

Prenatal HIV Testing in Ontario

Knowledge, Attitudes and Practices of Prenatal Care Providers in a Province with Low Testing Rates

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ABSTRACT

Objective: To describe the knowledge, attitudes and practices of prenatal care providers in relation to prenatal HIV testing.

Methods: A stratified random sample of 784 family physicians, 200 obstetricians and 103 midwives providing prenatal care in 3 health planning regions in Ontario received a questionnaire.

Results: Response was 622/1087 (57%). Almost half of participants (43%) were not aware of Ontario's prenatal HIV testing policy. Eighty-five percent of participants reported that they offered or ordered HIV testing for all pregnant women. Sixty-six percent agreed that women should have a choice about whether to test or not, and midwives were more supportive of having an informed consent process than were physicians.

Conclusion: Knowledge about the risks and benefits of prenatal HIV testing needs to be improved, and standards for informed consent should be re-evaluated to achieve the most ethical process with the least complexity.

La traduction du résumé se trouve à la fin de l'article.

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Pregnant women with HIV infection can benefit from treatment with antiretroviral therapy,¹ and the risk of transmission to their newborn infants can be reduced to 1% through a variety of interventions.² In order for these benefits to be realized, HIV infection must be diagnosed prior to or during pregnancy. Different prenatal HIV testing policies have been adopted in different Canadian provinces.³⁻⁵ In December 1998, the Ministry of Health and Long-Term Care in Ontario changed its policy of voluntary HIV testing for women in high-risk groups to a policy of offering testing to all pregnant women, regardless of risk.

The burden of preventable disease is increasing. It has been estimated that HIV prevalence among women in Ontario increased from 2.2/10,000 women in 1990 to 7.5/10,000 in 1998.⁶ One hundred seven confirmed childhood infections in Ontario occurred through vertical transmission from 1984 through 1998.⁶ In spite of this, laboratory data indicate that 51% of pregnant women in Ontario were tested for HIV during 1999 and 2000, substantially lower than in several other provinces.⁵ At least six children have thus far been identified as being infected during the same period through vertical transmission from mothers who were not tested.⁷

Substantial evidence suggests that offering HIV testing to women with risk factors for HIV is less effective than offering testing to all women. Studies from the United States and the United Kingdom report that 21% to 75% of women who are HIV positive are not known to have risk factors at the time a screening history is taken.⁸⁻¹³ More HIV infections are diagnosed by offering testing to all women than by offering testing to women with known risk factors.^{14,15}

Current testing rates in Ontario are insufficient to prevent all newborns from being infected. Understanding the knowledge, attitudes and practices of providers with respect to prenatal HIV testing may offer an explanation for this situation. To explore this possibility, we carried out a province-wide survey of family physicians, obstetricians and midwives in order to describe what they understood about prenatal HIV testing, how they felt about various aspects of the informed consent and testing procedure, and how they were actually carrying out HIV testing in their practices.

METHODS

Subjects

Three of the six health-planning regions in Ontario were selected for sampling: Northern, Central East (including Toronto), and Eastern (including Ottawa). These regions were selected to represent areas with high, low, and medium uptake of testing respectively, based on laboratory data available at the time that the study was planned. They represented 7,495,242/11,100,900 (67.5%) of the general population of Ontario (based on 1996 Canadian Census data).

The sample was drawn from *Souham Medical Lists* (Souham Medical Group, Don Mills, Ontario), which includes updated information from physician licencing bodies. Sampling was stratified based on region and discipline. All 768 family physicians in the Northern region, a random selection (using random number generator) of 1,025 family physicians from each of the Eastern region and the Central East region, and all 458 obstetricians in the 3 study regions were selected to undergo eligibility screening (Figure 1). All 107 midwives registered with the College of Midwifery were selected to receive a questionnaire.

A target of 600 respondents was chosen to detect a 14% difference in the rate of universal testing between regions at a power of 80% and $p < 0.05$ for a two-tailed test. To screen for eligibility, office staff were contacted by telephone and asked whether prenatal care was within the physician's scope of practice. Those providing prenatal care received a questionnaire.

