



Attitudes toward childbearing and changes in sexual and contraceptive practices among HIV-infected women

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- **BACKGROUND** Women now constitute 12% of persons with acquired immunodeficiency syndrome (AIDS), and three quarters of them are well within their childbearing age.
- **OBJECTIVE** To determine if women infected with human immunodeficiency virus (HIV) change their attitudes toward childbearing and their sexual and contraceptive practices.
- **METHODS** Questionnaire and interview.
- **RESULTS** Forty-six women age 18 to 44 participated; 33 were white, 12 were Hispanic, and 1 was black. Intravenous drug abuse was reported by 65%. Nineteen had symptomatic HIV disease or AIDS. Only 70% said they had received counseling after testing. Of these, 59% said they were counseled on avoiding pregnancy, and 81% said they were counseled on use of condoms. Before testing, 59% had wanted to have children; after testing, only 17% did. Only 4% said they had always used condoms before testing, but 54% said they did after testing; 39% said they used some form of birth control before testing compared with 70% who said they did after testing.
- **CONCLUSIONS** Counseling was not optimal. Sexual and contraceptive practices changed, but follow-up study will be needed to see if such changes are sustained.

■ **INDEX TERMS:** HIV INFECTIONS; PATIENT EDUCATION; CONTRACEPTION BEHAVIOR; FEMALE; PREGNANCY ■ CLEVE CLIN J MED 1994; 61:132-136

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AS THE EPIDEMIC of human immunodeficiency virus (HIV) spreads, the number of infected women, infants, and children continues to grow.¹⁻³ Of the 218 301 cases of acquired immunodeficiency syndrome (AIDS) reported to the Centers for Disease Control and Prevention from 1981 through March 1992, 22 607 (10%) were in women. Women comprised 9% of the first 100 000 persons with AIDS, but 12% of the second 100 000.³ Seventy-nine percent of these HIV-infected women were between 13 to 39 years of age, well within their childbearing years.⁴

The first 100 000 people with AIDS also included 1683 children, of whom 81% were born to mothers with HIV infection or at risk for it. The second 100 000 included 1702 children, of whom 87% were born to mothers with HIV infection or at risk for it. This study examines whether women infected with HIV change their attitudes toward childbearing and their sexual and contraceptive practices after they learn of their HIV status.

TABLE 1
DEMOGRAPHIC DATA IN 46 WOMEN INFECTED
WITH THE HUMAN IMMUNODEFICIENCY VIRUS

	No.	(%)
Race		
White	33	(72)
Hispanic	12	(26)
Black	1	(2)
Risk factors		
Intravenous drug abuse	30	(65)
Partners who abused intravenous drugs	1	(2)
Infected partners	6	(13)
Transfusion	1	(2)
Multiple risk factors*	8	(17)
Education		
Elementary school	2	(4)
High school and above	44	(96)
Employment		
Unemployed	41	(89)
Employed	5	(11)
Source of financial support if unemployed		
Welfare, Disability, or Social Security	29	(71)
Other	12	(29)
Parenting		
Both parents	15	(33)
Single parent	21	(46)
No children	10	(22)

*Multiple risk factors: 4 patients who abused intravenous drugs and whose partners also abused intravenous drugs, 2 patients with infected partners and with partners who abused intravenous drugs, 1 patient who abused intravenous drugs whose partner was infected with human immunodeficiency virus, and 1 patient who abused intravenous drugs and who practiced prostitution

METHODS

All HIV-infected women of reproductive age (18 to 44 years) at the HIV Clinic at the University of Massachusetts Medical Center were eligible for this study, which was conducted from January 1990 through June 1991. The recruitment took 18 months because 76% of our women patients abuse intravenous drugs, and recruitment in this patient group has been a slow process in our experience.⁵ The purpose of the study was explained to the subjects, and they signed a statement of informed consent approved by the Committee on the Protection of Human Subjects in Research. Despite reassurance that we would safeguard their anonymity, the fact that they had to sign consent forms may have made some patients reluctant to participate.

