

Medical Records and Women's Self-Report Are Not Reliable Sources for Determining Whether Prenatal HIV Testing Was Done

Mark H. Yudin, MD, MSc,¹ Angela M. Barbara, MSc,² Dale Guenter, MD,³ Randi Zlotnik Shaul, LLM, PhD,⁴ Robert S. Remis, MD,⁵ Susan M. King, MD⁶

¹Department of Obstetrics and Gynecology, St. Michael's Hospital, University of Toronto, Toronto ON

²The Hospital for Sick Children, University of Toronto, Toronto ON

³Department of Family Practice, McMaster University, Hamilton ON

⁴Department of Bioethics, The Hospital for Sick Children, University of Toronto, Toronto ON

⁵Department of Public Health Sciences, University of Toronto, Toronto ON

⁶Department of Pediatrics, The Hospital for Sick Children, University of Toronto, Toronto ON

Abstract

Objective: To determine whether medical records and the self-report of a postpartum patient provide reliable information about whether or not prenatal HIV testing has been done.

Methods: Women on the postpartum wards at three Toronto teaching hospitals who gave informed consent were included in the study. The presence or absence of prenatal HIV testing was determined by interviews with postpartum women, review of hospital charts, and search of the Public Health Provincial Laboratory and Prenatal Testing databases.

Results: Two hundred ninety-nine women were enrolled. All had had at least one prenatal visit, and 92% had copies of prenatal records in their hospital charts. Health records and patient reports were both unreliable for determining who had and who had not had HIV testing. HIV status was documented on 55% of the charts; on 46% it was noted that testing was performed, and on 46% there was documentation of pre- or post-test counselling. In interviews, 73% of the women reported having an HIV test during this pregnancy. Using the laboratory databases as the gold standard of whether testing had truly been done, medical record sensitivity and specificity were 65% and 62% respectively, and self-report sensitivity and specificity were 87% and 52% respectively. Using medical records resulted in an underestimation and self-reports an overestimation of the number of women who had been tested.

Conclusions: Both medical records and patient self-report are unreliable at the time of labour and delivery for determining whether or not a woman has been tested for HIV in pregnancy. Clinical and public health decisions may therefore be compromised by a lack of accurate testing information at the bedside.

Key Words: Human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), pregnancy, women, screening, testing

Competing Interests: None declared.

Received on April 20, 2006

Accepted on June 1, 2006

Résumé

Objectif : Déterminer si les dossiers médicaux et l'auto-signallement de la part d'une patiente en post-partum fournissent des renseignements fiables quant à savoir si un dépistage prénatal du VIH a eu lieu.

Méthodes : Les participantes de cette étude ont été des femmes séjournant au sein du service post-partum de trois hôpitaux universitaires torontois et ayant offert leur consentement éclairé. La présence ou l'absence d'un dépistage prénatal du VIH a été déterminée au moyen d'entrevues menées auprès de femmes en post-partum, d'un examen des dossiers hospitaliers et de recherches menées dans les bases de données *Public Health Provincial Laboratory et Prenatal Testing*.

Résultats : L'étude comptait 299 participantes. Chacune d'entre elles avait bénéficié d'au moins une consultation prénatale et les dossiers hospitaliers de 92 % d'entre elles disposaient de copies des dossiers prénataux. Tant les dossiers de santé que les signalements de la part des patientes ont présenté une fiabilité douteuse lorsque l'on cherchait à savoir si un dépistage prénatal du VIH avait eu lieu. L'état VIH était documenté dans 55 % des dossiers; dans 46 % des dossiers, une remarque indiquait qu'un dépistage avait eu lieu et, également dans 46 % des dossiers, l'offre de services pré et postdépistage faisait l'objet d'une documentation. Dans le cadre d'entrevues, 73 % des femmes ont signalé avoir bénéficié d'un dépistage du VIH au cours de leur grossesse. En utilisant les bases de données de laboratoire à titre d'étalon-or quant à savoir si un dépistage avait bel et bien été effectué, la sensibilité et la spécificité des dossiers médicaux ont été de 65 % et de 62 %, respectivement, et la sensibilité et la spécificité de l'auto-signallement ont été de 87 % et de 52 %, respectivement. Le recours aux dossiers médicaux a mené à une sous-estimation du nombre de femmes ayant bénéficié d'un dépistage, tandis que le recours à l'auto-signallement a mené à une surestimation de ce nombre.

