Barriers to Universal Prenatal HIV Testing in 4 US Locations in 1997

Rachel A. Royce, PhD, MPH, Emmanuel B. Walter, MD, MPH, M. Isabel Fernandez, PhD, Tracey E. Wilson, PhD, Jeannette R. Ickovics, PhD, and R. J. Simonds, MD, for the Perinatal Guidelines Evaluation Project

ABSTRACT

Objectives. We determined rates of prenatal HIV testing and investigated barriers to testing.

Methods. We surveyed 1362 representative parturient women from 7 hospitals in 4 locations of the United States.

Results. Overall, 89.9% of women reported being offered HIV testing and 69.6% reported being tested. Proportions of women not offered testing differed by location (range = 5.2%–16.3%), as did proportions not tested (range = 12.2%–54.4%). Among women who perceived that their clinicians had not recommended testing, 41.7% were tested, compared with 92.8% of women who perceived a strong recommendation ($P < .05$). Private insurance for prenatal care was also associated with not being tested. Women gave multiple reasons for not being tested, most commonly not being at risk, having been tested recently, and the test's not being offered or recommended, cited by 55.3%, 39.1% and 11.1% of women, respectively.

Conclusions. Although most parturient women were offered a prenatal HIV test and got tested, testing proportions did not reach national goals and differed significantly by location and payment status. Concern about testing consequences was not a major barrier. Perception of clinicians' recommendations strongly influenced testing. Changing provider practices will be essential to implementing universal prenatal HIV testing. (*Am J Public Health.* 2001;91: 727–733)

Worldwide each year, an estimated 2.3 million children are exposed perinatally to HIV, 6000 to 7000 of them in the United States.[1] Effective interventions such as the use of antiretroviral medications, obstetric practices that minimize exposure to maternal bodily fluids, and formula feeding can now dramatically reduce mother-to-child transmission.[2–11] Furthermore, treatment can prolong the lives of HIV-infected people. Most interventions to prevent perinatal HIV transmission require that women obtain prenatal care, that clinicians offer testing, that women accept testing, and that HIV-infected women adhere to treatment and other interventions—a complex interplay of behaviors. In response to the prevention opportunity afforded by antiretroviral prophylaxis during the perinatal period, the US Public Health Service issued guidelines in 1995 for universal voluntary prenatal HIV testing.[12] Recently, the Institute of Medicine recommended that universal prenatal testing become a routine component of prenatal care, a recommendation supported by the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics.[13,14]

To determine the extent to which the guidelines and recommendations have been implemented, and to identify barriers to implementation, we surveyed a representative sample of women delivering in 7 hospitals in 1997 in 4 locations of the United States. Most previous studies of perinatal HIV testing were limited to a single state, included mostly high-risk patients in public prenatal care settings, predated effective prophylaxis, and typically conducted assessment before the delivery.[15–18] By design, these studies excluded women with private care and women with late or no prenatal care, and they missed testing done late in the prenatal period. This survey overcame some of these limitations and provided results that reflect the recent experience of a broad segment of pregnant women in the United States.

Methods

Study Population

The sample comprised women who gave birth in 1997 at 7 hospitals in 4 states: North Carolina, Connecticut, New York, and Florida. All hospitals were teaching hospitals where care was financed by a number of different public and private sources. Four were in central North Carolina: Durham Regional Hospital (2785 deliveries in 1997) and Duke Medical Center (2085 deliveries) in Durham, University of North Carolina Hospitals (2075 deliveries) in Chapel Hill, and Wake Medical Center (3350 deliveries) in Raleigh. The remaining 3 were Yale New Haven Hospital in Connecticut (5200 deliveries), the University Hospital of Brooklyn in New York (2300 deliveries), and Jackson Memorial Hospital in Miami, Fla (6029 deliveries).

We designed selection procedures to obtain a representative sample of approximately 200 parturient women per hospital. Procedures were not designed to select a probabil-

At the time of the study, Rachel A. Royce was with the Department of Epidemiology, University of North Carolina at Chapel Hill, and M. Isabel Fernandez was with the Department of Psychiatry and Behavioral Science, University of Miami School of Medicine, Miami, Fla. Emmanuel B. Walter is with the Department of Pediatrics, Duke University Medical Center, Durham, NC. Tracey E. Wilson is with the Department of Preventive Medicine and Community Health, Down State Medical Center, State University of New York, Brooklyn, NY. Jeannette R. Ickovics is with the Department of Epidemiology and Public Health, Yale University Center for Interdisciplinary Research on AIDS, New Haven, Conn. R. J. Simonds is with the Centers for Disease Control and Prevention, Atlanta, Ga.

Requests for reprints should be sent to Rachel A. Royce, PhD, MPH, Research Triangle Institute, PO Box 12194, Research Triangle Park, NC 27709-2194 (e-mail: rroyce@rti.org).

This article was accepted August 24, 2000.

ity sample. Excluded were those women whose infant died or who were too sick to interview, who did not speak English, Spanish, or Haitian Creole (the study languages), or who were mentally incompetent. The study protocol was approved by institutional review boards at each site and by the Centers for Disease Control and Prevention. All participants provided informed consent.

