in labour.
5. All provinces should adopt routine HIV testing for pregnant women and take an opt out rather than an opt in approach. The level of HIV testing achievable in an opt in approach appears to have limits (perhaps in the range of 80%). Policy makers in each province will have to decide whether they will accept preventable HIV transmissions to newborns as the inevitable and acceptable price to pay for a system that probably offers a higher level of informed consent. Neither system, however, is likely to achieve perfection.
6. Educational campaigns should be carried out among women of childbearing age whether they are pregnant or not to sensitize them to the need for prenatal HIV testing and to increase the proportion of women whose HIV status is known during pregnancy.

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