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CDC Report Regarding Selected Public Health Topics Affecting Women's Health

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Foreword

CDC, the nation's prevention agency, collaborates with its partners to prevent disease, death, and disability. Through prevention, lives can be saved, quality of life improved, and the burden of health-care costs reduced. Prevention research helps us to understand conditions and diseases and who they affect, develop and implement effective strategies and programs to reduce disease and promote health, and develop policies and recommendations that strengthen systems and programs at local, state, and national levels.

This publication focuses on birth defects and human immunodeficiency virus infection/acquired immunodeficiency syndrome (HIV/AIDS), two preventable causes of death and disability. The articles focus on programs in several states that are designed to reduce disease and assess disease trends. The primary messages are not new, but need to be reinforced.

- Periconceptional intake of 0.4 mg of the B vitamin folic acid reduces the risk for neural tube defects 50%–70%.
- Zidovudine has been used successfully to reduce perinatal transmission of HIV infection.
- The use of surveillance systems and classification models can help states analyze and interpret HIV/AIDS trends, as well as plan prevention and other program services to address important public health problems.

Science-based prevention efforts must be communicated in a timely and effective manner, whether to a woman making a decision for herself or others, to a health-care professional making decisions regarding patient care, or to a researcher classifying new cases of HIV/AIDS. Communication plays a key role in prevention; this publication communicates public health recommendations that reflect recent research affecting the health of women. Prevention means staying healthy and living well, and prevention works for women.

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Are Women with Recent Live Births Aware of the Benefits of Folic Acid?

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Summary

Each year, approximately 4,000 pregnancies result in spina bifida or anencephaly, serious and often fatal conditions for the newborn. The B vitamin folic acid can reduce the incidence of these conditions by 50%–70%. To examine folic acid awareness among women who had recently delivered a live-born infant, CDC analyzed Pregnancy Risk Assessment Monitoring System (PRAMS) data for 1995–1998. The question used to measure awareness was, "Have you ever heard or read that taking the vitamin folic acid can help prevent some birth defects?" During the study period, overall folic acid awareness increased 15%, from 64% in 1996 to 73% in 1998, although changes varied by state. Despite this increase, differences in folic acid awareness were observed among different groups of women. Women who obtained a high school education or less; who were black, Hispanic, or from other racial/ethnic groups; who entered prenatal care after the first trimester; and whose pregnancies were unintended were less aware of folic acid.

This study indicates that gaps persist among women in low socioeconomic groups. Overall, PRAMS data indicated an increase in folic acid awareness among women with recent deliveries. However, this awareness might be too late for the pregnancy that has occurred, indicating a continued need to educate all reproductive-aged women regarding the need to take folic acid before they become pregnant.

BACKGROUND

Approximately 4,000 pregnancies are affected by neural tube birth defects each year in the United States (*1*). These conditions are serious defects in the formation of the brain and spine that are either fatal or have long-term health consequences. The formation of the neural tube occurs early in pregnancy — in many cases, before a woman realizes she is pregnant and long before her first prenatal visit. Approximately 50% of neural tube defects are cases of anencephaly, in which the infant's brain is completely or partially missing, and these infants die before or shortly after birth. The other half of cases are spina bifida, which is a malformation of the spinal column that causes the spinal cord to form outside the protective backbone. Most children with spina bifida need numerous surgeries and experience problems throughout their lives, including paralysis, bowel or bladder incontinence, and learning disabilities. The social and economic costs of these conditions are high (*2,3*).

Research has demonstrated that periconceptional intake of 0.4 mg of the B vitamin folic acid reduces the risk for neural tube defects 50%–70% (*4–8*). Periconceptional multivitamin use can also reduce the risk for other defects (e.g., orofacial clefts, conotruncal heart defects, and urinary tract defects) (*9–11*). In response to the findings that folic acid can prevent neural tube defects, several national initiatives were implemented. In 1992, the U.S. Public Health Service (PHS) recommended that all women capable of becoming pregnant consume 0.4 mg of folic acid per day to reduce the risk for neural tube defects (*12*). In 1996, the U.S. Food and Drug Administration (FDA) mandated that all enriched cereal grain products be fortified with folic acid beginning in January 1998 (*13*). In April 1998, the Food and Nutrition Board of the National Academy of Sciences recommended that all women of reproductive age consume 400 micrograms of synthetic folic acid daily from supplements or fortified foods, in addition to folate found naturally in foods (*14*). *Healthy People 2010* includes national objectives to increase folic acid consumption, increase red blood cell folate levels, and measure decreases in birth defects (*15*). Recent research has demonstrated that fortification and other health promotion efforts have caused a mean increase in blood folate levels among women of childbearing age (*16–19*). Given the association between folic acid consumption and reduction in neural tube defects and other birth defects, higher folate levels could reduce adverse birth outcomes in the United States (*19,20*). Many organizations and groups (e.g., CDC, March of Dimes) encourage clinicians and health-care providers to counsel reproductive-aged women regarding the need for periconceptional supplementation use to prevent neural tube defects (*20–23*). Despite these efforts, this information is apparently not getting to women of childbearing age quickly enough. An open-ended survey conducted by the Gallup Organization in 1998 for the national March of Dimes indicated that only approximately 13% of all women of childbearing age can spontaneously recall that folic acid can prevent birth defects, and even fewer (7%) know that folic acid must be consumed before pregnancy to provide this benefit (*1,24,25*). Based on surveys conducted in 1996 and 1997, the Behavioral Risk Factor Surveillance System (BRFSS) reported that approximately 35% of reproductive-aged women queried could correctly identify the purpose of folic acid from among four choices (*26*). The BRFSS is a state-based, random-digit–dialed telephone survey of the noninstitutionalized U.S. population aged ≥18 years.

This study sought to build on past research and promotion efforts by identifying changes and gaps in folic acid awareness among women who had recently delivered a live-born infant in the states that participate in the Pregnancy Risk Assessment Monitoring System (PRAMS). The specific research questions guiding this analysis were as follows:

- Has there been a change in women's awareness regarding folic acid use?
- How do the estimates of folic acid awareness among this population compare with estimates from national surveys (e.g., the March of Dimes survey and BRFSS)?
- Are there specific gaps that remain to be addressed in folic acid awareness among women who have recently given birth to a live-born infant and who are potentially at risk for future pregnancies, whether intended or unintended?

METHODS

Data

This study examined women's awareness regarding folic acid using data from PRAMS, which collects information on maternal behaviors and experiences during pregnancy from projects in 24 states* and New York City. Each month, PRAMS selects a stratified, systematic sample of 100–250 women who have recently given birth in a particular area from the birth certificates of the infants, and a survey questionnaire is mailed to the selected mothers approximately 2–6 months after delivery. Several attempts are made to contact the mother by mail. If that fails, the mother is contacted by telephone, and an attempt is made to interview her. The survey questionnaire is linked back to a select set of items from the birth certificate. The overall data are statistically weighted to adjust for the survey design, noncoverage, and nonresponse. Details of the methods and populations surveyed by PRAMS are provided elsewhere (*27*).

The current study used multiple years of data (1995–1998) from 13 states (n=58,625 births), with response rates ranging from 68% to >80%. Data from Alabama, Alaska, Arkansas, Colorado, Florida, Georgia, Maine, New York (excluding New York City), North Carolina, Oklahoma, South Carolina, Washington, and West Virginia were used. Because all of these states did not initiate data collection at the same time, earlier years of data did not exist for some states; for Georgia, no 1998 data were available. These states were chosen for analysis because they had the most years of data on folic acid awareness and adequate response rates to answer the research questions.

To define the measures used in this analysis, questions from the PRAMS survey and specific variables from birth certificates were used. The primary measure — folic acid awareness — was defined as women's responses to the following question: "Have you ever heard or read that taking the vitamin folic acid can help prevent some birth defects?" Response options were "yes" or "no." Reported race was classified as black, white, or other, and ethnicity was classified as either Hispanic or non-Hispanic. Education status was classified as less than high school, high school completion, or more than high school. Maternal age was divided into four categories ($\leq$19, 20–29, 30–39, and $\geq$40 years). Marital status was categorized as married or not married. Women who had >1 child were categorized as multipara, whereas those for whom the index birth was the first were categorized as primipara. Women who stated that they had insurance before they became pregnant were categorized as having insurance, and those who answered no were classified as not having any insurance before pregnancy. Women were asked what type of insurance paid for their prenatal care, with categories listed as Medicaid, private, and other. Enrollment in Medicaid or the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) was categorized as a dichotomous variable. Choices for place of prenatal care were hospital, health department, private doctor, Indian Health Service or other federally funded program, and other. In addition to demographic, health-care provider, and insurance variables, this study also examined women's pregnancy intention status, timing of prenatal-care initiation, and

*Alabama, Alaska, Arkansas, Colorado, Delaware, Florida, Georgia, Hawaii, Illinois, Louisiana, Maine, Maryland, Mississippi, Nebraska, New Mexico, New York, North Carolina, Ohio, Oklahoma, South Carolina, Utah, Vermont, Washington, and West Virginia.

whether the prenatal-care provider discussed nutrition and the baby's growth and development. Women's pregnancy intentions were divided into four categories — pregnancy was intended sooner, pregnancy was intended to occur at the time it did, pregnancy was intended for a later time, or pregnancy was not intended. Initiation of prenatal care was defined as entry into prenatal care during the first trimester or later/none. Women who had not obtained any prenatal care were put into the latter category. Whether women received professional advice on what to eat during pregnancy and whether their provider discussed fetal growth and development were defined as yes or no.

Software for Survey Data Analysis (SUDAAN) (Version 7.0; Research Triangle Institute, Research Triangle Park, North Carolina) was used for data analysis to ensure that the standard error estimates reflected the PRAMS survey design. Multiple logistic regression was used to examine overall gaps in folic acid awareness.