The patients either completed a questionnaire or underwent a structured interview in English that

TABLE 2
TOPICS RECALLED BY 32 WOMEN WITH
HUMAN IMMUNODEFICIENCY VIRUS INFECTION
WHO SAID THEY RECEIVED COUNSELING AFTER TESTING

Topic	Yes (%)	No (%)	No answer (%)
Avoidance of pregnancy	19 (59)	11 (34)	2 (6)
Use of condoms	26 (81)	5 (16)	1 (3)
Use of spermicidal agent	25 (78)	6 (19)	1 (3)
Avoidance of exchange of body fluids	28 (88)	3 (9)	1 (3)

TABLE 3
KNOWLEDGE OF POSITIVE HUMAN IMMUNODEFICIENCY
VIRUS SEROSTATUS AND CHANGE IN CONTRACEPTIVE
PRACTICES IN 46 WOMEN

	Before testing, No. (%)	After testing, No. (%)
Desired children	27 (59)	8 (17)
Always used condoms	2 (4)	25 (54)
Practiced birth control	18 (39)	32 (70)

followed the questionnaire. All recruited patients spoke, read, and understood English except for one, for whom an interpreter was provided. The questionnaires focused on three areas: demographic data, attitudes toward childbearing, and changes in sexual behavior.

RESULTS

Forty-six women chose to participate; 33 were white, 12 were Hispanic, and 1 was black. Their mean age was 35.4 years (range 23 to 43 years). An average of 1½ years had elapsed since the patients were tested for HIV. We determined the patients' risk factors for HIV: 31 (67%) abused intravenous drugs or had a partner who did, and 28% contracted HIV infection through heterosexual contact. Twenty-seven women had no symptoms, 19 had symptomatic HIV disease or AIDS, and 44 had Karnofsky performance scores higher than 90. Detailed demographic data are shown in Table 1. Of the 41 (89%) who were unemployed, 29 (71%) received some form of public assistance. Thirty-six women had a total of 102 children, whose ages ranged from 10 months to 19 years (mean 7.0 years). Single parenting was more common than was the presence of both parents in the family.

TABLE 4
CHANGES IN SEXUAL BEHAVIOR IN 46 WOMEN
INFECTED WITH THE HUMAN IMMUNODEFICIENCY VIRUS

	Yes (%)	No (%)	No answer or no partner (%)
Informed previous partner(s)	22 (48)	14 (30)	10 (22)
Informed current partner(s)	40 (87)	1 (2)	5 (11)
Intended to inform future partner(s)	39 (85)	1 (2)	6 (13)
Encouraged partner(s) to have HIV test	34 (74)	5 (11)	7 (15)
Has partner who is HIV-positive	38 (83)	7 (15)	1 (2)
Reasons cited by the 38 women who had changed their sexual behavior	No.	(%)	
To protect myself	27	(71)	
To protect my spouse or sexual partner	33	(87)	
To prevent unwanted pregnancy	7	(18)	
Not to harm others	27	(71)	
To stop the epidemic	21	(55)	
Will benefit from changes	13	(34)	
Decreased interest in sex	18	(47)	
Reasons cited by the 7 women who had not changed their sexual behavior	No.	(%)	
I do not like to use condoms	1	(14)	
I only have one sexual partner who is also HIV-positive	4	(57)	
I will have no more children	3	(43)	
My partner refuses to use condoms	2	(29)	

Only 32 (70%) of the women said they had received counseling after being notified that their blood had antibodies to HIV (Table 2). Patients who underwent testing in our medical center, in jail, in an outpatient drug treatment center, or in another health care center were more likely to receive counseling than were patients who obtained testing from their local physicians. Of those who said they had received counseling, 19 (59%) said the topic of pregnancy was discussed, 26 (81%) said they received information on the use of condoms to prevent transmission of disease and for contraception, 25 (78%) said they received information on the use of spermicidal agents, and 28 (88%) said they received information on avoiding exchange of body fluids during sexual intercourse.

Approximately half of the women believed that the chance of vertical transmission is 50% or less while the other half believed that the fetus would definitely be infected. Only three (7%) said they would want to have children if the chance of vertical transmission were 50%, and one said she would even if the chance were 100%. However, nine (20%) said they would carry a pregnancy to term if

they were to become pregnant. The women were not asked whether they would want to have children if the chance of transmission were 20% or 30%, which is the actual rate. Seven women became pregnant and carried their children to term after seroconversion, and only one of these children had antibodies to the HIV virus. Seven women had been pregnant and carried their children to term in the 18 months before they were tested. Ninety percent of the women with children had designated specific relatives to care for their children if and when they became unable to care for them themselves.