Survey

Ethical approval was received from the Hamilton Health Sciences-McMaster University Research Ethics Board. The survey was carried out from May through July, 2000. The questionnaire was based on comments and responses from two focus groups, the literature and the research team's professional experience with prenatal HIV testing. Two focus groups, each including members of the three provider disciplines, were conducted in February 2000. Discussions were audio-taped, transcribed and analyzed for thematic content. The final questionnaire was pilot tested among 30 prenatal care providers for face and content validity, and

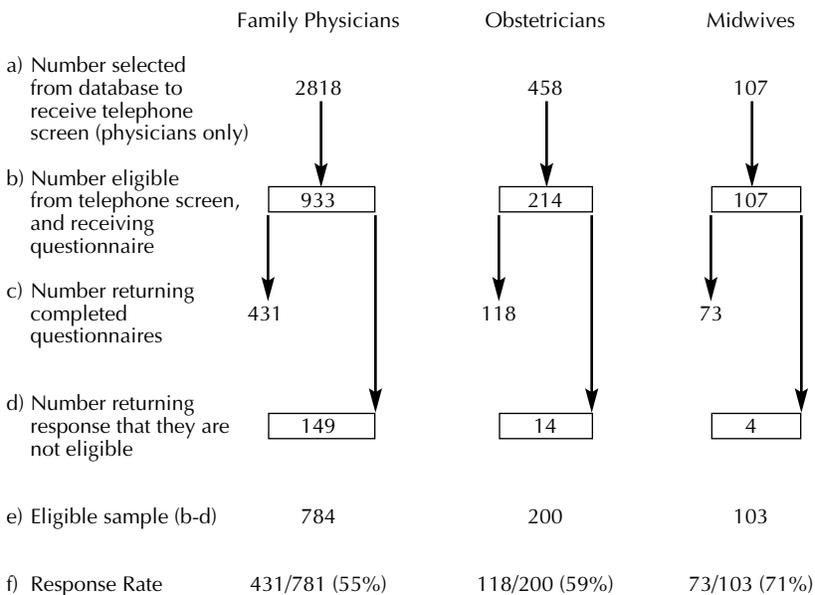


Figure 1. Sample Selection

TABLE I

Demographic Profile of Survey Respondents

Factor	Family Practice (n=431) n (%)	Obstetrics (n=118) n (%)	Midwifery (n=73) n (%)	Overall (n=622) n (%)
Female	199 (44.9)	33 (32.4)	73 (100)	306 (49.4)
Mean age (range)	43 (26-73)	49 (30-75)	40 (26-57)	44 (26-75)
Attend births	164 (37.0)	95 (93.1)	72 (98.6)	332 (54.0)
Mean prenatal patients in past 6 months (range)	17 (0-175)	121 (5-760)	47 (2-360)	40 (0-760)
Region				
Central East	122 (27.5)	64 (62.1)	39 (52.0)	225 (36.2)
Eastern	181 (40.8)	31 (30.1)	18 (24.0)	230 (37.0)
Northern	141 (31.8)	8 (7.8)	18 (24.0)	167 (26.8)
Years since graduation				
0-10	163 (37.0)	40 (39.2)	50 (69.4)	253 (41.1)
11-20	174 (39.5)	30 (29.4)	16 (22.2)	220 (35.8)
>20	104 (23.6)	32 (31.4)	6 (8.3)	142 (23.1)
Ever cared for HIV patient	264 (59.9)	67 (68.4)	4 (5.6)	335 (54.9)
Practice location				
Large urban	155 (34.9)	61 (59.8)	45 (62.5)	261 (42.2)
Medium urban	90 (24.3)	32 (31.4)	19 (26.4)	141 (22.8)
Town/Rural	199 (44.8)	9 (8.8)	8 (11.1)	216 (35.0)
Income				
Fee for service	372 (83.8)	89 (87.3)	6 (8.2)	467 (75.4)

minor changes were made based on their comments.