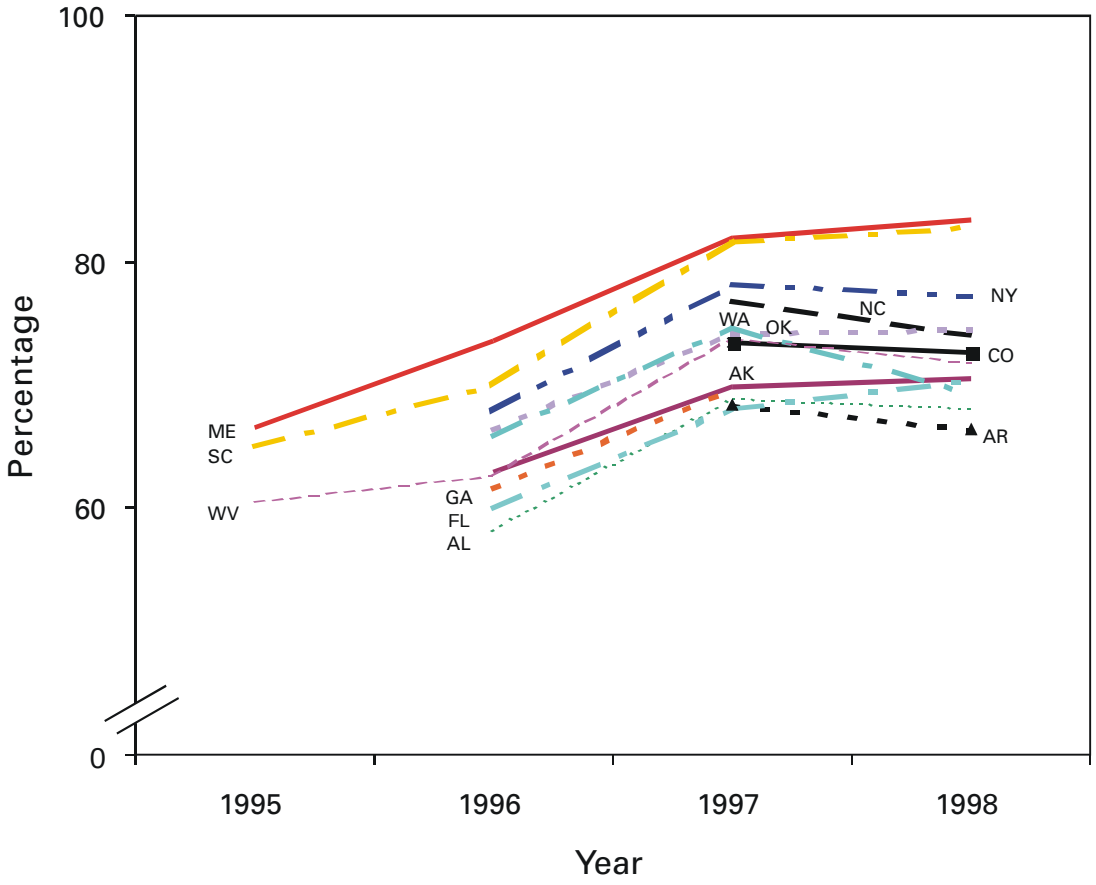
RESULTS

During 1995–1998, folic acid awareness increased overall and in most of the states in this analysis. The major shift appears to have occurred during 1996–1997 (Figure). Change in folic acid awareness is particularly noteworthy for the 10 states with data before 1997 (e.g., the percentage change in South Carolina was 27% during 1995–1998). However, not all states had large increases (e.g., the change in Washington was only 5% during 1996–1998), nor were all changes positive (Table 1). In 1998, the most recent year for which data were available, folic acid awareness ranged from 66.4% (95% confidence intervals [CI]=63.5%–69.3%) in Arkansas to 83.4% (95% CI=81.0%–85.7%) in Maine.

This study also examined folic acid awareness for 3 years (1996–1998), using certain demographic and prenatal-care characteristics, for all 13 states combined (Table 2). Prevalence estimates indicated an increase in folic acid awareness during 1996–1997 among all groups, although this increase appeared to level off during 1997–1998. Despite the overall increases, prevalence estimates remained lower among women who were younger; were not married; were black and Hispanic; had a high school education or less; were participating in WIC or received money from Medicaid for prenatal care; had no insurance before becoming pregnant; did not intend to become pregnant; began their prenatal care after the first trimester; and received prenatal care from the health department (Table 2).

The 1998 data were used to examine the correlates of folic acid awareness among women with recent live births. Multivariable analyses of these data indicated that women with a high school education or less and women who did not want to be pregnant at all were more than twice as likely to be unaware of the benefits of folic acid (Table 3). Compared with women who wanted their pregnancies to occur sooner, those who wanted their pregnancies then or later were also less likely to know about folic acid. Women who were black, Hispanic, or from other racial/ethnic groups, as well as those who entered prenatal care later than the first trimester or had no care and those whose providers did not discuss nutrition during prenatal visits were significantly less likely to be aware of the benefits of taking folic acid to prevent certain birth defects (Table 3). Women who were married and who reported that their place of prenatal care was the Indian Health Service or another federally funded program were more likely to know about folic acid.

FIGURE. Percentage of PRAMS* participants who were aware that folic acid prevented some birth defects, by state and year — selected states, 1995–1998†



*Pregnancy Risk Assessment Monitoring System.

†1995 data are from only three states and part of the year.

AL=Alabama, AK=Alaska, AR=Arkansas, CO=Colorado, FL=Florida, GA=Georgia, ME=Maine, NY=New York, NC=North Carolina, OK=Oklahoma, SC=South Carolina, WA=Washington, and WV=West Virginia.

DISCUSSION

PRAMS data indicate that women's awareness regarding folic acid use has increased since 1995–1996, with the level of increase varying by state. These findings suggest that health promotion efforts are working, albeit slowly in some populations, and that more women became aware of the benefits of folic acid during 1996–1998. Several national campaigns were implemented during the early to mid-1990s, including a March of Dimes campaign called Think Ahead in 1995. The Think Ahead campaign was designed to promote folic acid awareness through multiple channels (e.g., professional and public education, media campaigns, advertisements), and its efforts were supplemented by state initiatives designed to promote awareness and consumption of foods containing or fortified with folic acid (*28*). In 1997, the Florida Department of Citrus began to promote folic acid intake through consumption of orange juice, using paid

TABLE 1. Prevalence of folic acid awareness among Pregnancy Risk Assessment Monitoring System (PRAMS) participants — selected states, 1996–1998

State	Year 1995 % (SE*)	1996 % (SE)	1997 % (SE)	1998 % (SE)	Percentage change†
Alabama	—§	58.2 (1.5)	68.9 (1.4)	68.2 (1.4)	17.2
Alaska	—	63.0 (1.6)	69.9 (1.3)	70.5 (1.3)	11.9
Arkansas	—	—	68.4 (1.7)	66.4 (1.5)	-2.9
Colorado	—	—	73.4 (1.6)	72.7 (1.3)	-1.0
Florida	—	60.1 (1.5)	68.2 (1.4)	70.4 (1.4)	17.1
Georgia	—	61.6 (1.6)	69.7 (2.1)	—	13.2
Maine	66.6 (4.1)	73.6 (1.5)	81.9 (1.3)	83.4 (1.2)	23.0
New York	—	67.9 (1.7)	78.2 (1.6)	77.3 (1.7)	15.2
North Carolina	—	—	76.9 (2.0)	74.1 (1.4)	-3.6
Oklahoma	—	66.4 (1.8)	74.2 (1.7)	74.5 (1.7)	11.0
South Carolina	65.1 (2.3)	70.0 (1.4)	81.7 (1.7)	82.9 (1.6)	27.3
Washington	—	65.9 (1.8)	74.8 (1.4)	69.3 (1.5)	5.2
West Virginia	60.6 (3.7)	62.7 (1.8)	73.9 (1.5)	71.9 (1.5)	18.7

*Standard error.

†Calculated based on the following formula: [(base year X1 – base year X2)/base year X1]/100.

§No data available.

television and radio advertisements, and this campaign was cited most often by 1998 focus group participants (*29*). PRAMS data also indicate that states with folic acid awareness data before 1996 reported a greater increase in awareness compared with those that did not. This finding suggests that national efforts coupled with state and local efforts to promote folic acid awareness could be contributing to this increase. In 1997, the National Council on Folic Acid (NCFA) was established to expand education efforts to both women and health professionals by working in partnership with local and state coalitions. NCFA consists of professional associations, maternal and child health advocacy groups, and community-based health organizations that have implemented education and folic acid awareness campaigns among their own memberships, as well as with reproductive-aged women (*30*). NCFA developed targeted messages for women intending pregnancy as well as for those capable of becoming pregnant who might not intend to become pregnant, given that 50% of pregnancies in the United States are unplanned (*30,31*). More information on NCFA is available on the Internet at <http://www.cdc.gov/ncbddd/folicacid/council/htm>.