Conclusions : Tant les dossiers de santé que les signalements de la part des patientes présentent une fiabilité douteuse lorsque l'on cherche à déterminer, au moment du travail et de l'accouchement, si une patiente a bénéficié d'un dépistage du VIH au cours de la grossesse. Il est donc possible que les décisions cliniques et de santé publique, prises au chevet de la patiente, soient compromises par un manque de précision quant aux renseignements sur le dépistage.

J Obstet Gynaecol Can 2006;28(10):867-872

INTRODUCTION

In recent years, there has been a substantial decrease in perinatal human immunodeficiency virus (HIV) transmission rates in Canada and other countries.¹⁻¹¹ Many factors have contributed to this, including advances in HIV treatment, prevention of transmission in the antepartum, intrapartum, and postpartum periods (with the use of antiretroviral therapy, obstetric procedures that minimize exposure to maternal body fluids, and formula feeding), and increased adherence to guidelines recommending universal voluntary screening for HIV during pregnancy.¹⁻¹¹ Despite these advances, babies continue to be born with HIV infection in Ontario. At The Hospital for Sick Children in Toronto, the results of a retrospective chart review suggested that the major reason for failures of prevention was that women were not tested for HIV during their pregnancy.¹² Voluntary universal HIV testing of all pregnant women is recommended in Canada and the United States,^{13,14} but when this study was in preparation, the uptake of HIV testing among pregnant women in Ontario was only slightly greater than 50%.¹⁵ By 2003, the rate had increased to 83%.¹⁶

If the patient's HIV status is known during pregnancy and delivery, the clinician and the patient are better equipped to make decisions about HIV risk counselling and behaviour change and about HIV treatment during pregnancy, labour and delivery, and the postpartum period. As rapid testing technology becomes readily available, it may be appropriate to offer women a rapid HIV test in labour if she has not already been tested or if results are unknown. Short-course zidovudine or nevirapine peripartum has been shown to reduce perinatal transmission by about 50%, making it highly desirable for a potentially HIV infected woman to know her status before delivery.⁵⁻⁸ If testing is carried out during pregnancy but the result is not available to either the clinician or the patient, then opportunities for intervention are lost.

The objective of the current study was to evaluate strategies for determining which women presenting at delivery had not been tested for HIV during pregnancy. We wished to ascertain the reliability of clinical medical records and the self-report of postpartum patients about whether or not prenatal HIV testing had been done.

MATERIALS AND METHODS

Recruitment and data collection took place from November 2002 to February 2004. The research protocol was approved by the research ethics boards at each study site, The Hospital for Sick Children, and the University of Toronto.

Study Subjects

Women were recruited on the postpartum wards of three Toronto teaching hospitals, St. Michael's Hospital, Mount Sinai Hospital, and the Women's College campus of Sunnybrook and Women's College Hospital. Women were eligible to participate if they understood and spoke English sufficiently to communicate in a personal interview and if it was possible to secure a confidential environment for the interview where the interviewer and the study subject could be alone. The target enrolment was 100 subjects per site.

Data Collection

Data were collected in personal interviews lasting approximately 15 minutes. All interviews were conducted by the same individual (AMB) in order to ensure consistency. All interviews took place on weekdays. The interviewer sought to maintain confidentiality by asking family and friends to leave the hospital room before discussing details of the study. Once informed consent was obtained, the interviewer administered a structured questionnaire. Participants were asked to recall details of HIV counselling and testing, but were not asked about their HIV status. After the interview, data were extracted from the patient's hospital chart regarding prenatal care, documentation of HIV risk factors, counselling, and testing. Only medical records available on the labour and delivery and postpartum units were used for this study. Office charts were not searched as they are not usually available in the hospital, and the purpose of the study was to assess the reliability of the information available in the hospital chart.