The numbers of women who said they wanted to have children, who said they always used condoms, and who said they used any form of birth control before and after learning they were seropositive are shown in Table 3. Twenty-six (57%) said they were sexually active at the time of evaluation and another 20% indicated that they planned to be. Only 8 (17%) wanted to have children at the time of the survey compared with 27 (59%) who said they had wanted to have children before they were tested. The number of women who said they always used condoms increased from 2 (4%) to 25 (54%), and an additional 13 (28%) of the women said they used condoms some of the time. Eighteen (39%) said they had practiced birth control before testing; 32 (70%) said they did since.

The majority of the women said they had informed their current sexual partners of their HIV seropositivity and intended to inform future partners. They seemed less inclined to inform previous partners. Thirty-eight (83%) noted changes in sexual behavior after learning of their seroconversion. Reasons cited for changes or lack of changes in sexual behavior are shown in Table 4. Protection of

partners and self was a stronger motivating force in changing sexual behavior than protection of unborn children.

DISCUSSION

The apparent lack of counseling after testing in 30% of the women was rather startling. When counseling was provided, the quality and content varied considerably. Not all women who said they were counseled remembered receiving information on contraception and the practice of safer sex. Holman and colleagues⁶ suggest that counseling of HIV-positive women after testing should include, at a minimum, a brief review of HIV infection and information on the meaning of HIV-positive status, modes of transmission, prevention of HIV transmission, avoidance or postponement of pregnancy, guidelines for safer sex, use of latex condoms and spermicide, partner notification, and "safer needle use" in appropriate settings.

As health care providers establish a relationship with their patients, counseling should become a continuous process to ensure persistence in safer sexual practices and proper contraception. Reproductive counseling, in particular, should address emerging issues such as new information about HIV disease and its impact on pregnancies and patients' changing social support systems.

Berman⁷ discussed five essential areas to be covered in reproductive counseling and emphasized that the process should preferably begin when the patient is not pregnant. These areas include "the impact of HIV infection on pregnancy, the impact of pregnancy on HIV disease, the effect of treatment of HIV disease on the patient and her fetus during pregnancy, the risk of HIV transmission from the patient to her fetus or newborn, and the course of perinatally acquired pediatric HIV infection." Poor-quality counseling or lack of counseling does not provide HIV-positive women with a sufficient knowledge base to arrive at reasonably sound reproductive decisions.

Does knowledge of positive HIV serostatus influence reproductive decisions? Barbacci et al⁸ and Sunderland et al⁹ reported that knowledge of HIV infection was not associated with pregnancy termination or prevention of subsequent pregnancy. Scott and colleagues¹⁰ reported that 16 seropositive mothers who already had infected children subsequently had other babies. Of these 16 women, 14

were black. Selwyn and colleagues¹¹ followed up 191 women who abused intravenous drugs and whose HIV status was known before pregnancy; 17 (24%) of 70 seropositive and 26 (22%) of 121 seronegative women became pregnant during a 24-month follow-up. There were significantly fewer white women in the seropositive group ($P < .001$, whites vs non-whites). Furthermore, comparing seropositive with seronegative women, the rates of elective abortion and repeated pregnancies were virtually identical.

Our study, however, showed that after learning of their seropositive status, only 17% of the women wanted to have children, compared with 59% who said they had wanted to have children before testing. The number of women who said they practiced contraception increased from 39% to 69% after testing. Fifty-seven percent of the respondents were sexually active at the time of evaluation and another 20% planned to be. Over the study period of 18 months, only one woman became pregnant, and she elected to have an abortion. The population studied here was predominantly white (72%) and therefore different from the groups studied by Scott,¹⁰ Selwyn,¹¹ and Barbacci⁸ and their colleagues, where non-whites predominated.