PRAMS findings on folic acid awareness among women of childbearing age are similar to national estimates published by the March of Dimes from its 1998 survey of women aged 18–45 years. The March of Dimes reported that folic acid awareness increased from 52% in 1995 to 66% in 1997 to 68% in 1998 and to 75% in 2000 — an overall increase of 44% (*1,24,25*). At the same time, consumption of vitamins containing folic acid increased from 28% in 1995 to 34% in 2000, a 22% increase (*25*). Although folic acid consumption behaviors lag behind knowledge/awareness, both behavior and knowledge have increased substantially among women aged 18–45 years, perhaps indicating that awareness is a precursor to voluntary behavior change (*25*). Although PRAMS estimates on awareness are slightly higher than those reported in the literature, they represent somewhat different populations. The PRAMS survey collects data

TABLE 2. Demographic and behavioral characteristics of Pregnancy Risk Assessment Monitoring System (PRAMS) participants and the prevalence of folic acid awareness — 1996–1998

	Year					
Characteristic	**1996**	**(95% CI*)**	**1997**	**(95% CI)**	**1998†**	**(95% CI)**
Overall	**63.7**	**62.4–65.0**	**72.9**	**71.8–74.0**	**73.0**	**71.9–74.1**
Maternal age (yrs)						
<19	46.7	43.3–50.1	57.6	54.5–60.7	52.0	49.3–54.7
20–29	61.9	60.1–63.7	71.3	69.7–72.9	72.0	70.4–73.6
30–39	72.7	70.5–74.9	81.2	79.4–83.0	82.5	80.7–84.3
≥40	80.1	71.9–88.3	81.5	74.6–88.4	85.5	79.4–91.6
Marital status						
Married	70.1	68.5–71.7	78.9	77.6–80.2	80.3	79.1–81.5
Not married	50.4	48.0–52.8	60.3	58.1–62.5	57.5	55.3–59.7
Parity						
Primipara	65.3	63.3–67.2	73.5	71.8–75.2	73.4	71.8–75.0
Multipara	62.6	60.9–64.3	72.4	71.0–73.9	72.9	71.8–74.1
Race/ethnicity						
Hispanic	48.6	43.5–53.7	55.3	51.0–59.6	62.3	58.2–66.4
Non-Hispanic	65.1	63.7–66.5	74.5	73.3–75.7	74.3	73.1–75.5
White	67.4	65.8–69.0	76.6	75.2–78.0	76.5	75.3–77.7
Black	51.5	49.1–53.9	59.7	57.3–62.1	59.3	56.8–61.8
Other	54.5	48.6–60.4	65.2	60.5–69.9	67.0	62.7–71.3
Maternal education						
<High school	46.0	42.9–49.1	54.2	51.3–57.1	54.1	51.4–56.8
High school	56.2	53.8–58.6	67.7	65.7–69.7	67.6	65.6–69.6
>High school	77.2	75.6–78.8	84.8	83.4–86.2	85.5	84.1–86.9
WIC§ participation						
Yes	53.0	51.0–55.0	62.8	61.0–64.6	62.6	60.8–64.4
No	72.3	70.5–74.1	81.3	79.9–82.7	81.5	80.1–82.9
Insurance before pregnancy						
Yes	72.6	71.0–74.2	81.2	80.0–82.4	80.5	79.3–81.7
No	49.8	47.6–52.0	60.2	58.2–62.2	60.6	58.6–62.6
Type of insurance for prenatal care						
Medicaid	50.4	48.2–52.6	61.9	59.9–63.9	60.0	58.0–62.0
Private	75.1	73.3–76.9	82.9	81.5–84.3	82.3	80.9–83.7
Other	64.7	60.4–69.0	70.9	67.4–74.4	74.9	71.8–78.0
Type of prenatal-care provider						
Hospital	55.5	51.6–59.4	64.4	60.9–67.9	64.6	61.3–67.9
Health department	49.4	45.3–53.5	59.0	55.5–62.5	57.5	54.0–61.0
Private doctor	67.7	66.1–69.3	77.0	75.6–78.4	78.1	76.9–79.3
IHS/federal¶	60.9	53.5–68.3	77.6	71.5–83.7	81.2	76.1–86.3
Other	65.4	59.1–71.7	72.9	68.2–77.6	67.8	63.1–72.5
Timing of prenatal care						
1st trimester	68.1	66.7–69.5	76.5	75.3–77.7	77.3	76.1–78.5
>1st trimester or none	49.4	46.7–52.1	61.1	58.6–63.6	58.4	55.9–60.9
Pregnancy intention						
Wanted sooner	72.9	70.0–75.8	79.5	77.0–82.0	82.4	80.2–84.6
Right timing	70.5	68.3–72.7	77.5	75.7–79.3	79.5	77.7–81.3
Wanted later	56.3	53.9–58.7	70.0	68.0–72.0	66.7	64.7–68.7
Not wanted	52.3	48.2–56.4	61.0	57.5–64.5	59.2	55.5–62.9
Health-care provider discussed nutrition						
No	61.2	57.1–65.2	72.9	69.7–76.2	73.5	71.1–75.9
Yes	64.4	63.1–65.8	73.4	72.2–74.6	74.9	73.9–75.8
Baby's growth						
No	64.8	61.1–68.6	73.3	70.2–76.4	74.6	72.0–77.2
Yes	63.9	62.5–65.3	73.3	72.1–74.5	74.7	73.8–75.6

* Confidence interval.
† Does not include Georgia data.
§ Special Supplemental Nutrition Program for Women, Infants, and Children.
¶ Indian Health Service or other federally funded program.

TABLE 3. Correlates of lack of folic acid awareness among women with recent live births — Pregnancy Risk Assessment Monitoring System (PRAMS), 1998

Variable	Adjusted OR*	95% CI†
Maternal age (yrs)		
<19	1.70	0.90–3.20
20–29	1.47	0.80–2.71
30–39	1.14	0.62–2.10
≥40	Ref§	Ref
Marital status		
Married	0.76	0.64–0.90
Not Married	Ref	Ref
Parity		
Primipara	0.92	0.79–1.08
Multipara	Ref	Ref
Race		
Black	1.54	1.29–1.84
Other	1.50	1.10–2.05
White	Ref	Ref
Ethnicity		
Hispanic	1.29	1.01–1.65
Non-Hispanic	Ref	Ref
Maternal education		
<High school	2.57	2.06–3.19
High school	2.12	1.80–2.51
>High school	Ref	Ref
WIC¶ participation		
No	0.88	0.74–1.04
Yes	Ref	Ref
Insurance before pregnancy		
No	1.16	0.95–1.41
Yes	Ref	Ref
Type of insurance		
Medicaid	1.26	0.98–1.61
Private	1.11	0.86–1.44
Other	Ref	Ref
Place of prenatal care		
Hospital	1.10	0.80–1.51
Health department	1.07	0.77–1.47
Private doctor	0.88	0.67–1.17
IHS/federal program**	0.56	0.33–0.97
Other	Ref	Ref
Timing of prenatal care		
>1st trimester or none	1.35	1.15–1.59
1st trimester	Ref	Ref
Pregnancy intention		
Not wanted	2.16	1.65–2.83
Wanted later	1.67	1.34–2.09
Right timing	1.45	1.17–1.80
Wanted sooner	Ref	Ref
Health-care provider discussed nutrition		
No	1.27	1.03–1.57
Yes	Ref	Ref
Fetal growth		
No	1.14	0.92–1.42
Yes	Ref	Ref

* Odds ratio. All variables are adjusted for each other and the state of residence in a single multivariable logistic regression model. Weighted sample size is 167,488 women who were not aware of folic acid and 481,692 women who were aware. Georgia data are not included in this analysis.
† Confidence interval.
§ Reference level.
¶ Special Supplemental Nutrition Program for Women, Infants, and Children.
** Indian Health Service or other federally funded program.

from women who have recently given birth to a live-born infant, whereas the March of Dimes survey assessed awareness among women aged 18–45 years who are capable of becoming pregnant.

The format of the questions used by different surveys could also contribute to the differences observed in prevalence estimates. The March of Dimes survey used an open-ended format to collect information regarding folic acid knowledge/awareness. The PRAMS survey is intended to gauge general awareness, not a) whether respondents know how much folic acid to take, b) whether they know that they need folic acid before and during the earliest days of pregnancy, or c) when (i.e., before or during pregnancy) they became aware of the importance of taking folic acid. Another survey, the BRFSS survey, uses multiple choice questions that query reproductive-aged women regarding the purpose of folic acid. For 1996–1997, the BRFSS reported that approximately 35% of women recognized the "correct" answer from four options (*26*).

The analysis of PRAMS data also indicated that gaps in folic acid awareness exist among women who have had live births. Women from racial or ethnic minorities, who had attained a high school education or less, who received later or no prenatal care, and whose pregnancies were unintended were less likely to be aware of the benefits of folic acid. Other national studies have also reported gaps in folic acid awareness and consumption among low-income populations (*25*). One reason for these gaps could be that message dissemination within the health-care system is less likely to reach some women before pregnancy, and folic acid information must compete with many other health messages. Further research on the reasons for the gaps in folic acid awareness could offer opportunities to learn more regarding the effect of socioeconomic status (including available resources) on women's prepregnancy health and pregnancy intentions.

Data in this study indicated that no substantial differences in folic acid awareness existed among women of different age groups, parity, type of insurance, or WIC participation. Analysis also indicated that women whose health-care providers discussed nutrition during pregnancy were more likely to know the benefits of folic acid intake. Similarly, focus group research conducted by CDC reported that health professionals had more opportunity to discuss folic acid with women who were already pregnant (*32*). Although this education probably occurs too late to help many women prevent neural tube defects in their current pregnancy, the information could help them plan for future pregnancies. All reproductive-aged women, including uninsured women, should be provided the opportunity to discuss proper nutrition with their primary-care providers before conception.

In contrast to other studies, the research in this study is strengthened by its large, population-based sample from recent live births and its ability to identify gaps in women's awareness regarding the benefits of folic acid in preventing some birth defects. Although this study will be useful for promoting specific targeted efforts, several limitations exist. First, this research focuses on women's awareness, and no behavior data were available to assess folic acid consumption. Other studies of folic acid consumption have demonstrated a substantial gap between folic acid awareness and consumption behavior (*25*). Second, data from PRAMS could be biased because its surveys are administered after the birth of an infant, creating a time lapse since early pregnancy when women might have learned about folic acid. Third, the format of the PRAMS survey does not measure whether respondents know how much folic acid to take or that they need folic acid before and during the earliest days of pregnancy.

