Access to prenatal HIV testing

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Editorial

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In this issue (page 1449), Drs. Lindy Samson and Susan King review the evidence concerning the benefits and risks of testing for HIV infection in pregnant women in Canada. The results of the ACTG (AIDS Clinical Trials Group) 076 trial, released in early 1994, showed that zidovudine administered to HIV-infected pregnant women and their newborns reduced the rate of transmission by almost 70%. Since then, each province has had to decide how to apply these findings.

The speed with which the provinces have implemented prenatal screening programs for HIV infection does not appear to be a direct function of the seriousness of the problem they are facing. Quebec, one of the provinces most affected, began planning soon after the ACTG 076 results were announced but did not announce a province-wide program until May 1997. In Ontario, a study carried out in the early 1990s indicated that the problem was less serious than in Quebec, but more recent estimates suggest that HIV prevalence among pregnant women in Ontario is about 0.6 per 1000, or almost 3 times the rate observed early in the decade.[1,2] Concerned physicians in that province are hopeful that the ministry of health will soon announce a prenatal screening program. Manitoba and BC (where HIV prevalence among pregnant women is lower than in Quebec or Ontario) reacted the most expeditiously, implementing prenatal screening programs in the first half of 1994.

Several cost-effectiveness studies have been carried out since the ACTG 076 trial.[3–5] A study conducted in Quebec in 1995[5] showed that universal screening in that province would cost approximately $242 000 per infection prevented. Although this may seem expensive, the cost of treating an HIV-infected infant is also high.[6–9] If a child born to an HIV-positive mother enjoys an increase in lifespan from 10 to 74 years, this cost would be equivalent to approximately $4000 per quality-adjusted life-year, considerably less than that of other widely accepted therapeutic interventions.

One could argue that testing only women at high risk is a more attractive option. The Quebec study showed that such selective screening would cost about $56 000 per infection averted and would reach 73% of those infected. Nevertheless, there are good arguments against this approach. First, it would exclude the 20%–30% of infected women who do not have readily identifiable risk factors. It would be unethical to limit the benefits of testing to women with identified risk factors for whom it may be cost effective. Second, it is not obvious that selective screening based on physicians' risk assessments is effective. Studies in the US have consistently demonstrated that physicians do not always follow risk assessment guidelines for hepatitis B[10–12] or for HIV infection[13] among pregnant women. Third, difficulties can arise from targeting particular groups, since they may feel defensive about being singled out. Women at high risk may be more likely to accept testing if they know it is being offered to all pregnant women.

There are a number of potential obstacles to the effective implementation of prenatal HIV testing programs. First, physicians need to be aware of the availability and utility of testing and must be willing to offer it systematically to all of their pregnant patients. Although we strongly believe that universal testing is desirable and beneficial, it cannot be carried out without informed consent. As for any other important diagnostic or therapeutic intervention, the patient must have a basic understanding of the benefits and risks. Surprisingly, some politicians have advocated mandatory testing; we feel that this would be ethically unacceptable.

Another potential obstacle is the argument that pretest counselling in this context must be detailed and extensive, requiring 30 or more minutes. Some have even advo-

cated the referral of all women to specialized counsellors since, in their opinion, physicians are unwilling and unable to carry out this important task. This appears to be an example of letting the perfect be the enemy of the good. Most pregnant women attach a high value to the life and health of their child and, given basic information about the benefits of testing, would consent to testing. There is little doubt that, if in-depth counselling were required, fewer physicians would take the time to offer the test, and many infants would be unnecessarily infected with HIV. Pre- and post-test counselling should be integrated into standard prenatal care. The small proportion of women who require more lengthy counselling could be referred to specialized centres where available. To facilitate the integration of HIV testing and counselling into prenatal care, prenatal forms should be modified to allow physicians to indicate that HIV testing has been offered. Checklists detailing the key elements of time-efficient pre- and post-test counselling should be made available.

Counselling a pregnant woman with regard to HIV infection clearly involves more than obtaining informed consent. It can also provide information and awareness that will help uninfected women remain so (after all, well over 99% of pregnant women are not infected). Although this type of counselling is important and potentially very effective, it can be done at any time during or after the patient's pregnancy and should not be confused with that provided for the purpose of prescribing a test that may save the life of her child.

A third potential obstacle to universal prenatal HIV testing is the perception that HIV infection is limited to those at high risk. The epidemiology of HIV infection among women in Canada is now reasonably well characterized. The problem was initially most concentrated among women from HIV-endemic countries, among whom, according to several studies, the prevalence of HIV infection was over 100 times greater than among women born in Canada or other non-endemic countries.[14] Women born in Haiti have historically comprised a substantial proportion of HIV-infected women in Quebec. A similar phenomenon is now being observed in Ontario among women from HIV-endemic countries in Africa and, to a lesser extent, the Caribbean. This situation may be relatively recent. The explosive epidemics of HIV infection among injection-drug users in Montreal and, more recently, Vancouver have not spared women. Although injection-drug users probably still account for a minority of pregnant women infected with HIV in Ontario and Quebec, the proportion will no doubt grow, as has already occurred in BC. The third group, which constitutes the majority of other HIV-infected women, are women who have had sex with HIV-infected men (primarily injection-drug users and, especially in Quebec, men from HIV-endemic countries). The problem is that many of these women are unaware that they are at risk. For this and the reasons stated earlier, it would be a mistake to limit our focus to women at high risk. The prescription of an HIV test with informed consent is rapidly becoming the standard of practice for prenatal care in Canada. A physician who fails to offer testing could potentially be sued for malpractice if an infant acquires HIV infection from his or her mother.

In light of the present situation, the remaining provinces should, without delay, implement programs to offer HIV screening to all pregnant women. Physicians and pregnant women should be made aware of the availability, utility and potential risks of testing. This message may be effectively communicated using the health promotion model: experience in public health has taught us that if we wish to achieve true access to an intervention we must do more than just make it available.

Finally, the role of evaluation must not be underestimated. It is not enough simply to implement these programs; indicators must be put in place in a systematic fashion to determine to what extent testing programs are succeeding and how any necessary improvements can be made.

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