The average number of days spent interviewing at each hospital was 54.4 (range = 29–65). On the basis of the average number of births per day in each hospital and the number of days we spent interviewing in each hospital, we estimated that we interviewed on average 44.3% of the women whose deliveries had occurred on the interview days (range = 31.7%–53.7%). The overall refusal proportion among the women approached was 10.5%. At all sites, floor nurses helped study staff determine eligibility. In North Carolina, we used the delivery log to ascertain all births in the prior 24 hours (vaginal births) or 48 hours (cesarean births). We approached by birth order all eligible women in each group. Between 11% and 18% of mothers were not approached because only English-speaking interviewers were available. In New Haven, we used the delivery log to identify and approach all eligible women who had given birth in the previous 48 hours. In Brooklyn, we approached every other woman identified on the postpartum ward nurses' daily log. In Miami, we approached every third room containing postpartum women.

Data Collection

Using centrally trained interviewers and a structured interview lasting approximately 10 minutes, we gathered information about prenatal care, sociodemographic factors, and HIV counseling and testing during prenatal care and prepregnancy. To determine perception of the strength of the provider's recommendation of testing, we asked whether women thought their prenatal care provider wanted them to be tested for HIV not at all, a little, some, much, or very much. We elicited with open-ended questions reasons for not being tested. Reasons were coded independently by 2 readers; 1 investigator resolved discrepancies. We asked women about payment for prenatal care and categorized sources into a mutually exclusive hierarchy: public financing for those with any public sources (Medicaid, Medicaid-funded health maintenance organization, Medicare, military or Veterans Administration); private insurance for those with private insurance financed by themselves, their spouse, their employer, or their spouse's employer; self-financing for those who paid out-of-pocket; or other. Source of funding was further dichotomized into private insurance and no private insurance, with the latter referred to as public funding.

Statistical Analysis

We calculated proportions and 95% confidence intervals by using binomial distributions.[19] Relative proportions, or relative risks, and 95% confidence intervals were computed as the measure of association for 2 primary outcomes—not being offered a test and not being tested—with being offered a test and being tested as the respective comparison groups. Bivariate and multivariate analyses included the following factors: demographics (age, race/ethnicity, education, marital status), economic information (annual household income and source of payment for prenatal care), trimester in which prenatal care began, history of prepregnancy HIV testing, women's perception of the strength of the provider's recommendation, and location. North Carolina was the reference location for reasons of statistical efficiency. For analysis of predictors of not being tested, we included only women who had received prenatal care and who had been offered testing. We used adjusted odds ratios estimated by logistic regression[19] to gauge the relative contribution of factors, although these odds ratios are biased away from the null relative risk.

Results

A total of 1362 parturient women were interviewed (753 from central North Carolina, 208 from New Haven, 201 from Brooklyn, and 200 from Miami). Sociodemographic characteristics differed substantially by location, with women in North Carolina and New Haven more likely to be older, White, and married and to have higher incomes, private insurance, and earlier entry into prenatal care (Table 1). At each location, key sociodemographic characteristics of the study population matched those of parturient women in 1997 at each hospital (data not shown).

Of the total sample, 57.6% had been tested for HIV before the current pregnancy: 49.9% during an earlier pregnancy and 23.4% within 6 months of the current pregnancy (53.7% had been tested more than once). We excluded from further analysis 3 Miami women who were known to be HIV infected prior to pregnancy; they were neither offered testing nor retested.

Prenatal Counseling and Offering of Testing

Most women (88%) had received information about HIV, AIDS, and HIV testing at their prenatal clinic. The most common sources for this information were an individual session with a health care provider (78%) and written materials (56%).

Overall, 1192 women (89.9%; 95% confidence interval [CI] = 88.1%, 91.5%) reported being offered an HIV test during a prenatal visit (Table 2), including 56 women who had not received information about HIV/AIDS at the prenatal clinic. Of the 134 women who said they were not offered an HIV test, 74 reported receiving no information on HIV/AIDS.

The proportions of women offered prenatal HIV testing differed by location. Compared with women in North Carolina, significantly more New Haven women were not offered testing (Table 2). In a multivariate model of not being offered testing that included location, demographics, and trimester in which prenatal care was initiated, relative to North Carolina, the adjusted odds ratio for not being offered a test was elevated for New Haven (odds ratio [OR] = 1.9; 95% CI = 1.2, 3.1) and Miami (OR = 2.0; 95% CI = 1.1, 3.6). Also, older age (OR = 1.2 per 5-year increment; 95% CI = 1.0, 1.4) and third-trimester initiation of prenatal care (OR = 3.1; 95% CI = 1.3, 7.6) were significant independent factors associated with not being offered a test, as were higher educational attainment (OR = 1.4; 95% CI = 0.9, 2.2) and private insurance (OR = 1.5; 95% CI = 0.9, 2.4), albeit with marginal statistical significance.

Prenatal HIV Testing

Overall, 916 women (69.6%; 95% CI = 67.0%, 72.0%) reported getting an HIV test during a prenatal care visit and 401 women (30.4%; 95% CI = 28.0%, 33.0%) did not. Of all women tested, 56% had first-trimester tests, 33% second-trimester tests, and 11% third-trimester tests. Of the 561 women who had not been tested before, 66% got tested, accounting for 41% of all women who got tested. Of women not tested, 11 (6 from Miami) were tested after entering the hospital for delivery.