Although this study only assessed women's awareness of folic acid, other findings were reported. Some states had high rates of awareness overall, whereas others are lagging behind, and some populations are more disadvantaged than others. *Healthy People 2010* objectives call for a 50% reduction in neural tube defect cases and an increase in daily consumption of 0.4 mg of folic acid from a baseline of 21% in the early 1990s to 80% by 2010 among nonpregnant women aged 15–44 years (Objectives 16-15 and 16-16) (*15*). Recent research indicates that red blood cell folate levels have increased among reproductive-age women (*16–18*), likely because of a) food fortification and b) increased folic acid awareness efforts coupled with some voluntary increase in folic acid consumption. Whether this increase has resulted in a reduction of neural tube defects is unknown because of the current status of research and the lag time in obtaining reliable data.

The results of this study could be used to promote healthier pregnancies by encouraging a) more prepregnancy planning, b) greater consumption of diets rich in vitamins (including folic acid) and minerals by women, and c) increased preconceptional health education for all women of reproductive age. Given the observed increase in women's awareness regarding folic acid over several years, particularly after the implementation of major national and state efforts, CDC recommends that health education efforts continue and expand on multipronged strategies to reach women in low socioeconomic and cultural groups. Specific messages and avenues of communication (e.g., media, interpersonal) for women in racial and ethnic groups should be identified and mobilized. In addition, health-care providers in general and prenatal-care providers in particular should take advantage of every preconceptional and early prenatal encounter to educate women and their families regarding pregnancy planning to ensure optimal pregnancy outcomes for women and infants. Also, comprehensive reproductive health policies that provide resources and opportunities for both men and women to make optimal preconceptional decisions should be implemented by health-care providers.

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Successful Implementation of Perinatal HIV Prevention Guidelines

A Multistate Surveillance Evaluation

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Successful Implementation of Perinatal HIV Prevention Guidelines

A Multistate Surveillance Evaluation

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Summary

In 1994, zidovudine (ZDV) was demonstrated to substantially reduce perinatal transmission of the human immunodeficiency virus (HIV). Guidelines regarding the use of ZDV to reduce transmission and regarding counseling and voluntary testing of pregnant women were issued in 1994 and 1995, respectively. Surveillance methods were used to evaluate the implementation of these guidelines and to understand reasons for continued perinatal transmission of HIV.

Population-based enhanced perinatal surveillance was used in seven states to collect information regarding mother-infant pairs in 1993, 1995, and 1996. Birth registries and HIV/Acquired immunodeficiency virus (AIDS) registries were matched to determine the number of HIV-infected women with diagnosis before delivery. Supplemental epidemiologic information was collected for 1,321 pairs. The estimated total number of HIV-infected women giving birth each year was derived from the Survey of Childbearing Women, an anonymous serologic survey of the prevalence of HIV infection among women giving birth.

From 1993 through 1996, the proportion of HIV-infected women with diagnosis before delivery increased from 70% to 80%. The proportion of women with a diagnosis who received ZDV prenatally increased from 27% to 83% and intrapartum, 6% to 75%; for neonates, the increase was from 8% to 77%. Overall, 14% of women received no or only one prenatal care visit. A total of 36% of women who used illicit drugs during pregnancy had not had prenatal care. Of the children who received any ZDV, 8% were infected compared with 16% of those who received no ZDV.

ZDV, used for treating pregnant HIV-infected women, has been rapidly adopted in clinical practice and has reduced the transmission of HIV. To achieve continued declines in perinatal transmission of HIV infection, continued progress is needed in the following areas: a) increases in the proportion of women who receive prenatal care and an HIV diagnosis; and b) implementation of rapid testing methods (when licensed rapid tests are available) or rapid turnaround of standard tests (expedited EIA tests).

BACKGROUND

Adult women accounted for 17% of U.S. cases of acquired immunodeficiency virus (AIDS) reported to CDC through June 2000. Most (78%) of the women reported with AIDS are members of racial/ethnic minority populations. During the 1990s, women, minorities, and persons infected through heterosexual contact represented a growing proportion of annual AIDS diagnoses. Because women might transmit the human immunodeficiency virus (HIV) infection perinatally to their infants (prenatally, during labor and delivery, or postpartum during breastfeeding), the HIV/AIDS epidemic in children closely paralleled the epidemic in women until the mid-1990s.

In February 1994, zidovudine (ZDV) was demonstrated to be effective in reducing perinatal transmission of HIV infection (*1*). In August 1994, the U.S. Public Health Service published guidelines regarding the use of ZDV to prevent perinatal transmission of HIV infection; guidelines regarding routine counseling and voluntary testing were published in 1995 to promote timely testing and treatment of HIV-positive pregnant women (CDC unpublished data, U.S. Public Health Service Task Force Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States; <http://www.hivatis.org>) (*2,3*). In collaboration with state and local health department HIV/AIDS surveillance programs, CDC implemented enhanced surveillance strategies in selected states to determine the extent to which testing and ZDV treatment are occurring in clinical practice and to identify barriers to the universal implementation of the guidelines. The surveillance strategies were designed to enhance the completeness of ascertainment of mother-infant pairs and to collect relevant epidemiologic data from multiple sources. Key objectives included determining the proportion of HIV-infected pregnant women who received the diagnosis of HIV before delivery, the proportion of those who were offered ZDV, and the proportion of children who were infected. In addition, supplemental information (e.g., information concerning prenatal care use) was collected to help identify barriers to the full implementation of the prevention guidelines. The enhanced population-based surveillance was conducted statewide in the participating states as an extension of routine perinatal HIV/AIDS surveillance activities. The data have provided state and local prevention programs with information needed to guide efforts to maximize the reduction of HIV perinatal transmission. The data also provided the scientific basis for current recommendations of the Institute of Medicine to make HIV voluntary testing a routine part of prenatal care (*4*). As a result, in the United States, intensive programmatic efforts are being implemented in geographic areas heavily affected by the HIV epidemic with the goal of eliminating perinatal HIV transmission.

Etiologic Factors

Current program efforts for perinatal HIV prevention focus on a cascade of events that must occur in sequence to achieve maximum reductions in HIV transmission from mother to child. Pregnant women must access prenatal care, ideally early during pregnancy. Their prenatal-care provider must counsel women regarding the benefits of knowing their HIV status for their own health and for the health of their babies. Health-care providers must offer women the opportunity for voluntary HIV testing. Pregnant women must accept testing and return to receive their test results. For those women who are found to be HIV-infected, their health-care provider must offer antiretroviral treatment using ZDV (currently often part of a combined antiretroviral regimen), and

the woman must accept and adhere to treatment during the recommended intervention periods, antenatally and intrapartum, as well as consent to treatment for her newborn. Mothers and babies must receive ongoing care postpartum. To monitor factors associated with the implementation of voluntary testing and treatment guidelines, the study in this report describes enhanced perinatal surveillance activities undertaken in seven states during the period following the publication of the guidelines. The indicators of prevention effectiveness (e.g., proportions in prenatal care, proportions tested prenatally, and proportions receiving ZDV) are compared for the period immediately preceding (1993) and following (1995–1996) the guidelines that were published during 1994.

METHODS

Enhanced Perinatal HIV/AIDS Surveillance

State and local health departments that conduct surveillance of adult and pediatric HIV infection seek to identify perinatally exposed infants, collect demographic and clinical information (including HIV diagnostic tests, birth history, and maternal and newborn ZDV receipt), and follow up with infants until sufficient laboratory information is available to classify them as infected or not infected, based on the recently expanded case definitions (*5*). The seven states that collected data on 1993 (i.e., the baseline year before publication of the 1994 findings of the Pediatric AIDS Clinical Trials Group 076 [PACTG 076] that ZDV treatment of pregnant women and newborns reduced the risk for HIV transmission), 1995, and 1996 births were Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina. All seven states had HIV reporting in place for at least 3 years before initiating the matching of case and birth registries and had required reporting of all prevalent HIV cases in adult and adolescent women when HIV reporting was implemented. Cases were ascertained by soliciting case reports from institutions and health-care providers as well as laboratory reports of tests diagnostic of HIV infection.

Enhanced surveillance consisted of a) increased efforts to completely ascertain mother-infant pairs by matching birth registries to HIV/AIDS registries; and b) the abstraction of information on pairs from all available medical charts, including the mother's prenatal care chart, HIV clinic chart, labor and delivery chart, the child's birth chart, and the child's HIV clinic chart. The information collected included not only the information required for the surveillance case report form but more detailed information on prenatal care, illicit drug use during pregnancy, additional information on ZDV prescription, reasons for discontinuing ZDV, characteristics of labor and delivery, and the mother's disease status.

Determining the Proportion of HIV-infected Women With Diagnosis Before Delivery

In the participating states, birth registries for 1993, 1995, and 1996 were matched to women reported with HIV/AIDS. HIV-infected women in the mother-infant pairs were considered to have received the diagnosis before delivery if the date of their first HIV-positive test result (in the HIV/AIDS registry) preceded the child's date of birth. The number of HIV-infected women who gave birth during each year and whose HIV infection had been diagnosed before delivery was derived from the total number of matches

(including previously identified mother-infant pairs and pairs identified through the registry match) provided. The estimated total number of HIV-infected women who gave birth each year was obtained from the Survey of Childbearing Women (SCBW) when available. The SCBW was an anonymous population-based seroprevalence survey of routinely collected blood specimens from newborns tested for maternal HIV antibody (*6*). New Jersey and South Carolina had SCBW data for 1993–1996; Colorado, Michigan, and Louisiana had data for 1993–1995; Missouri for 1993 and 1994; and Indiana for 1994. Data from the most recent year were used when data were not available for a given year. These seven states represented approximately 15% of HIV-infected women who gave birth nationwide in 1995.

Supplemental Data Collection

In six of seven states (all except New Jersey), all HIV-infected women who gave birth during 1993, 1995, and 1996 and whose HIV infection was diagnosed before delivery, and whose children were born during those years were eligible for supplemental chart abstraction. In New Jersey, because of the large number of mother-infant pairs, supplemental data in 1993 and 1996 were limited to women who gave birth during July through December of those years; for 1995, all pairs were eligible. Thus, the total number of pairs eligible for chart abstraction was smaller than the total number of women with diagnosis before delivery. Supplemental data were also collected for mother-infant pairs where mothers were tested at or after delivery.