Laboratory Evidence of HIV Testing

Participants consented to have their names sent to the Central Public Health Laboratory in order to determine whether or not HIV testing had been carried out. All HIV assays in Ontario are carried out through this laboratory, and results are kept in either the prenatal screening database (if sample identified as "prenatal") or the HIV diagnostic database. Name and date of birth were extracted from the health record and used by laboratory staff to carry out a manual search. If no match was found, the case was linked using the first name, last name, and date of birth to records in the prenatal and HIV diagnostic databases. The matching technique allowed for different spellings (using Soundex codes) and variations in the structure of the name (allowing matching when given or family names were hyphenated but when one entry included only one part of a hyphenated name) and the reversal of month and day in the birth date. The matches were examined manually to determine whether they were plausible.

Data Analysis

All data were entered into a database and analyzed using SPSS (release 11.0.1 SPSS for Windows, Chicago, IL). Demographic data were presented using descriptive statistics. Both self-reported data and medical record documentation were compared with HIV testing results documented in the Public Health Laboratory databases. The reliability of the self-report and medical record information was evaluated by calculating sensitivity and specificity.

RESULTS

Of 446 women approached, 299 (67%) agreed to participate. Of the 147 women who declined to participate, 51 (35%) stated the timing was inconvenient, 36 (24%) declined because of fatigue or feeling unwell, 34 (23%) did not understand or speak English sufficiently well, 16 (11%) declined because they were not interested in participating, and 10 (7%) declined because they did not want anyone looking at their medical records. Interviews took place 3 to 162 hours postpartum (mean time since delivery 40 hours). Table 1 presents the demographic data and prenatal histories of the study subjects. Most of the women in the sample were married and highly educated, and the majority were working full time before their pregnancy. Slightly more than one half of the women were born in Canada, and almost all had comprehensive prenatal care with multiple visits. The majority obtained care from an obstetrician or a family doctor.

Two hundred eighteen women (73%) claimed they had been tested for HIV during their pregnancy. One hundred eighty-six (62%) claimed to have had an HIV test before the current pregnancy, and 76 (40%) were tested for HIV during a prior pregnancy.

HIV status was noted on the medical charts of 165 women (55%), 138 charts (46%) showed that HIV testing had been performed, and 136 (46%) indicated the patient had received HIV test counselling. Documentation was poor with respect to the offering and acceptance of HIV testing. Only 19 of the charts (6%) had documentation of a test being offered, 7 (2%) showed that a test had been accepted, and 6 (2%) showed that a test had been declined. HIV risk factor documentation was similarly poor: only 13 of the medical charts (4%) had notes about risk factors.

We were able to find results of HIV tests performed within nine months of delivery date in the two Public Health Laboratory Databases (prenatal and HIV databases) for 193 women (65%). Table 2 presents the reliability data for medical records with respect to HIV testing. Both sensitivity and specificity for medical record documentation were low, at 65% (95% CI 58–72) and 62% (95% CI 53–71), respectively. Over-reporting and under-reporting of HIV testing