Five women reported positive HIV test results determined during pregnancy. However, none of the 5 indicated whether they had had a prior HIV test. Thirty women who were tested did not know their test results, including 4 who had not returned for test results and 9 who had test results pending.

Factors Associated With Not Being Tested

In addition to those known to be HIV seropositive, those without prenatal care, and those not offered a test, we also excluded from the analysis 21 women whose testing status was unknown. Of the remaining 1171 women, 23.7% were not tested. Testing proportions

TABLE 1—Social and Demographic Characteristics of Study Women

	All Sites, % (n=1362)	Central North Carolina, % (n=753)	New Haven, % (n=208)	Brooklyn, % (n=201)	Miami, % (n=200)
Age, y (mean±SD)	(27.4±6.4)	(27.3±6.4)	(29.3±5.9)	(26.8±6.4)	(26.8±6.5)
15–19	12.5	13.4	6.8**	12.9	15.6
20–29	47.6	48.2	40.1	50.3	49.8
≥30	40.0	38.3	53.1	36.8	34.7
Married	58.5	61.7	72.6*	40.8**	46.7**
Education≤high school	42.9	35.7	31.1	54.7**	70.2**‡
Hispanic ethnicity	12.4	2.1	12.6**	8.0**	54.8**‡
Race[a]					
White	42.9	51.4	63.7**	1.5**	34.7**‡
Black	43.4	40.3	20.4	83.1	41.2
Mixed	7.0	4.0	4.0	9.0	19.6
Other	5.7	4.3	11.9	6.5	4.0
Annual household income, $					
≤15 000	37.0	25.2	23.7*	58.9**	76.0**†
15 001–60 000	45.5	52.6	45.5	39.1	23.4
>60 000	17.5	22.2	30.8	2.0	0.6
Source of payment for prenatal care					
Public	47.3	43.9	25.0**	64.0**	65.8**‡
Private insurance	46.2	53.5	73.5	28.5	8.5
Self	4.4	1.5	1.0	0.5	23.1
Other	2.1	1.1	0.5	7.0	2.5
Received prenatal care	99.3	99.7	100.0	99.0	97.0**
Trimester of first prenatal care visit					
First	81.8	84.3	89.3	74.5**	71.1**
Second	15.3	13.7	10.2	20.9	21.6
Third	2.9	2.0	0.5	4.6	7.4
Prior HIV test	57.6	58.7	53.2	50.8*	65.3†
Within 6 mo of conception	23.4	24.0	14.7*	21.8	30.4
More than once	53.7	55.0	55.0	47.5	53.2
During a prior pregnancy	49.9	50.1	54.1	43.6	50.8

Note. Central North Carolina includes Chapel Hill, Durham, and Raleigh. Percentages may not sum to 100.0% owing to rounding. All *P* values are from 2-tailed tests.

[a]Race characterization as Black, White, or mixed was selected by the woman being interviewed. Other included women who selected the categories Native American and Alaskan Native, Asian and Pacific Islander, or other.

*$P<.01$ for each location compared with Central North Carolina; **$P\leq.001$ for each location compared with Central North Carolina; †$P<.01$ for Brooklyn compared with Miami; ‡$P\leq.001$ for Brooklyn compared with Miami.

TABLE 2—Proportions of Women Offered HIV Testing and Tested During Prenatal Care and the Relation of Geographic Location, Not Being Offered Testing, and Not Being Tested

	Prenatal HIV Testing Offered[a]					Tested for HIV During Prenatal Care									
						All Women[b]					Only Among Women Offered Testing[c]				
	Yes		No			Yes		No			Yes		No		
	n	%	n	%	RR (95% CI)	n	%	n	%	RR (95% CI)	n	%	n	%	RR (95% CI)
Central North Carolina	672	90.8	68	9.2	1.0	494	67.8	235	32.2	1.0	483	73.4	175	26.6	1.0
New Haven	170	83.7	33	16.3	1.8 (1.2, 2.6)	94	45.6	112	54.4	1.7 (1.4, 2.0)	91	54.2	77	45.8	1.7 (1.4, 2.1)
Brooklyn	182	94.8	10	5.2	0.6 (0.3, 1.1)	163	84.0	31	16.0	0.5 (0.4, 0.7)	160	89.9	18	10.1	0.4 (0.2, 0.6)
Miami	168	87.0	23	12.0	1.3 (0.8, 2.0)	165	87.8	23	12.2	0.4 (0.3, 0.6)	159	95.2	8	4.8	0.2 (0.1, 0.4)
All sites	1192	89.9	134	10.1		916	69.6	401	30.4		893	76.3	278	23.7	

Note. RR=relative risk; CI=confidence interval. Central North Carolina (including Chapel Hill, Durham, and Raleigh) is the reference group for the relative risk.

[a]Excluded 36 women: 3 known to be HIV seropositive prior to pregnancy, 22 who did not recall if they had been offered testing, and 11 for whom answers were missing.