The survey was carried out using a modified Dillman method. Questionnaires were delivered by courier. Data analysis was performed using SPSS software (version 8.0, SPSS Inc., Chicago, IL). Comparison of proportions between groups was analyzed using the chi-square test or Fischer's Exact test. Three provider groups (family physicians, obstetricians and midwives) were compared for differences on 30 survey questions. To account for multiple comparisons, statistical significance (Type I error level) was set at $p < 0.001$.

RESULTS

Respondents

There were 1,254 providers receiving questionnaires, including 933 family physicians, 214 obstetricians and 107 midwives. All recipients were asked to indicate whether they were currently practicing prenatal care. (Only office staff of the physicians had been asked this question in telephone screening.) They were instructed to return the uncompleted questionnaire if they were not. Among the 1,254 questionnaire recipients, 167 indicated that they were not practicing prenatal care, leaving 1,087 who were considered eligible for the

TABLE II
Knowledge and Attitudes About Prenatal HIV Testing

Knowledge and Attitude Statements	Respondents Who Agree or Strongly Agree*	
	n	(%)
Knowledge		
Aware of prenatal HIV testing policy in Ontario	347	(57.0)
HIV diagnosis can benefit the woman	555	(90.4)
Treating HIV in pregnancy can decrease risk to infant	578	(93.7)
HIV diagnosis important to decrease risk to providers	471	(76.7)
My knowledge of prenatal HIV testing is adequate	390	(63.3)
Attitudes About Universal vs. Selective Testing		
It is best never to test for HIV in pregnancy	5	(0.8)
It is best to offer all women testing in pregnancy	533	(86.7)
My patients are too low risk to test all	136	(22.1)
I have increased medico-legal risk if I do not offer test	326	(53.3)
Counselling for prenatal HIV testing takes too long	183	(29.7)
Health dollars better spent elsewhere than HIV testing	88	(14.4)
Attitudes About Informed Consent		
HIV testing should be part of routine bloodwork, like Hepatitis B	444	(71.8)
HIV testing should include counselling about test	465	(76.0)
Women should have choice whether to be tested	409	(66.4)

* Respondents who agree or strongly agree on a 5-point Likert scale from "strongly disagree" to "strongly agree". Denominator is all who responded to the specific question.

TABLE III
Pre-test Counselling Practices

Counselling Practices	Respondents Who Perform Procedure Usually or Always	
	n	(%)*
I have ordered the HIV test as I would routine prenatal blood work, such as Hepatitis B.	241	(43.7)
I have explained that the HIV test is optional.	517	(91.2)
I have strongly encouraged pregnant women to have HIV testing.	365	(64.6)
I have told women that an HIV test is not important for them to have.	4	(0.7)
I have given written information about the HIV test.	120	(21.4)
I have counselled about the reasons, risks and benefits of HIV testing.	494	(67.1)
I have provided education about HIV transmission.	327	(57.7)
I have counselled women following HIV test results.	359	(64.6)

* Number who have performed the procedure usually or always (scale: never, sometimes, usually, always), as percent of all who responded to the question.

study (Figure 1). The final response was 431/784 family physicians (55%), 118/200 obstetricians (59%), and 73/103 midwives (71%). Table I summarizes demographic characteristics and practice attributes of providers.

Universal vs. selective approach to testing

Most respondents agreed with and practiced a universal approach to HIV testing for pregnant women, rather than a selec-

tive approach based on risk factors for HIV. Eighty-five percent stated that they generally offered or ordered HIV testing for all pregnant women (82% of family physicians, 88% of obstetricians, 97% of midwives, p=0.012). This included 20% who reported ordering the test for all women without offering it, and 65% who offered the test to all women. Six percent did not offer or order testing for any pregnant women, and 10% offered or ordered testing for selected women.

Knowledge

Knowledge was assessed for general concepts. Table II illustrates significant gaps in real and perceived knowledge levels. Although knowledge of the value of diagnosis in pregnancy was generally high, knowledge of the Ministry's testing policy, and self-perceived adequacy of knowledge were low. Seventy-seven percent also felt that prenatal HIV testing was important for decreasing risk to providers.