Table 1. Characteristics of women surveyed on postpartum wards

Characteristic	No. (%)
Age	
16–19 years	6 (2)
20–29 years	64 (22)
30–39 years	210 (71)
40–46 years	17 (6)
Relationship Status	
Married	255 (85)
Common law partner	24 (8)
Single, no partner	13 (4)
Coupled, not living together	7 (2)
Country of Birth	
Canada	172 (58)
First Language	
English	208 (70)
Education	
Some high school	8 (3)
High school diploma	38 (13)
Some post-secondary	19 (6)
Bachelor's degree	177 (59)
Master's degree	42 (14)
PhD or more	14 (5)
Parity	
nulliparous	177 (60)
multiparous	122 (40)
Duration of Gestation	
28–31 weeks	2 (1)
32–36 weeks	23 (8)
37–41 weeks	272 (92)
Mode of Delivery	
Vaginal	175 (59)
Elective CS	55 (19)
Urgent/emergency CS	67 (22)
Number of Weeks at First Prenatal Visit	
5–12	157 (59)
13–20	75 (28)
20–39	33 (13)
Number of Prenatal Visits	
1–5	22 (8)
6–12	233 (87)
13–20	12 (5)
Health Care Provider	
Obstetrician	201 (67)
Obstetrician and family doctor	49 (16)
Family doctor	39 (13)
Midwife	6 (2)
Obstetrician and midwife	1 (0.3)
Perinatologist	1 (0.3)
Family practice resident	1 (0.3)

CS: Caesarean section.

were comparable (38% and 35%, respectively). Table 3 presents the reliability data for patient self-report with respect to HIV testing. Sensitivity was high (87%; 95% CI 82–91), but specificity was low (52%; 95% CI 42–61). Thus, 87% of women who had been tested reported that they had been tested. Among women who had not been tested, however, only 52% accurately reported that they had not been tested. These results indicate that women over-report HIV testing three times as frequently as they under-report (48% vs. 13%). There were 51 women who reported that they were tested, but for whom no HIV test could be found in the laboratory databases. For one of these women there was not enough information to search the databases, three had prenatal care outside of Canada for the first seven months of pregnancy, 10 had an HIV test more than nine months prior to delivery (according to laboratory databases), and 37 had prenatal care in Ontario but had never been tested for HIV (according to laboratory databases). There were 15 women who reported that they had not been tested for HIV during their pregnancy, but for whom a record of an HIV test ordered within the past nine months was found in the laboratory databases.

DISCUSSION

The results of this study suggest that, in the immediate postpartum period, both self-report and medical records have limited reliability for determining whether HIV testing was done during pregnancy. Medical record documentation was worse than self-report.

Our findings showed that medical record documentation of HIV testing in pregnancy was extremely poor. Hospital charts were an unreliable source of information about HIV status, counselling, and testing. The medical records tended to under-report the true frequency with which health care providers performed HIV testing, with more than one third of women who had been tested having no record of this in their chart. There are several reasons why medical record documentation may be poor. Copies of prenatal records must be transferred from physicians' offices to the labour and delivery suite near the end of pregnancy, and sometimes this does not happen. Even when records are present, however, HIV documentation is not consistent. Further, the actual report from the Public Health Laboratory stays in the office chart and does not get transferred to the hospital chart. Finally, busy clinicians may forget or may not have time to fill in the HIV test result section or to document the details of pre- and post-test counselling on the prenatal record. In Ontario, the prenatal record does have a space to document HIV test results, but no specific area to remind care providers about pre- and post-test counselling or to document that it has been done. It has been reported that health care provider compliance with performing and

Table 2. HIV testing—medical record reliability

Laboratory HIV test within 9 months of birth	Documentation in medical record of HIV testing being done		Total
	Yes	No	
Yes	125	68*	193
No	40†	66	106
Total	165	134	299

*False negative
†False positive

Table 3. HIV testing—self-report reliability

Laboratory HIV test within 9 months of birth	Did you have an HIV test during this pregnancy?		Total
	Yes	No/Don't know	
Yes	167	26*	193
No	51†	55	106
Total	218	81	299

*False negative
†False positive

documenting pre- and post-test counselling for prenatal HIV testing is poor.^{17,18} Our results also support the findings of a European study by Perez et al., showing that HIV risk factors were very infrequently recorded in medical records.¹⁹ It has been shown that medical records are more likely to document prenatal testing for hepatitis B and syphilis than for HIV.¹⁹ However, even if they were carefully documented, HIV test results, just like other prenatal blood work, are of limited value if they are not available at the time of labour and delivery. If HIV test results were available on hospital computer databases, as many other results are, this would greatly improve the reliability of the medical record.