[b]Excluded 45 women: 3 known to be HIV seropositive prior to pregnancy, 37 who were unsure if they were tested, and 5 who did not answer the question.

[c]Excluded 21 women: 18 who had been offered testing but were unsure if they were tested, 2 whose data on whether they were tested were missing, and 1 who refused to answer.

TABLE 3—Association Between Perception of Provider's Recommendation and Prenatal HIV Testing Among Women Offered an HIV Test, and Comparison of Testing Proportions Among Women With Private Insurance vs Public Funding for Prenatal Care

	HIV Testing During Pregnancy											
			Private Insurance for Prenatal Care					Public Funding for Prenatal Care				
					Tested					Not Tested	Tested	Not Tested
Perceived Strength of Provider's Recommendation	n[a]	%[b]	n	%[c]	n	%[c]	RR (95% CI)	n	%[c]	n	%[c]	RR (95% CI)	RR[d] (95% CI)
Very strong	348	30.2	103	91.2	10	8.9	(Reference)	218	93.6	15	6.4	(Reference)	1.4 (0.6, 3.0)
Strong	195	16.9	60	76.9	18	23.1	2.6 (1.3, 5.3)	108	93.1	8	6.9	1.1 (0.5, 2.5)	3.3 (1.5, 7.5)
Somewhat strong	279	24.2	84	60.4	55	39.6	4.5 (2.4, 8.4)	116	84.7	21	15.3	2.4 (1.3, 4.5)	2.6 (1.7, 4.0)
A little strong	223	19.3	55	47.4	61	52.6	5.9 (3.2, 11.0)	85	80.2	21	19.8	3.1 (1.7, 5.7)	2.7 (1.7, 4.0)
Not at all strong	108	9.4	15	23.4	49	76.6	8.7 (4.7, 15.9)	30	68.2	14	31.8	4.9 (2.6, 9.5)	2.4 (1.5, 3.8)
Total	1153	100.0	317	62.2	193	37.8		557	87.6	79	12.4		3.0 (2.4, 3.9)

Note. Public funding for prenatal care includes 79 who paid out-of-pocket for care or had other financing. RR = relative risk; CI = confidence interval.

[a]Excluded 209 women who were not offered test (n = 136) or for whom data were missing on woman's perception (n = 18), test offering (n = 34), or testing (n = 21).

[b]Column percentages.

[c]Row percentages. Excluded were 7 women for whom data on source of funding for prenatal care were missing.

[d]Relative risk comparing proportions who were not tested according to financing of prenatal care (private insurance vs public funding) at each level of perception of how much provider recommended testing.

differed significantly by location, with the proportion not tested ranging from 4.8% (Miami) to 45.8% (New Haven) (Table 2).

Women with private insurance were 3 times more likely not to get tested than women with public funding (Table 3). Possessing private insurance was also associated with the perception that the provider did not recommend testing ($P < .001$).

Proportions of women who were tested increased incrementally with increased perception that the provider considered testing to be important, regardless of funding source (P trend $< .05$ for each source) (Table 3). Among women who perceived that the provider wanted very much for them to be tested, 91.2% and 93.6% of those with private insurance and with public funding, respectively, were tested. Within each of the other levels of perceived provider recommendation, the proportion of those with private insurance who were not tested was at least twice as high as the proportion of those with public funding who were not tested, a statistically significant difference. Among women who perceived that the provider did not at all want them to be tested, 23.4% and 68.2% of those with private insurance and with public funding, respectively, were tested.

In all but 1 location, the proportion of untested women who had perceived that the provider did not at all recommend that they be tested was higher than the proportion of untested women who had perceived some level of recommendation by the provider (Table 4). The measure of association ranged from 2.0 in New Haven, where 21% of women perceived that the provider had not recommended testing, to 5.8 in Miami, where 2% had this perception. In Brooklyn, provider recommendation was not associated with HIV testing, although only 18 women were not tested. In a multivariate analysis to predict the perception that the provider had not recommended testing, location and higher income were significant predictors after adjustment for sociodemographic factors (data not shown). Compared with women in North Carolina, women in New Haven were twice as likely to have this perception; women in Miami were one third as likely.

Length of time since the last prior HIV test was associated with not being tested during pregnancy; however, having a prior test itself was not. Women who had been tested within 6 months before pregnancy were significantly more likely not to be tested than women with a longer interval. The magnitude of this association was similar in all locations (range of relative risk = 1.5–1.8) but reached statistical significance only in North Carolina and New Haven (Table 4).

Several sociodemographic factors were associated with not being tested in North Carolina and in New Haven (Table 4). More of the women in these locations who were not tested were older, were married, had an annual household income greater than $15 000, or had education beyond high school. Also, in North Carolina those of White race/ethnicity and with first-trimester initiation of prenatal care were more likely not to be tested than other women. In Brooklyn, no sociodemographic factor was associated with testing. In Miami, only late initiation of prenatal care was associated with not being tested. Six of the 8 women not tested initiated care after the first trimester.