Attitudes

Table II summarizes attitudes about universal testing and informed consent. Providers generally agreed with the value and cost-effectiveness of a universal approach to testing, although a significant minority did not. Twenty-two percent believed that HIV risk among their patients was too low to warrant universal testing. Many providers disagreed with providing information and choice in testing. Seventy-six percent felt that HIV testing should include counselling about the test, 44% did not agree with women having a choice about testing, and 72% agreed that HIV testing should be carried out like Hepatitis B testing, which is usually done routinely without counselling or consent.

Most providers did not perceive substantial risk to women as a result of HIV testing (results not shown). Sixty-two percent felt that the likelihood of women experiencing anxiety while waiting for a test result was moderate to high. Twenty-eight percent thought that women would have difficulty getting medical care if they were HIV positive, 24% believed women would be denied life insurance merely as a result of having a test done, 9% believed it was likely that women would have a false-negative test, and 7% believed it was likely they would have a false-positive test.

TABLE IV
Summary of Statistically Significant Differences Between Disciplines

Statement	Family Practice		Obstetrics		Midwifery	
	n	(%)	n	(%)	n	(%)
Aware of the prenatal HIV testing policy in Ontario.	217	(50.0)	75	(75.0)*	55	(74.0)*
HIV diagnosis important to decrease risk to providers. (agree or strongly agree)	349	(79.6)	86	(85.1)	36	(48.6)*
Counselling for prenatal HIV testing takes too long. (agree or strongly agree)	140	(31.7)	40	(39.6)	3	(4.0)*
HIV testing should be part of routine bloodwork, like Hepatitis B. (agree or strongly agree)	328	(74.4)	89	(87.3)	27	(36.0)*
HIV testing should include counselling about the test. (agree or strongly agree)	327	(75.0)	66	(65.3)	72	(96.0)*
I have ordered HIV test as I would routine prenatal bloodwork, like Hepatitis B. (usually or always)	195	(50.0)	41	(43.1)	4	(6.2)*
I have strongly encouraged pregnant women to have HIV testing. (usually or always)	275	(69.7)	74	(74.0)	16	(22.9)*
I have given written information about the HIV test. (usually or always)	59	(15.0)	26	(26.2)	35	(50.0)*
Women should have choice in whether to be tested. (agree or strongly agree)	287	(65.2)	50	(49.5)	72	(96.0)*
Women will be denied life insurance as a result of having HIV test. (moderate to high risk)	80	(20.2)	26	(29.2)	23	(41.8)*
Spouse/partner will react negatively as a result of having HIV test. (moderate to high risk)	104	(23.7)	23	(22.8)	33	(44.6)*

* p<0.001 for comparison with family practice

Counselling practices

Table III summarizes the frequency of various pre-test counselling procedures reported by respondents. While many reported strongly encouraging women to have HIV testing, information and education about the test was not always provided, and the test was not always explained as being optional.

Differences among disciplines

Table IV summarizes the attitudes and practices for which statistically significant differences between disciplines were identified. Awareness of prenatal HIV testing policy was greater among obstetricians and midwives than among family physicians. In general, midwives appeared to agree more strongly with providing information and choice than did physicians, as reflected in their greater rate of agreement with counselling, providing information, and conveying choice about testing. There was also greater concern among midwives about the risks of HIV testing for women.

DISCUSSION

Although most participants agreed with, and practiced, a universal approach to prenatal HIV testing, there remained significant disagreement with this strategy. Eighty-five percent of providers offered or ordered HIV testing for all women, and 57% were aware of the government's current policy on prenatal HIV testing. Direct comparisons cannot be made between our study and previous studies in Ontario, due to differences in methodology. However, this study suggests a trend toward higher agreement with universal testing in more recent years. In 1995, Oglivie et al. reported that 8% of general practitioners in Hamilton, Ontario discussed HIV testing with all pregnant women, and 5% offered the test to all women.¹⁶ Between 1997 and 1998, MacDonald et al. reported that 39% of family physicians and obstetricians in Ontario were offering prenatal HIV testing to all pregnant women.¹⁷ Since nearly half of providers remain unaware of the Ministry's testing policy, other mechanisms such as position statements of professional associations and publication of evidence supporting testing are likely to have played a role in increasing adoption of universal offering of testing.