Most of our patients were single parents and received some form of public assistance. Ninety percent of the mothers had designated relatives to care for their children; these arrangements were verbally expressed except in one patient who had appointed her sister to be legal guardian to her children. Most women were aware that HIV infection is a terminal illness and some had lost friends and relatives to AIDS. An estimated 80 000 children and adolescents will be orphaned by maternal deaths caused by the HIV epidemic by the year 2000,^{12,13} and the vast majority will come from poor communities of color. Few programs address the needs of the uninfected siblings. Increasing attention should be focused on this group in addition to finding foster homes for the HIV-infected children. Planning for child custody should be a crucial part of reproductive counseling.

Sexual and contraceptive practices among these HIV-infected women changed toward greater protection of partners, self, and unborn children. However, the protection of partners and self was a stronger driving force in changing sexual behavior than the avoidance of pregnancy. Follow-up study on this cohort will be of interest to see if such changes are sustained over time.

RECOMMENDATIONS

Women with HIV infection should have ready access to preventive reproductive counseling. This counseling should provide a knowledge base to help them make informed reproductive decisions, identify and formulate a support system, and plan for child custody. Counseling should be an ongoing process as new knowledge of HIV disease becomes available and the social situations of the women counseled change.

Psychological assessment and support should also be made readily available. Women who are HIV-infected are often confronted with the emotional conflicts of desiring to bear children, yet risking transmitting a potentially fatal disease to their child. Undoubtedly, these women would seek guidance and emotional support from their health care providers, were it offered. However, many health care providers may find it difficult to put aside personal biases and opinions and try to understand the patient's views and decisions. Nevertheless, if reproductive counseling is to succeed, health care provid-

ers should refrain from making judgements.

Public health officials are faced with the ethical issues posed by the risk of transmission from parent to child and the seriousness of the illness when the child is infected. The greater the risk of transmission, the harder it is to morally justify the risk of exposing the child to unnecessary suffering. Moreover, arranging for continued parenting for such children and other uninfected children is a poignant ethical obligation for HIV-infected parents. Nonetheless, programs should be developed that promote disease prevention within an ethical framework that recognizes the patients' right to make informed decisions.

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REFERENCES

1. Guinan ME, Hardy A. Epidemiology of AIDS in women in the United States. *JAMA* 1987; 257:2039-2042.
2. Centers for Disease Control. US AIDS cases reported through March 1992. HIV/AIDS Surveillance Report. 1992 Apr;1-18.
3. Centers for Disease Control. The second 100 000 cases of acquired immunodeficiency syndrome—United States, June 1981-December 1991. *MMWR* 1992; 41:28-29.
4. Constance WB. Human immunodeficiency virus infection in women. *JAMA* 1987; 257:2074-2076.
5. Fairchild P, Jaffarian C, Cheeseman S, Bova C, et al. Impediments to IVDA enrollment in ACTG clinical trials. Programs and Abstracts of the Fifth International Conference on AIDS; June 4-9, 1989, Montreal, Quebec. Abstract WBP 240.
6. Holman S, Berthaud M, Sunderland A, et al. Women infected with human immunodeficiency virus: counseling and testing during pregnancy. *Semin Perinatol* 1989; 13:7-15.
7. Berman N. Family and reproductive issues: reproductive counseling. *AIDS Clinical Care* 1993; 5:45-47.
8. Barbacci M, Chaisson R, Anderson J, Horn J. Knowledge of HIV serostatus and pregnancy decisions. Programs and Abstracts of the Fifth International Conference on AIDS; June 4-9, 1989 Montreal, Quebec. Abstract No. MBP10.
9. Sunderland A, Moroso G, Holman S, Berthaud M, et al. Influence of HIV infection on pregnancy decisions. Programs and Abstracts of the Fifth International Conference on AIDS; June 4-9, 1989, Montreal, Quebec. Abstract No. WDP 58.
10. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with the acquired immunodeficiency syndrome. Evidence for both symptomatic and asymptomatic carriers. *JAMA* 1985; 253:363-366.
11. Selwyn PA, Schoenbaum EE, Davenport K, et al. Prospective study of human immunodeficiency virus infection and pregnancy outcome in intravenous drug users. *JAMA* 1989; 261:1289-1294.
12. Michaels D, Levin C. Estimates of the number of motherless youth orphaned by AIDS in the United States. *JAMA* 1992; 268:3456-3461.
13. Nicholas SW, Abrams EJ. The "silent" legacy of AIDS children who survive their parents and siblings. *JAMA* 1992; 268:3478-3479.



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