Although more reliable than medical records, self-report was not consistently accurate. Of the women who believed they were tested, 23% actually were not. Also of concern was that other women appear to have been tested without any notice that testing was being done, although this number is encouragingly small (13%), and similar to that found in other studies.¹⁹ It is unclear why some postpartum women were unaware of whether or not they had been tested and the results of that testing. This may reflect poor communication between health care provider and patient. Whatever the reason, these results show that for prenatal care providers there is still substantial room for improvement in the dissemination of HIV information to pregnant women. Further, it is crucial that women in labour know not only whether they have been tested for HIV but also the results of that testing.

These results suggest that information from hospital medical charts or the self-report of women in labour about their HIV status is unreliable. If a rapid HIV test were performed during labour on the basis of information found in medical records or patient self-report, some women would be retested unnecessarily, and others who had not truly been tested during pregnancy would not be offered the rapid test. Therefore, the decision to offer rapid HIV testing at the time of labour and delivery may have to be based on criteria other than previous testing. The Mother-Infant Rapid Intervention at Delivery (MIRIAD) trial concluded that offering counselling and rapid HIV testing at the time of labour and delivery to women of unknown status was acceptable and feasible.²⁰ The Centers for Disease Control and Prevention has encouraged the availability of rapid testing, citing advantages such as prevention of vertical transmission and initiation of comprehensive medical care and follow-up.

There are limitations to our conclusions. We had no access to HIV or prenatal testing databases other than those at the Ontario Provincial Laboratory. Therefore, we were unable to confirm or refute the reporting of women who claimed to have been tested outside Ontario. The data obtained from the study subjects may not represent the general population of postpartum women or be applicable to all women. The sample had a high proportion of women with higher education and married women, and excluded women who did not speak English. Also, almost all women had prenatal care. Educational level is a determinant of awareness of HIV screening, and women with lower levels of education are less likely to report having been tested.^{19,21} Therefore, our sample of women may actually overestimate the reliability of self-report. Interviews occurred in patient rooms on the postpartum ward, so some women may not have felt comfortable answering questions about HIV and may not have answered as candidly as they might have in other circumstances. Interviews took place only during daytime hours on weekdays, so women who were admitted and discharged during a weekend were not included. Because not every postpartum woman was approached, the possibility of selection bias exists. Finally, the study focused on prenatal HIV testing patterns of women following labour and delivery. Therefore, the experiences of women who had a pregnancy loss or who terminated a pregnancy were not explored.

We believe that the findings of this study provide important information for professionals caring for pregnant women. It is clear that both medical records and patient self-report are unreliable methods for determining who has had an HIV test during pregnancy. There is a lack of documentation in medical records, and at the time of testing women

receive inadequate information and may not even be aware that testing has been performed. In order to overcome these obstacles, prenatal care providers must be reminded of the importance of informed consent for prenatal HIV testing and the advantages of testing in pregnancy. Staff must be trained to improve recording of HIV testing, counselling, and results. To this end, it is important to develop mechanisms that would significantly improve the accuracy, consistency, and standardization of HIV testing documentation in the medical records. One possibility would be to have HIV test results available on hospital computer databases or on a central provincial database with access provided to prenatal care providers. Until this can be accomplished, consideration should be given to offering HIV testing to all women in labour unless an HIV test result is available.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the funding support of the Ontario HIV Treatment Network.