RESULTS

In the participating states during 1993, 1995, and 1996, women for whom HIV infection had been diagnosed before delivery (ascertained through enhanced surveillance) accounted for 1,769 births. In addition, supplemental data were collected for 143 of 348 pairs in those instances when mothers were diagnosed at delivery or later.

The matching of birth registries and HIV/AIDS registries to find more mother-infant pairs resulted in an additional 11%–20% of pairs compared with standard surveillance practices. Based on SCBW, an estimated 2,350 births to HIV-infected women were reported in these states during 1993, 1995, and 1996. A total of 2,117 pairs of an estimated total of 2,350 or 90% ascertainment of infants born to HIV-infected women was found.

In the seven states, among the estimated births to HIV-infected mothers, the proportion with a diagnosis of HIV before giving birth was 70% (585/831) in 1993 (median: 79%; range: 47%–87%); 76% (595/779) in 1995 (median: 77%; range: 58%–100%); and 80% (589/740) in 1996 (median: 83%; range: 50%–95%). The proportions of women with diagnosis before delivery and who were first tested during pregnancy were 51% for 1993, 44% for 1995, and 47% for 1996.

A total of 1,534 pairs that included mothers who had an HIV diagnosis before delivery were eligible for abstraction (464 in 1993, 595 in 1995, and 475 in 1996). Supplemental data were collected in addition to data on the case report form for 1,321, or 86% of eligible pairs (413 [89%] in 1993; 487 [82%] in 1995; 421 [89%] in 1996). The supplemental data for 1,321 mother-infant pairs represented a total of 1,222 women, 99 of whom had two births. The proportion of eligible pairs for whom supplemental data was obtained differed by state (range: 77%–94%; median: 90%). Three states (Louisiana, New Jersey, and South Carolina) accounted for 73% of women; black women

accounted for 76%; women infected through heterosexual contact accounted for 51%; women aged 20–29 years accounted for 63%; and women for whom AIDS had been diagnosed before or during pregnancy accounted for 15% (Table 1).

A substantial increase occurred in the use of prenatal, intrapartum, and neonatal ZDV and in the proportion of mothers and their HIV-exposed infants who received ZDV during all three periods between 1993 and 1995; a smaller increase occurred between 1995 and 1996 (Chi square for trend $p<0.05$) (Table 2). In 1996, among women who had 2–4, 5–9, and >9 prenatal care visits, 84%, 89%, and 95%, respectively, were offered ZDV prenatally. The median week for initiation of ZDV was week 20, and 14% of women were prescribed ZDV during the first trimester. ZDV was refused by 39 (5%) of 824 pregnant women, and this proportion differed little by state or by year. Women who were injection-drug users were more likely to refuse ZDV than other women

TABLE 1. Characteristics of HIV-infected women who gave birth* — Selected states, United States, 1993, 1995, and 1996

Characteristic	No.	(%)
Colorado	35	(2.9)
Indiana	47	(3.8)
Louisiana	301	(24.6)
Michigan	146	(11.9)
Missouri	103	(8.4)
New Jersey	368	(30.1)
South Carolina	222	(18.2)
Race/ethnicity		
Black	934	(76.4)
White	207	(16.9)
Hispanic	73	(6.0)
Asian/Pacific Islander	3	(0.2)
American Indian/ Alaska Native	1	(0.1)
Unknown	4	(0.3)
Mode of exposure		
Heterosexual contact	619	(50.7)
Injection-drug use	345	(28.2)
Hemophilia/Transfusion	11	(0.9)
No risk reported	247	(20.2)
Age at delivery (yrs)†		
<20	113	(9.2)
20–29	766	(62.7)
30–39	329	(26.9)
≥40	14	(1.1)
Clinical status before or during pregnancy†		
HIV+	945	(77.3)
AIDS: CD4 <200 μL	145	(11.9)
AIDS: opportunistic illness	38	(3.1)
Unknown	94	(7.7)

* A total of 1,222 HIV-infected women accounted for 1,321 births.

† For women with >1 pregnancy, data reflect earliest pregnancy.

TABLE 2. Proportion of HIV-infected women who were offered prenatal, intrapartum, and neonatal zidovudine and who received HIV diagnosis before delivery — Selected states,* United States, 1993, 1995, and 1996†

	1993§ (N=403)			1995 (N=487)			1996 (N=421)		
Received zidovudine	**Pooled¶**	**Median****	**Range****	**Pooled¶**	**Median****	**Range****	**Pooled¶**	**Median****	**Range****
Prenatal	27%	27%	13%–34%	74%	77%	58%–93%	83%	90%	64%–92%
Intrapartum	6%	6%	0%–17%	60%	59%	53%–85%	75%	80%	55%–86%
Neonatal	8%	8%	0%–14%	69%	73%	48%–92%	77%	78%	66%–92%
All periods	0%	4%	0%– 8%	45%	39%	31%–61%	65%	58%	41%–77%

* Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina.

† Receipt of zidovudine was unknown for <10% of mother-infant pairs.

§ Excludes a small number of pregnant HIV-infected women (n=10) of whom a large proportion were enrolled in 1993 in the Pediatric AIDS Clinical Trials Group 076 (PACTG 076) from a single state.

¶ Pooled data represent data aggregated across states.

**Median data represent the proportions among states, and the range data represent ranges of the percentages of the individual states.

(13/179 [7%] versus 17/581 [3%]; p<0.05). Of the women who were prescribed ZDV, based on chart notations, 33 (4%) of 785 stopped taking it before delivery.

Overall, 14% of women received no or minimal prenatal care (0–1 prenatal care visit), and 19% initiated prenatal care in the third trimester (Table 3). The proportion of women with no or minimal prenatal care differed by state, and a lack of prenatal care was much more common among women who had used drugs during pregnancy than among women who had not used drugs during pregnancy (36% versus 5%). Differences of this magnitude were observed in six of seven states; in one state, only a small proportion of women received no prenatal care in both groups. The proportion of women receiving prenatal ZDV and the proportion who used drugs during pregnancy varied according to the number of prenatal care visits (Figure 1). The proportion of HIV-infected women (28%) who used drugs during pregnancy (based on chart notation or positive toxicologic test result) was stable over time but differed substantially among states.

Among 45 women tested at or within 7 days of delivery, 71% received no or minimal prenatal care, and 67% had used drugs during pregnancy. Among 85 women tested >7 days after delivery, 27% received no or minimal prenatal care, and 26% had used drugs during pregnancy. Among women who had received no or minimal prenatal care, the proportion who had used drugs during pregnancy was 72%, 77%, and 61%, respectively, for those tested before or during pregnancy, at delivery, or later.

No changes occurred from 1993 through 1996 in the proportion of deliveries that were performed by cesarean delivery or by elective cesarean delivery (before labor); in addition, no changes occurred in the proportion of women with ruptured membranes for >4 hours (Table 3). The proportion of women who had a tubal ligation during each year remained stable but was larger for women with ≥2 previous live births (36%) compared with women with 1 or no previous live births (25% and 13%, respectively; p<0.05). Women tested at delivery or later (n=143) were less likely to have a tubal ligation (12%; p<0.05) and more likely to have ruptured membranes for >4 hours (39%; p<0.05).

TABLE 3. Characteristics of prenatal care and delivery of mother-infant pairs* — Selected states,† United States, 1993, 1995, and 1996

	Mother-infant pairs		
Characteristic	**Pooled§**	**Median¶**	**Range¶**
No or minimal prenatal care	14%	12%	(3%–27%)
Prenatal care initiated in 3rd trimester	19%	20%	(8%–23%)
Drug use during pregnancy**	28%	19%	(17%–46%)
Positive toxicologic screen	24%	15%	(11%–41%)
Ruptured membranes for >4 hours	31%	33%	(27%–42%)
Cesarean delivery	22%	21%	(17%–27%)
Elective cesarean delivery	11%	11%	(8%–17%)
Tubal ligation	27%	27%	(16%–38%)

* Number of mother-infant pairs = 1,321.

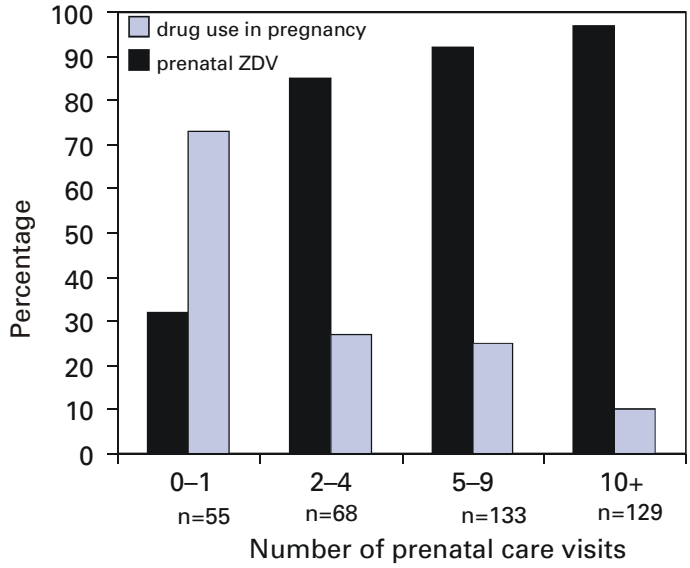
† Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina.

§ Pooled data represent data aggregated across states.

¶ Median data represent the proportions among states, and the range data represent ranges of the percentages of the individual states.