Reports from other countries have described varying levels of offering testing. In London, England in 1999, 13% of general practitioners reported offering HIV testing to all pregnant women, and 79% believed that all pregnant women should be offered the test.¹⁸ In the United States in 1997, 79% of obstetricians routinely offered HIV counselling and 76% routinely offered HIV testing.¹⁹ In a recent study from New Zealand, 52% of providers agreed with a universal testing program, but rates of counselling and testing were substantially lower.²⁰

Current Canadian guidelines recommend comprehensive counselling about risks and benefits, and verbal consent prior to HIV testing.²¹ Many physicians in our study did not agree with or practice this procedure. Midwives appear to be unique among providers in their level of support for informed choice. This may reflect a difference in values concerning patient autonomy.^{22,23} In a qualitative study conducted in Ontario in 1999, Leonard found that prenatal HIV testing was often conveyed to women as mandatory or routine, and often without adequate information.²⁴ Defining adequate informed consent is problematic in many clinical situations, and practitioners may be concerned that too much information will lead to testing being rejected.²⁵⁻²⁸

Our study has several limitations. Without information about providers who chose not to participate, our findings cannot be generalized to all Ontario providers. In addition, only self-reported testing practices were measured. Participants may have tended to report favourably toward attitudes and behaviours that reflect compliance with formal recommendations. Since actual testing rates in Ontario were near 50% at completion of this study,⁵ we must assume either that rates of offering testing have been overestimated in our study, or that women frequently decline the offer to test. In previous reports, even when testing has been offered to all pregnant women, rates of refusal have varied from 1% to 65%.^{29,30}

Several explanations for the observed prenatal HIV testing rates in Ontario are suggested by our data. First, not all providers have adopted a practice of universal offering of prenatal HIV testing. Many providers do not feel they have ade-

quate knowledge about prenatal HIV testing, and many are not aware of the Ministry's policy. Providers perceive a small but significant risk to women as a result of testing for HIV. There is significant disagreement with providing information and choice in the testing process, and support for making the procedure more routine. Finally, although not measured in this study, our data suggest that refusal rates among women may be high.

There is a need for further education for providers, as well as for pregnant women outside the clinical setting, in order to address what appears to be a high refusal rate. Confusion surrounding the risks of testing should be addressed. The standards for informed consent in the context of prenatal HIV testing should be re-evaluated, and consideration given to making testing more routine and informed consent less complex.^{31,32} New guidelines for prenatal HIV testing should be adopted, with a clearly defined minimum standard for informed consent, statements addressing the *actual* risks of testing, and streamlined pre-test information that can be conveyed in a practical and efficient manner in the clinical setting.

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RÉSUMÉ

Objectif : Décrire les connaissances, les attitudes et les pratiques des fournisseurs de soins prénatals à l'égard du dépistage anténatal du VIH.

Méthode : Nous avons envoyé un questionnaire à un échantillon stratifié aléatoire de 784 médecins de famille, 200 obstétriciens et 103 sages-femmes offrant des soins prénatals dans trois régions de planification sanitaire de l'Ontario.

Résultats : Le taux de réponse était de 622/1 087 (57 %). Près de la moitié des participants (43 %) ne connaissaient pas la politique ontarienne de dépistage anténatal du VIH. Quarante-vingt-cinq p. cent ont indiqué qu'ils proposaient ou administraient un test de sérodiagnostic du VIH à toutes les femmes enceintes. Soixante-six p. cent convenaient que les femmes devraient avoir le choix de se faire tester ou non; les sages-femmes étaient plus favorables que les médecins à un processus de consentement éclairé.

Conclusion : La connaissance des risques et des avantages du dépistage anténatal du VIH doit être améliorée, et les normes de consentement éclairé devraient être réévaluées afin d'en arriver au processus le plus conforme à l'éthique et le moins complexe possible.



Immunization questions?
Questions d'immunisation ?

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