Multivariate modeling was performed, which confirmed that not being tested had an independent association with study location, private insurance status, perception of the strength of the provider's recommendation, having been tested within 6 months before pregnancy, older age, and being married (Table 4). Even after adjustment for all other factors, it was found that more women in Brooklyn and Miami and fewer women in New Haven got tested compared with women in North Carolina.

Reasons for Not Being Tested

396 women who were not tested gave a total of 515 reasons for not being tested. Few women cited possible negative consequences, such as being too worried, concerned, or scared to be tested (6.6%), fear of discrimination (1.8%), or testing's being contrary to their beliefs (1.5%). The most common reason, mentioned by 55.3% of women, was having no perceived need for the test, and the next most common reason was having been tested before this pregnancy (39.1%). Women raised other explanations much less commonly: not having been offered testing or perceiving that testing was not recommended (11.1%); no particular reason (4.0%); partner had tested HIV negative (3.0%); a scheduling problem (2.5%); just did not think about getting it done (2.3%); cost (1.0%); intended to but just did not get tested (0.5%); and already knew she was HIV seropositive (0.5%).

The reasons for not being tested differed by location. North Carolina (203 women giving 305 reasons) and New Haven (110 women giving 144 reasons) had responses as described above. In Miami (25 women giving 31 reasons) 48.0% of women said that testing was

TABLE 4—Factors Associated With Not Getting an HIV Test When the Test Was Offered During Prenatal Care

	Central North Carolina		New Haven		Brooklyn		Miami		Adjusted OR, All Locations
	No.	RR (95% CI)	No.	RR (95% CI)	No.	RR (95% CI)	No.	RR (95% CI)	(95% CI)
Woman perceived that provider did not recommend getting an HIV test									
True	35/56	2.7 (2.1, 3.5)	26/35	2.0 (1.5, 2.7)	1/13	0.7 (0.1, 5.1)	1/4	5.8 (0.9, 36.4)	4.2 (2.5, 7.0)
False	137/593	1.0	48/128	1.0	17/163	1.0	7/161	1.0	
Private insurance for prenatal care									
Yes	127/346	2.4 (1.8, 3.2)	63/117	1.8 (1.2, 3.0)	9/47	2.8 (1.2, 6.6)	0/14	. . .[a]	1.9 (1.2, 3.1)
No	48/310	1.0	14/48	1.0	9/130	1.0	8/152		
Timing of prior HIV test									
≤6 months prior to pregnancy	38/88	1.8 (1.4, 2.4)	9/13	1.6 (1.0, 2.3)	3/19	1.7 (0.5, 5.2)	3/34	2.3 (0.6, 9.1)	3.8 (2.4, 5.9)
>6 months prior to pregnancy	133/552	1.0	68/153	1.0	15/157	1.0	5/129	1.0	
Age, y									
≥30	100/245	2.3 (1.8, 3.0)	49/86	1.6 (1.2, 2.3)	6/65	0.9 (0.3, 2.2)	4/57	2.3 (0.7, 7.2)	1.6 (1.1, 2.2)
<30	73/408	1.0	28/81	1.0	12/113	1.0	4/109	1.0	
White									
Yes	121/328	2.2 (1.7, 3.0)	45/99	1.0 (0.7, 1.4)	0/3	. . .[b]	0/57	0.2 (0.0, 1.4)	1.2 (0.8, 1.7)
No	54/326	1.0	29/63	1.0	18/175		8/109	1.0	
>High school education									
Yes	170/576	4.9 (2.1, 11.5)	72/145	2.3 (1.0, 5.1)	15/141	1.3 (0.4, 4.4)	3/107	0.5 (0.2, 1.5)	1.4 (0.9, 1.5)
No	5/82	1.0	5/23	1.0	3/37	1.0	5/60	1.0	
Household income, $									
>15 000	150/470	2.6 (1.7, 3.9)	60/117	1.3 (0.9, 2.1)	8/72	1.2 (0.5, 2.8)	1/38	0.3 (0.0, 2.2)	0.9 (0.6, 1.5)
≤15 000		1.0	16/42	1.0	10/103	1.0	7/107	1.0	
Married									
Yes	141/401	2.6 (1.9, 3.7)	62/119	1.7 (1.1, 2.7)	8/72	1.2 (0.5, 2.9)	6/78	2.0 (0.6, 6.7)	2.0 (1.2, 3.1)
No	34/255	1.0	15/49	1.0	10/106	1.0	2/88	1.0	
Initiation of prenatal care									
1st trimester	146/525	1.6 (1.0, 2.5)	64/142	1.0 (0.6, 1.7)	15/128	2.4 (0.6, 10.3)	2/116	0.1 (0.0, 0.6)	0.9 (0.5, 1.4)
2nd or 3rd trimester	18/103	1.0	9/20	1.0	2/43	1.0	6/46	1.0	
New Haven[c]	. . .	. . .	. . .	. . .	. . .	. . .	. . .	. . .	1.8 (1.2, 2.8)
Brooklyn	. . .	. . .	. . .	. . .	. . .	. . .	. . .	. . .	0.5 (0.3, 0.9)
Miami	. . .	. . .	. . .	. . .	. . .	. . .	. . .	. . .	0.2 (0.1, 0.4)

Note. Central North Carolina includes Chapel Hill, Durham, and Raleigh. RR = unadjusted relative risk for not getting an HIV test during pregnancy vs getting a test, comparing bivariate levels of each factor. OR = odds ratio derived from logistic regression model containing all factors.