**Includes either a chart notation or a positive toxicologic test result.

FIGURE 1. Percentage of women diagnosed with HIV infection before delivery who used drugs during pregnancy and received prenatal zidovudine, by number of prenatal care visits — Selected states,* United States, 1996



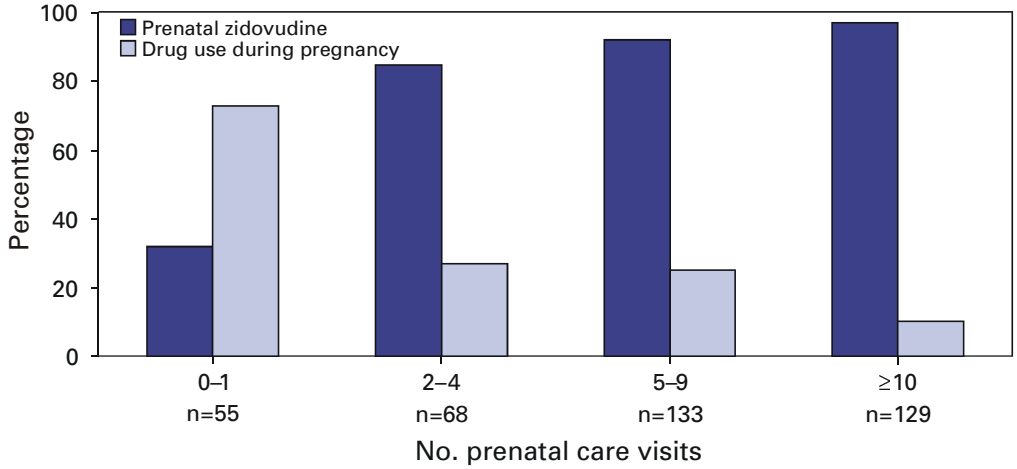
* Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina.

Of the children who received any ZDV (prenatal, intrapartum, or neonatal), 8% were infected compared with 16% of those who did not receive ZDV (Figure 2). The rate was 12% for those for whom ZDV use was unknown, suggesting that at least some children might have received ZDV.

Recommendations for Prevention

In these seven states, the implementation of the guidelines to use ZDV to prevent perinatal transmission of HIV infection was rapid and has been effective at reducing perinatal HIV transmission. The large proportion of pregnant women who already had a diagnosis before delivery in 1993 undoubtedly contributed to the rapid response to the findings from PACTG 076 and the Public Health Service guidelines on ZDV use. By 1996, all except an estimated 20% of HIV-infected women had received a diagnosis before delivery. Given the large proportion of women who are treated according to recommendations and studies demonstrating that transmission can be reduced to even lower levels through the use of combination antiretroviral treatment and obstetric procedures (e.g., elective cesarean delivery) (*2,7,9*), eliminating perinatal HIV transmission is theoretically possible in the United States. Certain segments of the population (e.g., women who do not receive a diagnosis before or during pregnancy, women with little or no prenatal care, and women who use drugs during pregnancy), however, might not benefit from these advances. A preliminary review of data from pediatric HIV surveillance for 1997, 1998, and 1999 indicated that the levels of ZDV prescription increased from 1996 through 1997 and remained stable through 1999 (CDC, unpublished data) (*10*). The proportion (16%) of infected infants among those who did not receive ZDV was lower in these states than for participants in PACTG 076 (25%); characteristics of mothers (e.g., stage of illness and obstetric factors) likely played an important role.

FIGURE 2. HIV infection status of children born to women diagnosed before delivery, by receipt of zidovudine* — Selected states,† United States, 1993, 1995, and 1996



* ZDV.
† Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina.

Continued increases in the proportion of women who receive effective antiretroviral therapies will be necessary to further reduce perinatal transmission and will depend on the success of efforts to increase testing, access to and use of prenatal care, and the use of rapid testing and short-course treatments for women who are first seen in labor. Because women who use drugs during pregnancy disproportionately receive inadequate or no prenatal care, targeted interventions such as community-based outreach are being implemented in 16 states to promote increased access to care and testing among pregnant women who might not otherwise receive prenatal care.

In 1997, a total of 63%–87% of women in 14 states had received HIV counseling during pregnancy, and 58%–81% had been tested for HIV infection (*11*). Compared with 1996, increases were modest, and preliminary data from 1998 suggest that only modest increases continued (CDC, unpublished data). Surveys of health-care providers indicate that they are more likely to offer HIV testing only to women they consider at risk, although they tend to agree that all pregnant women should be tested for HIV. When providers recommend that pregnant women be tested, acceptance rates are high (*12,13*). Some health-care providers also consider pretest counseling according to standard practice guidelines to be a barrier to offering the test universally. The Institute of Medicine recommended the integration of HIV testing into the standard prenatal test battery and the adoption of a national policy of universal prenatal testing (*4*). The national policy of universal prenatal testing is described in the revised draft guidelines which a) recommend HIV testing for all pregnant women and b) affirm that informed consent is essential, including providing the patient with the right to refuse testing (*4,14*).

A lack of prenatal care has been a long-standing problem in certain population subgroups (*15*) and might be a more difficult barrier to overcome, possibly becoming the leading reason for continued transmission in some geographic areas. Recent studies have demonstrated the effectiveness of short-course ZDV and single-dose nevirapine to the mother at delivery and to the neonate (*16,17*). As a result, evaluations are being conducted regarding the feasibility of rapid testing and the use of intrapartum antiretroviral therapy for women whose HIV status is unknown at the time of labor (*18*).

Tubal ligation rates were high but consistent with findings from a study of contraceptive choices among HIV-infected women, which indicated that 27% of HIV-infected women chose tubal ligation compared with 15% of demographically similar women who were not infected (*19*). The smaller proportion of women having a tubal ligation among those who did not know their HIV status at the time of delivery is also consistent with previous findings.

Enhanced pediatric surveillance methods can provide more complete data to estimate the number of HIV-infected pregnant women giving birth. In many areas, such data will be valuable as a proxy for the SCBW data, which are no longer collected but were used previously as a basis for HIV prevalence estimates in the population (*20*). In addition, if new HIV diagnoses in pregnant women can be assessed for recency of infection using developmental assays that can distinguish incident infections from prevalent infections, enhanced perinatal surveillance methods might contribute to development of a population-based approach to estimating HIV incidence in the United States (*21*).

These data have several limitations. First, uncertainty regarding the number of HIV-infected women who gave birth during 1996 in most states that lacked SCBW data is a limitation. Using 1995 data as a proxy for 1996 might systematically bias the results. For example, if the number of infected women giving birth in 1996 was larger than in 1995, the calculated percentage tested would be too small or vice versa. In addition, state-level fluctuations were observed, especially in states with smaller numbers of infected women; therefore, the aggregate estimate is likely more stable than state-level estimates. Second, the proportion of infected women with a diagnosis before delivery might be an underestimate because women who had not been reported could not be included in the registry matching. Second, the proportion of infected women with a diagnosis before delivery might be an underestimate: although the completeness of HIV reporting is estimated to be $\geq$85% (*22*), women who had not been reported could not be included in the registry match. Third, supplemental information could be collected only on 86% of the charts eligible for review. Women whose charts were not abstracted because they were more difficult to find possibly were less likely to have received ZDV. Finally, supplemental data were incomplete for the pairs with mothers who were tested at or after delivery.

Research Agenda

Based on findings from this study, an important component of CDC's initiative to eliminate perinatal transmission is targeting outreach to women who use illicit drugs. The outreach is designed to increase timely access to and use of prenatal care in this population. Research to accomplish this goal includes the development of effective social marketing tools. Additional research is under way to identify effective methods of training health-care providers to increase the offering of HIV testing. Programmatic research is needed to develop effective case management methods for HIV-infected pregnant women that achieve sustained access to and use of prevention and treatment services for women and children. These efforts must include behavioral risk reduction and substance abuse treatment and prevention. Finally, for women whose HIV status is unknown at the time of labor and delivery, research is focused on developing and implementing rapid HIV testing strategies to provide antiretroviral treatment to prevent HIV transmission.

CONCLUSION

To monitor the outcomes of perinatal testing and treatment programs, enhanced perinatal surveillance is needed in all states to assess perinatal prevention needs and to monitor the effect of prevention programs (*5,23*). Enhanced surveillance, initially conducted in the states mentioned in this report, has recently been extended to 22 states in conjunction with a CDC initiative to eliminate perinatal transmission of HIV. The surveillance system can adapt rapidly, providing an efficient means of collecting relevant information as clinical developments occur. As the perinatal transmission of HIV continues to decrease, surveillance data will continue to play a central role in specifying the reasons for continuing transmission and in identifying the areas where transmission continues (*24*).

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A Method for Classification of HIV Exposure Category for Women Without HIV Risk Information

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A Method for Classification of HIV Exposure Category for Women Without HIV Risk Information

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Summary

An increasing number of cases of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) among women is reported to state and territorial health departments without exposure risk information (i.e., no documented exposure to HIV through any of the recognized routes of HIV transmission). Because surveillance data are used to plan prevention and other services for HIV-infected persons, developing methods to accurately estimate exposure risk for HIV and AIDS cases initially reported without risk information and assisting states to analyze and interpret trends in the HIV epidemic by exposure risk category is important. In this report, a classification model using discriminant function analysis is described. The purpose of the classification model is to develop a proportionate distribution of exposure risk category for cases among women reported without risk information. The distribution was estimated based on behavioral and demographic data obtained from interviews with HIV-infected women; the interviews were conducted in 12 states during 1993–1996. Variables used in the analysis were alcohol abuse, noninjection-drug use, and crack use; year of HIV/AIDS diagnosis; age; employment; and region. As a result of the classification procedure, nearly all cases among women with no reported risk were classified into an exposure risk category: 81%, heterosexual contact; and 16%, injection-drug use. These proportions are higher than the current redistribution fractions (calculated from risk reclassification patterns and weighted by demographic characteristics) and reflect the increasing proportion of cases among women attributable to heterosexual contact with an infected partner.

This report provides one method that could be applied to HIV surveillance data at the national level to estimate the proportion of cases in exposure risk categories. However, because the study in this report is limited in sample size and geographic representativeness, other models are also needed for adjusting risk exposure data at the national, state, and local levels.