REFERENCES

1. Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ, et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *N Engl J Med* 1994;331:1173-80.
2. The European Mode of Delivery Collaboration. Elective caesarean-section versus vaginal delivery in prevention of vertical HIV-1 transmission: a randomised clinical trial. *Lancet* 1999;353:1035-9.
3. The International Perinatal HIV Group. The mode of delivery and the risk of vertical transmission of human immunodeficiency virus type 1: a meta-analysis of 15 prospective cohort studies. *N Engl J Med* 1999;340:977-87.
4. Leroy V, Newell ML, Dabis F, Peckham C, Van de Perre P, Bulterys M, et al. International multicentre pooled analysis of late postnatal mother-to-child transmission of HIV-1 infection. Ghent International Working Group on Mother-to-Child Transmission of HIV. *Lancet* 1998;352:597-600.
5. Shaffer N, Chuachoowong R, Mock PA, Bhadrakom C, Siriwasin W, Young NL, et al. Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: a randomised controlled trial. *Lancet* 1999;353:773-80.
6. Wiktor SZ, Ekpini E, Karon JM, Nkengasong J, Maurice C, Severin ST. Short-course oral zidovudine for prevention of mother-to-child transmission of HIV-1 in Abidjan, Cote d'Ivoire: a randomised trial. *Lancet* 1999;353:781-5.
7. Dabis F, Msellati P, Meda N, Welffens-Ekra C, You B, Manigart O. 6-month efficacy, tolerance, and acceptability of a short regimen of oral zidovudine to reduce vertical transmission of HIV in breastfed children in Cote d'Ivoire and Burkina Faso: a double-blind placebo-controlled multicentre trial. *Lancet* 1999;353:786-92.
8. Guay LA, Musoke P, Fleming T, Bagenda D, Allen M, Nakabiito C. Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial. *Lancet* 1999;354:795-802.
9. Wade NA, Birkhead GS, Warren BL, Charbonneau TT, French PT, Wang L, et al. Abbreviated regimens of zidovudine prophylaxis and perinatal transmission of the human immunodeficiency virus. *N Engl J Med* 1998;339:1409-14.

10. Nduati R, John G, Mbori-Ngacha D, Richardson B, Overbaugh J, Mwatha A, et al. Effect of breastfeeding and formula feeding on transmission of HIV-1: a randomized clinical trial. *JAMA* 2000;283:1167–74.
11. Ioannidis JPA, Abrams EJ, Ammann A, Bulterys M, Goedert JJ, Gray L, et al. Perinatal transmission of human immunodeficiency virus type 1 by pregnant women with RNA virus loads < 1000 copies/mL. *J Infect Dis* 2001;183:539–45.
12. Bitnun A, King SM, Arneson C, Read SE. Failure to prevent perinatal HIV infection. *CMAJ* 2002;166:904–5.
13. Samson L, King S. Evidence-based guidelines for universal counselling and offering of HIV testing in pregnancy in Canada. *CMAJ* 1998;158:1449–57.
14. The Centers for Disease Control and Prevention. U.S. Public Health Service recommendations for human immunodeficiency virus counseling and voluntary testing for pregnant women. *MMWR* 1995;44(RR-7):1–15.
15. Remis RS, Guenter D, King SM. Testing pregnant women in Canada for HIV: how are we doing? *Can Fam Phys* 2001;47:2199–2202.
16. Remis RS, Swantee C, Fikre Merid M, Palmer RWH, Fisher M, Wu K, et al. HIV testing among pregnant women: results from the Ontario HIV seroprevalence study. Abstract Annual Meeting, XV International AIDS Conference, Bangkok, Thailand; 2004.
17. Sherr L, Bergstrom A, Hudson CN. Consent and antenatal HIV testing: the limits of choice and issues of consent in HIV an AIDS. *AIDS Care* 2000;12:307–12.
18. Parazzini F, Ricci E, Grasso P, Surace M, Benzi G. Italian obstetricians often don't ask women to take test. *BMJ* 1998;316:1901.
19. Perez K, Blanch C, Casabona J, Almeda J, Coll O. Coverage of HIV testing among pregnant women in Catalonia, Spain. *Eur J Public Health* 2004;14:261–6.
20. Bulterys M, Jamieson DJ, O'Sullivan MJ, Cohen MH, Maupin R, Nesheim S, et al. Rapid HIV-1 testing during labor: a multicenter study. *JAMA* 2004;292:219–23.
21. Vayssiere C, Du Mazaubrun C, Breart G. Human immunodeficiency virus screening among pregnant women in France: results from the 1995 National Perinatal Survey. *Am J Obstet Gynecol* 1999;180(3Pt1):564–70.