[a]Relative risk was undefined owing to zero cells. Chi-square *P* value was 0.323.

[b]Relative risk was undefined owing to zero cells. Chi-square *P* value was 0.56.

[c]Reference group is Central North Carolina.

not offered or was not recommended. Another 20.0% mentioned having no perceived need for testing. In Brooklyn (31 women giving 35 reasons) 35.5% mentioned having had a prior test; 35.5% cited no particular reason; 19.4% included feeling no need to be tested; and 12.9% stated that testing was not offered or not recommended.

Discussion

HIV testing during pregnancy is a key component of efforts to eliminate mother-to-child HIV transmission. In this 1997 sample of births in 7 hospitals in 4 states, almost 90% of women were offered a prenatal HIV test, and about 75% of those women offered were tested. Although our data demonstrate that most women were offered and chose testing, they also indicate that nearly one third of women overall gave birth unaware of their HIV status. While some may consider these proportions adequate, there was important variation within and between locations, driven by differences in health system factors such as private insurance status and strength of provider recommendation. Women rarely mentioned fear of adverse consequences as the reason for not getting tested. Thus, the recommendation by public health and medical care leadership for universal testing,[13] if implemented by prenatal providers, would be likely to gain acceptance by most women.

All 4 states had adopted the recommendation of universal voluntary testing before the study began, but only in Miami and Brooklyn did HIV testing proportions reach 90%. In locations with lower testing proportions (North Carolina and New Haven), demographic factors were associated with lack of testing, indicating that prenatal HIV testing may have been guided by notions of risk status identified by women or their providers. Although HIV testing has been associated with several demographic and clinic-level factors,[16,20,21] we had expected that this phenomenon would have changed by 1997.

Health care providers' recommendation strongly influenced women's decisions on prenatal testing, independently of other factors. Among women who perceived that providers strongly recommended testing, 93% were tested, a proportion 2.2 times greater than that among women who perceived that providers did not recommend testing. The perception of a recommendation to get tested was associated with women's location and younger age, indirect evidence that the providers may have been assessing HIV risk. Although clinicians voice support for universal prenatal testing, their clinical practice often hinges on appraisal of women's risk,[22,23] even though such appraisal has been

shown to be inaccurate.[24] Inexperience, discomfort with discussing HIV, or lack of time may also lead providers to not recommend testing strongly.[25–28] Clinic policies also may affect clinicians' practices.[29] Finally, our finding that more women with late initiation of prenatal care were not offered testing may indicate a barrier related to competing clinical care priorities late in pregnancy.

Private insurance for prenatal care was associated with lack of testing after other factors were adjusted for, except in Miami, where all 14 women with private insurance were tested. Others have documented lower prenatal testing proportions among private prenatal clinic patients.[30] The 1999 Institute of Medicine report provides specific recommendations for changing the actions of prenatal care providers, including increasing the public health and medical communities' emphasis on educating prenatal care providers, updating clinical practice guidelines, and periodically evaluating the performance of practice guidelines.[13]

Women most commonly cited no perception of risk and having been tested recently as rationales for not being tested. Most prepregnancy HIV tests had been obtained relatively close to the start of this pregnancy; those tested within 6 months before pregnancy were more than 1.5 times as likely not to be tested. Other researchers have reported a similar association.[16] The US Public Health Service 1995 guidelines specify that all women be offered testing regardless of risk behavior or prior tests.[12] These guidelines free clinicians and women from having to judge whether their assessment of risk is accurate or how recent a test is adequate.

Some women may have good reasons for not being tested, such as fear of adverse consequences or not being psychologically prepared. However, few women in our study gave such reasons. Others also have reported that these reasons were uncommon.[16,20,25,29] It is important to elicit such concerns from women, and when voiced, they should signal the need for more counseling or psychological support rather than simply a deferral of testing.

Since this study was conducted, recommendations for treatment to prevent perinatal transmission of HIV have been expanded to include treatment of women with advanced disease, treatment during labor and delivery even when prenatal antiretroviral therapy was not given, and treatment of infants whose mothers received no antiretroviral therapy during the prenatal period or during labor and delivery.[31] The effect on current testing practices of this expansion, other advances in therapeutics and prevention measures,[3–11] and changes in policies is unknown. One report showed that testing between 1995 and 1998 remained stable in public clinics but increased 29% in private clinics.[32] In New York State, where HIV testing of newborns became mandatory in 1996, prenatal testing increased 12% by 1997.[33]

A strength of this study is its sample of parturient women, representing a wide mix of geography with a range of HIV prevalence. Because we sampled hospital births, women receiving care under all prenatal care settings participated, regardless of when they entered prenatal care. By conducting postpartum interviews, we assessed testing for the entire prenatal period.