BACKGROUND

Women account for a steadily increasing proportion of cases of acquired immunodeficiency syndrome (AIDS), representing 23% of cases reported to CDC in 1999 (*1*). Since 1995, an average of approximately 11,600 cases of AIDS have been diagnosed in women each year. The expansion of the AIDS case definition in 1993 (*2*) was associated with a large increase in the total (i.e., men and women) number of reported cases, from 42,290 reported cases in 1992 (*3*) to 72,967 reported cases in 1995 (*4*). An increase in the number of reported cases of human immunodeficiency virus (HIV) infection also is expected as additional states implement reporting of HIV infection, including cases among women with a previous diagnosis of HIV infection (*5*).

RISK FACTORS

For surveillance purposes, each reported case of HIV or AIDS is counted once in a list of exposure risk categories (i.e., men who have sex with men; injection-drug users; men who have sex with men and are injection-drug users; recipients of clotting factor for hemophilia or other coagulation disorders; persons who have had heterosexual contact with a partner who is HIV-infected or who has one of the risks already listed; or recipients of HIV-infected blood or blood components other than clotting factor or of HIV-infected tissue [*1*]). Among persons who have AIDS and are reported as having multiple possible routes of HIV acquisition, a single exposure risk category is assigned based on the most probable or efficient mode of transmission (*1*). However, all risk information is retained in the database.

In 1994, the proportion of women with AIDS infected through heterosexual contact surpassed the proportion infected through injection-drug use; overall, heterosexual transmission accounted for 40% of AIDS cases reported among women in 1999 (*1*). A total of 11% of these women reported heterosexual contact with an injection-drug user, and the other 29% reported sexual contact with men of unspecified or other risks (e.g., men who have sex with men and women). Thirty-two percent of the cases among women were initially reported with no exposure risk category, which is common for recently reported cases.

HIV and AIDS cases reported without exposure risk information (i.e., no documented exposure to HIV through any of the routes listed in the exposure risk categories) are assigned to a "no reported risk" category. Cases in this category might be reclassified into a defined category after follow-up by the local health department as part of routine surveillance or a supplemental surveillance project.

The proportion of all reported AIDS cases in the United States initially reported without exposure risk information increased from 5% in the early 1980s (*3*) to approximately 20% in 1999 (*1*). The proportion of HIV cases reported without exposure risk information is higher among women than men; in 1998, a total of 51% of HIV cases among women and 37% of HIV cases among men were reported without exposure risk information (*1*). Tracking trends in the proportionate distribution of cases by exposure risk category is an important step in understanding the dynamics of HIV transmission and in planning effective prevention programs at the state and local levels.

Because of the number of cases reported without exposure risk information, local health departments are unable to conduct follow-up and ascertain risk information for all cases. To analyze surveillance trends, CDC has used a statistical adjustment to as-

sign a risk for cases reported without exposure risk information (*6*). This adjustment method has been based on historical patterns of reclassification of AIDS cases initially reported without risk, which accounts for sex, race/ethnicity, and geographic region (*7*). However, these adjustments from the AIDS case surveillance database might be biased because an increasing proportion of recent AIDS cases are not followed up to ascertain risk. A method based on AIDS case surveillance also might not be representative of HIV cases. As more states implement HIV reporting, several strategies will need to be used to track epidemiologic trends for newly reported cases of HIV infection or AIDS without exposure risk information.

In this report, methods of making statistical adjustments to the HIV infection surveillance data for cases reported without exposure risk information are described. The information used for the adjustments included behavioral and demographic data from interviews with women who have HIV infection but not AIDS and women with a recent AIDS diagnosis. Using discriminant function analysis, cases were classified into an exposure risk category. Results from the classification were compared with the exposure risk category noted in the case report. For cases reported without exposure risk information, the redistribution fractions derived from the classification model were also compared with those fractions derived from the current method of redistribution, which is based primarily on demographic information.

Statistical Redistribution of Exposure Risk

Materials and Methods

All states and territories in the United States report cases of AIDS to CDC through the HIV/AIDS Reporting System (HARS); as of December 1999, a total of 33 states and territories also report cases of HIV infection without AIDS (*1*). HIV and AIDS cases are reported to state health departments, which forward the data to CDC with no personally identifying information. The Supplement to HIV/AIDS Surveillance (SHAS) is a surveillance project in which persons who have been reported to state or local health departments in 12 states are interviewed using a standardized, confidential questionnaire. Participants must be aged ≥18 years, give consent, and be able to complete the interview. SHAS has been ongoing since 1990; detailed methods of this project have been described elsewhere (*8*). Data from HARS and SHAS are linked by using an identification number assigned by the state health department.

Data from women who completed a SHAS interview from January 1993 through December 1996 were analyzed. The analysis was restricted to women with a diagnosis of HIV infection (not AIDS), regardless of when they learned of their diagnosis, and women who had learned of their AIDS diagnosis within the 12 months before the interview. Women whose exposure risk category was transfusion or hemophilia were excluded because these categories account for a small proportion of cases.

Trained interviewers administered a 45-minute standardized questionnaire to eligible persons who gave oral consent to be interviewed. The instrument included, but was not limited to, questions regarding sociodemographics, sexual behaviors during the previous year, and substance use during the previous 5 years. Each health department ensured privacy during the interview. The SHAS project was approved by local human subjects review boards. Names and other personal identifiers were removed before data were sent to CDC.

The variables for exposure risk category used in this analysis came from HARS. In most instances, exposure risk information in HARS came from medical records; however, in some states, risk information obtained during the SHAS interview might be used to determine exposure risk category for cases initially reported without exposure risk information. The race/ethnicity variable also came from HARS. Behavioral and demographic data that were used as independent variables in the model to predict exposure risk category came from SHAS. A history of the following behaviors and diseases was examined: crack use (previous 5 years, >5 years ago, or never); noninjection-drug use, including crack but excluding marijuana (previous 5 years); sexually transmitted disease (previous 10 years); alcohol abuse (as defined by the CAGE questions*) (*9*); exchange of sex for money or drugs (previous 5 years); and number of male sex partners (previous 5 years). Demographic variables that came from SHAS were age, years of education, household income in the previous year, employment status, year of interview, disease status (AIDS or HIV infection) at the time of the interview, and region of the country where the person lived at the time of the interview.

We used the chi-square test to assess the bivariate relation between each of the independent variables and exposure risk category. Discriminant function analysis was used to classify respondents by exposure category using SPSS version 7.5 (*10*). Variables were entered into the analysis using a backward elimination procedure to select a minimum subset of predictors. Data from the interview and case report form were used to predict membership in three exposure risk categories (injection-drug users, heterosexual contact, and no reported risk). The data were randomly split into two parts with an equal number of observations in each. With one part of the data, a discriminant function analysis was conducted to identify the classification model, which was then applied to the other part of the data to classify exposure risk category. These analyses were conducted repeatedly using split random samples (Table 1). The overall correct classification never varied more than two percentage points for any of the randomly generated split samples; the data from one analysis is presented in this report.

Results

Of 1,297 women who were interviewed, 410 (32%) had injection-drug use as their exposure risk category in HARS; 638 (49%), heterosexual contact; and 249 (19%), no reported risk (Table 1). Women whose exposure risk category was injection-drug use were more likely than those whose exposure risk category was heterosexual contact and those with no reported risk to be white, older, and unemployed; have lower income; and have received their diagnosis before 1993. In addition, most other risk behaviors were more prevalent among injection-drug users than among other groups (Table 1).

In the discriminant function analysis, the variables selected by backward elimination as having the ability to discriminate among the exposure categories were alcohol abuse, noninjection-drug use, crack use, diagnosis year, age, employment, and region. The classification resulting from the discriminant function analysis was able to correctly categorize 72% of women (not including those whose HARS exposure risk

*The CAGE questions ask if the respondent had ever wanted to **C**ut down on their drinking, had **A**nnoyed others with their drinking, felt **G**uilty about drinking, or needed a drink in the morning as an **E**ye-opener.

TABLE 1. Characteristics of women interviewed for the Supplement to HIV/AIDS Surveillance (SHAS) Project, by HIV exposure category* — Selected states, United States, 1993–1996

Characteristic[§]	HIV exposure category: Injection-drug user No.	(%)	Heterosexual contact No.	(%)	Risk not reported No.	(%)	Total[†] No.	(%)
Demographics								
Race								
White, non-Hispanic	97	(24)	97	(15)	28	(11)	222	(17)
Black, non-Hispanic	236	(58)	363	(57)	139	(56)	738	(57)
Hispanic	70	(17)	172	(27)	79	(32)	321	(25)
Other	7	(1)	6	(1)	3	(1)	16	(1)
Age (yrs)								
18–34	179	(44)	335	(53)	139	(56)	653	(50)
≥35	231	(56)	303	(47)	110	(44)	644	(50)
Education (yrs)								
0–11	212	(52)	278	(44)	130	(52)	620	(48)
≥12	197	(48)	360	(56)	119	(48)	676	(52)
Household income								
<$10,000/yr	315	(86)	406	(71)	151	(69)	872	(75)
≥$10,000/yr	53	(14)	169	(29)	68	(31)	290	(25)
Employed								
Yes	47	(11)	148	(23)	61	(24)	256	(20)
No	363	(89)	490	(77)	188	(76)	1,041	(80)
Region								
Northeast	100	(24)	137	(22)	28	(11)	265	(21)
Midwest	72	(18)	62	(10)	12	(5)	146	(11)
South	122	(30)	226	(36)	103	(42)	451	(35)
West	116	(28)	202	(32)	103	(42)	421	(33)
Diagnosis year								
1981–1992	142	(37)	132	(24)	23	(14)	297	(27)
1993–1997	241	(63)	416	(76)	144	(86)	801	(73)
Diagnosis								
HIV infection	253	(62)	349	(56)	153	(62)	755	(59)
AIDS	157	(38)	278	(44)	93	(38)	528	(41)
Risks								
Noninjection-drug use[¶]**								
Yes	240	(59)	115	(18)	42	(17)	397	(31)
No	170	(41)	523	(82)	207	(83)	900	(69)
Crack use								
≤5 yrs ago	204	(50)	101	(16)	42	(17)	347	(27)
>5 yrs ago	20	(5)	18	(3)	3	(1)	41	(3)
Never	184	(45)	506	(81)	201	(82)	891	(70)
Exchanged sex for money or drugs[¶]								
Yes	119	(29)	62	(10)	21	(8)	202	(16)
No	291	(71)	576	(90)	228	(92)	1,095	(84)