There are some limitations to these data. They rely on women's recall in the immediate postpartum period. We are currently investigating a comparison of women's recall with documentation of testing in medical records for a subsample of the North Carolina women.[34] One comparison of women's reports with clinical records found minor discrepancies in test reporting.[20] Another report, which used hospital laboratory data, found larger discrepancies.[35] Others have noted that women commonly assume that blood samples drawn during prenatal care are tested for HIV.[25] At a low level of misclassification, our key findings on the testing proportions would not change appreciably, although the analysis of barriers to testing may be biased. The accuracy of women's perception of a provider's recommendation cannot be validated; however, it is probably the women's interpretation of the recommendation that informs their decision making. Finally, the study hospitals were all teaching facilities, most with considerable experience caring for HIV-infected women and children. HIV testing at the prenatal care practices delivering at the study hospitals may be more common than at practices delivering at other hospitals in these states.

This study suggests that the US health care system is falling short of the goal of universal offering of voluntary HIV counseling and testing, and it supports the need to increase HIV testing if HIV infection is to be eliminated among US children.[13] Our data emphasize the importance of improving private caregivers' understanding of the importance of universal HIV counseling and testing to implement fully US Public Health Service guidelines. In this era of effective interventions, providers should routinely encourage prenatal testing during each pregnancy, while recognizing that our society still attaches stigma to HIV infection and that a few women may have legitimate reasons to reject testing. As a society, we should actively seek to mitigate the stigma associated with HIV infection, a goal that will also help prevent new infections. Implementing the strategy of routine universal prenatal testing would help reduce the stigma to individuals and to communities, as well as the unavoidable errors of basing test recommendation on individual risk factors or the community prevalence of infection. □

Contributors

R. A. Royce and E. B. Walter conceived of and designed the study in collaboration with all the other authors. R. A. Royce analyzed the data and drafted and finalized the paper with the assistance of E. B. Walter and R. J. Simonds. R. A. Royce, E. B. Walter, M.I. Fernandez, T. E. Wilson, and J. R. Ickovics directed study activities in their respective cities. All coauthors contributed to the interpretation of the results and the revision of the paper.

Acknowledgments

Financial support for this project came from Centers for Disease Control and Prevention grants U64/CCU412273 (Drs Royce and Walter), U64/CCU412294 (Dr Fernandez), 64/CCU212267 (Dr Wilson), and U64/CCU112274 (Dr Ickovics).

We are grateful to the study staff who conducted the in-hospital interviews; the hospital staff who assisted us; Anne Eckmann, TaiAsha Milton, Vani Vannappagari, and Dave Gibbons, who coded the open-ended data; Lynn Sampson and Tom Goodwin, who helped with the analysis; and Matthew Farrelly for helpful comments on the manuscript. We also thank the women who participated in the study and allowed us to interview them at a very special moment in their lives.

The following persons also participated in the Perinatal Guidelines Evaluation Project: in Brooklyn, Howard Minkoff, MD, and Jack deHovitz, MD; in New Haven, Kathleen Ethier, PhD, Amy Grennen, and Aleta Tierney; at Duke University, Karen Carter, Elizabeth Kahn-Meine, MD, Margaret Lampe, RN, LuAnn McAdams, RN, Lisa Pulley, RN, and Palmar Plonk; at the University of North Carolina, Sylvia Crudup, PhD, Anne Eckmann, PhD, and Jacqueline Montgomery; in Miami, Sally Dodds, PhD, and Mary Jo O'Sullivan, MD; at the Centers for Disease Control and Prevention, Daphne Cobb, Ken Dominguez, MD, Meagan Kennedy, MPH, Linda Koenig, PhD, Kay Lawton, MN, Jan Moore, PhD, and Dan Whitaker, PhD.

References

1. Riley L, Greene M. Elective cesarean delivery to reduce the transmission of HIV. *N Engl J Med.* 1999;340:1032–1033.
2. Connor EM, Sperling RS, Gelber R, et al. Reduction of maternal–infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *N Engl J Med.* 1994; 331: 1173–1180.
3. Wiktor S, Ekpini E, Karon J, et al. Short-course oral zidovudine for prevention of mother-to-child transmission of HIV-1 in Abidjan, Côte d'Ivoire: a randomised trial. *Lancet.* 1999;353: 781–785.
4. Shaffer N, Chuachoowong R, Mock P, et al. Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: a randomised controlled trial. *Lancet.* 1999;353:773–780.
5. Dabis F, Msellati P, Meda N, et al. Six-month efficacy, tolerance, and acceptability of a short regimen of oral zidovudine to reduce vertical transmission of HIV in breastfed children in Côte d'Ivoire and Burkina Faso: a double-blind placebo-controlled multicentre trial. *Lancet.* 1999;353:786–792.
6. Guay L, Musoke P, Fleming T, et al. 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.
7. Wade NA, Birkhead GS, Warren BL, et al. Abbreviated regimens of zidovudine prophylaxis and perinatal transmission of the human immunodeficiency virus. *N Engl J Med.* 1998;339: 1409–1414.
8. Leroy V, Newell M, Dabis F, 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.
9. 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; 353:1035–1039.
10. 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;340:977–987.
11. Nduati R, John G, Mbori-Ngacha D, et al. Effect of breastfeeding and formula feeding on transmission of HIV-1: a randomized clinical trial. *JAMA.* 2000;283:1167–1174.
12. Centers for Disease Control and Prevention. US Public Health Service recommendations for human immunodeficiency virus counseling and voluntary testing for pregnant women. *MMWR Morb Mortal Wkly Rep.* 1995;44(RR-7):1–15.
13. Institute of Medicine. *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States.* Washington, DC: National Academy Press; 1999.
14. Human immunodeficiency virus screening. Joint statement of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. *Pediatrics.* 1999;104:128.
15. Lindsay M, Feng T, Peterson H, Slade B, Willis S, Klein L. Routine human immunodeficiency virus infection screening in unregistered and registered inner-city parturients. *Obstet Gynecol.* 1991;77:599–603.
16. Faden RR, Gielen AC, Kass N, et al. Prenatal HIV-antibody testing and the meaning of consent. *AIDS Public Policy J.* 1994;9:151–159.
17. Walter EB, Elliott AJ, Regan AN, Drucker RP, Clements DA, Wilfert CM. Maternal acceptance of voluntary human immunodeficiency virus antibody testing during the newborn period with the Guthrie card. *Pediatr Infect Dis J.* 1995;14: 376–381.
18. Carusi D, Learman L, Posner S. Human immunodeficiency virus test refusal in pregnancy: a challenge to voluntary testing. *Obstet Gynecol.* 1998;91:540–545.
19. *Stata Statistical Software: Release 5.0.* College Station, Tex: Stata Corp; 1997.
20. Healton C, Messeri P, Abramson D, Howard J, Sorin MD, Bayer R. A balancing act: the tension between case-finding and primary prevention strategies in New York State's voluntary HIV counseling and testing program in women's health care settings. *Am J Prev Med.* 1996;12: 53–60.
21. Lindsay MK, Adefris W, Peterson HB, Williams H, Johnson J, Klein L. Determinants of acceptance of routine voluntary human immunodeficiency virus testing in an inner-city prenatal population. *Obstet Gynecol.* 1991;78:678–680.
22. Phillips KA, Morrison KR, Sonnad SS, Bleecker T. HIV counseling and testing of pregnant women and women of childbearing age by primary care providers: self-reported beliefs and practices. *J Acquir Immune Defic Syndr Hum Retrovirol.* 1997;14:174–178.
23. Walter EB, Lampe MA, Livingston E, Royce RA. How do North Carolina prenatal care providers counsel and test pregnant women for HIV? *N C Med J.* 1998;59:1–5.
24. Barbacci M, Repke J, Chaisson R. Routine prenatal screening for HIV infection. *Lancet.* 1991; 331:709–711.
25. Meadows J, Catalan J. Why do antenatal attenders decide to have the HIV antibody test? *Int J STD AIDS.* 1994;5:400–404.
26. Jones J, Hutto P, Meyer P, Dowda H, Gamble W, Gunn R. HIV seroprevalence and reasons for refusing and accepting HIV testing. *Sex Transm Dis.* 1993;20:334–337.
27. Myers ER, Thompson JW, Simpson K. Cost-effectiveness of mandatory compared with voluntary screening for human immunodeficiency virus in pregnancy. *Obstet Gynecol.* 1998;91: 174–181.
28. Cartoux M, Msellati P, Meda N, et al. Attitude of pregnant women towards HIV testing in Abidjan, Côte d'Ivoire and Bobo-Dioulasso, Burkina Faso. *AIDS.* 1998;12:2337–2344.
29. Cozen W, Mascola L, Enguidanos R, et al. Screening for HIV and hepatitis B virus in Los Angeles County prenatal clinics: a demonstration project. *J Acquir Immune Defic Syndr.* 1993; 6:95–98.
30. Limata C, Schoen E, Cohen D, Black S, Quesenberry C Jr. Compliance with voluntary prenatal HIV testing in a large health maintenance organization (HMO). *J Acquir Immune Defic Syndr Hum Retrovirol.* 1997;15:126–130.
31. Centers for Disease Control and Prevention. US Public Health Service Task Force recommendations for the use of antiretroviral drugs in pregnant women infected with HIV-1 for maternal health and for reducing perinatal HIV-1 transmission in the United States. *MMWR Morb Mortal Wkly Rep.* 1998;47(RR-2):1–30.
32. Royce R, Napravnic S, Walter E, Girlando M, McDonald T III. Trends in prenatal HIV counseling and testing from 1995 to 1998 in North Carolina. Paper presented at: Global Conference to Prevent Mother-to-Child Transmission; September 1–5, 1999; Montréal, Quebec.
33. Wilson T, Minkoff H. Mandatory HIV testing of infants and rates of follow-up care. *Am J Public Health.* 1999;89:1583.
34. Royce R, Walter E. Does the medical record available during labor and delivery provide test results for HIV and other STDs? Paper presented at: 128th Annual Meeting of the American Public Health Association; November 12–16, 2000; Boston, Mass. Abstract 5136.0.
35. O'Campo P, de Boer M, Faden R, Kass N, Gielen A, Barbacci M. Confirmation of self-report of HIV testing among a cohort of pregnant women. *J Clin Epidemiol.* 1997;50: 57–61.