TABLE 1. *(Continued)* Characteristics of women interviewed for the Supplement to HIV/AIDS Surveillance (SHAS) Project, by HIV exposure category* — Selected states, United States, 1993–1996

	HIV exposure category							
	Injection-drug user		Heterosexual contact		Risk not reported		Total†	
Characteristic§	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Sexually transmitted disease††								
Yes	161	(40)	238	(38)	78	(32)	477	(37)
No	245	(60)	396	(62)	167	(68)	808	(63)
Alcohol abuse§§								
Yes	167	(41)	116	(18)	36	(14)	319	(25)
No	243	(59)	522	(82)	213	(86)	978	(75)
No. male sex partners¶								
1	105	(28)	219	(37)	180	(36)	404	(34)
≥2	271	(72)	368	(63)	144	(64)	783	(66)
Total†	**410**	**(100)**	**638**	**(100)**	**249**	**(100)**	**1,297**	**(100)**

* Based on reports in the HIV/AIDS Reporting System (HARS).

† Some categories might not add to total because of missing responses.

§ P-value for chi-square test of differences by exposure risk category was ≤0.05 for all variables except Diagnosis and Sexually Transmitted Disease. For these two variables, the differences in exposure risk category were not statistically significantly different (p>.05).

¶ Previous 5 years.

**Includes crack use.

†† Previous 10 years.

§§ As defined by CAGE questions, which ask if the respondent had ever wanted to **C**ut down on their drinking, had **A**nnoyed others with their drinking, felt **G**uilty about drinking, or needed a drink in the morning as an **E**ye-opener.

category was no reported risk). Classification was considered "correct" if it was assigned to the same category as the exposure risk category reported in HARS.

Nearly all (97.5%) women with no reported risk were classified to heterosexual contact (81%) or injection-drug use (16%) (Table 2). These proportions (redistribution fractions) are the basis for adjustments made to the no reported risk category when analyzing trends.

Redistribution fractions were compared with those from the current method of adjusting exposure risk information, which is based on data from reclassified AIDS cases initially reported with no reported risk. The redistribution fractions derived from this study, which included HIV and AIDS cases, would distribute a higher proportion of women with no reported risk into the heterosexual contact category (81%) than the current method (69%–70%) (Tables 2 and 3). This difference is consistent with trends toward an increasing proportion of women with known risk being classified in the heterosexual contact category (*1,11*).

TABLE 2. Classification of HIV exposure risk category*

HARS exposure risk category¶	Classification by discriminant function analysis†					
	Injection-drug user		Heterosexual contact		Risk not reported§	
	No.	(%)**	No.	(%)**	No.	(%)**
Injection-drug user (n=197)	117	(59.4)	80	(40.6)	0	(0.0)
Heterosexual contact (n=297)	56	(18.9)	239	(80.5)	2	(0.7)
Risk not reported (n=122)	20	(16.4)	99	(81.1)	3	(2.5)
Total	**193**	**(31.3)**	**418**	**(67.9)**	**5**	**(0.8)**

* Exposure risk category as reported in the HIV/AIDS Reporting System (HARS).

† Classification based on data obtained from interviews and case reports of persons with HIV/AIDS used in discriminant function analysis, which identified behaviors predictive of membership in the exposure risk categories.

§ Cases with no risk information reported had no documented exposure to HIV through any of the routes listed in the following categories: men who have sex with men; injection-drug users; men who have sex with men and are injection-drug users; recipients of clotting factor for hemophilia or other coagulation disorders; persons who have had heterosexual contact with a partner who is HIV-infected or who has one of the risks already listed; or recipients of HIV-infected blood or blood components other than clotting factor or of HIV-infected tissue.

¶ N=616.

**Percentages add to 100% across row.

TABLE 3. Redistribution fractions for HIV cases with no risk information reported,* by comparison of classification model and redistribution method

Classification model/ Redistribution method	HIV exposure risk category		
	Injection-drug user	Heterosexual contact	Risk not reported
Classification results†	0.164	0.811	0.025
Redistribution method§ SHAS sites¶ only, 1993–1996	0.281	0.705	0.014
Redistribution method§ United States, 1993–1996	0.290	0.693	0.018

*Cases with no risk information reported had no documented exposure to HIV through any of the routes listed in the following categories: men who have sex with men; injection-drug users; men who have sex with men and are injection-drug users; recipients of clotting factor for hemophilia or other coagulation disorders; persons who have had heterosexual contact with a partner who is HIV-infected or who has one of the risks already listed; or recipients of HIV-infected blood or blood components other than clotting factor or of HIV-infected tissue.

† Classification model is based on behavioral and demographic information.

§ Redistribution method is primarily based on demographic information.

¶ Supplement to HIV/AIDS Surveillance (SHAS) sites are Arizona; Los Angeles, California; Denver, Colorado; Connecticut; Delaware; Florida; Georgia; Michigan; New Jersey; New Mexico; South Carolina; and Washington.

RECOMMENDATIONS FOR PREVENTION

Exposure risk information is used to monitor trends in routes of HIV transmission, to plan prevention programs, and to allocate resources to priority populations at risk for HIV infection. However, with an increasing proportion of cases reported with no exposure risk information, statistical adjustments must be made to the surveillance data to monitor trends. Findings in this report indicate that a statistical model based on data reported in interviews and case report forms of persons with HIV/AIDS can be used to classify most cases among women into the same exposure risk category recorded on their case report form. In addition, the model can classify nearly all cases among women reported without risk. Behaviors, including crack use, other noninjection-drug use, and alcohol use, were stronger predictors of exposure risk category than demographic characteristics. These findings emphasize the need for behavioral surveillance to improve HIV prevention planning at the state and local levels.

The findings indicate that use of crack and other noninjection-drugs was more prevalent among injection-drug users than among women in the heterosexual contact exposure category (Table 1). Crack is a risk for heterosexual transmission of HIV because of its relation with risky sexual behaviors (*12*). Injection-drug use in combination with crack use has also been associated with a higher prevalence of risky sexual behaviors (*13*). Given that the model in this report would likely classify crack users into the injection-drug use exposure category, rather than the heterosexual contact category, the link between crack use and heterosexual transmission of HIV should be further explored.

RESEARCH AGENDA

Additional research is needed to address the limitations in this risk adjustment method. Classification results based on the method used in this report might differ from other populations according to background prevalence of infection and risk behaviors and the distribution of exposure risk categories. The data available for analysis from 12 states participating in SHAS were too sparse to make reliable estimates by sex, region, and race at the national level, which is currently done with the AIDS surveillance data; SHAS data would be needed from a large number of additional states to be able to make such estimates. Therefore, at the present, this method will not be adopted as a statistical method to adjust HIV and AIDS surveillance data at the national level to examine trends in exposure risk category until SHAS interview data are available on all or a representative sample of new HIV/AIDS cases in additional states. This method could be used in areas that conduct SHAS to make estimates for classifying cases reported without exposure risk information.

The study in this report highlights the complexities of estimating exposure risk without a reference method for comparison. The self-reported data from SHAS might be biased by recall or social desirability, which might result in over- or underreporting of risk behaviors. During the study period in which the proportion of cases reported without exposure information was lower, some states updated a small proportion of HARS records with data obtained from SHAS. Thus, the findings in this report might overestimate the proportion of cases "correctly" classified. HARS data abstracted from medical record review might be biased by what health-care providers document or how the record abstractor interprets the documentation. Without a reference — for example,

knowing whether self-report or chart review provides more accurate and valid risk data — a comparison of results can only be made from different methods of adjusting risk and deciding which methods are best from a practical point of view. Thus, the reference might be a combination of interview and chart review cross-validated with biological tests (e.g., testing for sexually transmitted diseases, including HIV). If exposure risk information was obtained from SHAS interviews and from medical chart reviews on a representative sample of cases in all states with high or moderate prevalence of HIV, an accurate probability distribution for exposure risk category for HIV infection at the state and national levels could be produced.

As more states adopt HIV reporting and the volume of reported cases increases, an important task for CDC is to develop methods to accurately estimate risk for HIV and AIDS cases initially reported without risk exposure information and to assist states in analyzing and interpreting trends in risk exposures. The methods in this report provide one possible solution that can be applied to HIV surveillance data at the national level. However, until these methods are evaluated and verified in additonal states, the method of applying demographic data and the risk reclassification information from investigated HIV cases to cases with no reported risk (the method is used with the AIDS data for cases with no reported risk) will be used as a short-term, retrospective adjustment to the HIV data. The future application of the discriminant function analysis and classification will depend on having complete, high quality data from chart reviews and interviews with representative samples of cases as described in this report.

CONCLUSIONS

Women account for a steadily increasing proportion of AIDS cases in the United States. At the same time, the proportion of cases among women reported without exposure risk information is increasing, and collecting this information on all cases is not practical. Therefore, statistical adjustments to surveillance data are needed to monitor trends in exposure categories. Reliable data on exposure risk categories are crucial for HIV prevention because allocation and direction of resources is based on this kind of risk information. The model presented in this report is one potential option for making the needed statistical adjustments to exposure risk information, particularly at the state and local levels. Given the limitations of sample size and geographic representativeness of the data, other options, including investigations on a sample of cases and statistical estimation, should continue to be explored.

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