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# Sexual Practices and AIDS Knowledge Among Women Partners of HIV-Infected Hemophiliacs

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## Synopsis

*About 12 percent of the women sex partners of hemophilic men who are seropositive for the human immunodeficiency virus (HIV) have themselves become seropositive. Questionnaires were completed in January 1988 by 15 women who were in long-term, monogamous relationships with HIV-positive hemophiliacs; 11 of the women were not HIV seropositive and 4 were. None of the couples was abstaining from sexual intercourse, and during the 4 weeks prior to responding, the couples had intercourse a mean of 6.2 times. Sixty percent always used condoms, 13 percent did so most of the time, and the remaining 27 percent did sometimes. Condom use was not significantly related to either frequency of intercourse, the women's knowledge of acquired immunodeficiency syndrome (AIDS) and AIDS-risk reduction, the actual HIV status of both partners and the women's perceived status of both, the extent of the women's worry about contracting AIDS, their reported degree of negative impact from AIDS, or to their mood, age, or education.*

*All women who reported not always using condoms had been informed of their own and their partner's HIV status; were counseled repeatedly regarding risk reduction; acknowledged the possibility of heterosexual HIV transmission; said they knew of recommendations for the use of condoms; recognized their risk of HIV infection; claimed some degree of worry about acquiring HIV through sexual activity; had children at home; and were not, with one exception, trying to become pregnant. There were several possible factors influencing the decision by women at high risk for acquiring HIV not to use condoms. Among them were complaints that the women found condoms unpleasant or an unwanted reminder of AIDS, a sense of obligation or a drive to continue unaltered sexual relations, the false reassurance of HIV-negative test results for some of the women who did not always use condoms, a willingness to sacrifice and to share their partner's fate, a desire to avoid communicating rejection and adding to their partner's burdens, and difficulty changing long-standing behavior patterns despite logical understanding of the risks involved.*

THE FIRST REPORT of acquired immunodeficiency syndrome (AIDS) among hemophiliacs was published by the Centers for Disease Control (CDC) in July 1982 (*1*). Hemophiliacs were at particularly high risk for human immunodeficiency virus (HIV) infection and AIDS because of exposure through transfusions with contaminated blood products. That risk has been reduced sharply by improved donor screening and the use of improved methods for inactivating the AIDS virus in clotting factor concentrates, such as heat treatment (*2*).

Data from the period 1985–88 indicate that hemophiliacs accounted for only 1 percent of the total AIDS cases among men in the United States (*2*). Similarly, 1 percent of AIDS-related deaths from 1981–90 occurred among persons with hemophilia (*3*). However, the overall prevalence of HIV infection within this subgroup is substantial. Based on a survey of 6,857 hemophiliacs, 52 percent were HIV positive as of November 1989 (*4*). These figures do not reflect those hemophiliacs who had died from AIDS-related causes.

By 1984, HIV was isolated in the semen of AIDS patients (*5*), suggesting that sex partners of HIV-positive men were at risk for contracting the virus. Published research studies from 1985–89 (*6–14*) showed that 7.1 to 19.0 percent of women who were sex partners of HIV-positive hemophilic men were seropositive, with a mean across studies of 10.6 percent (105 of 994). Recent national data from hemophilia treatment centers (*15*) indicate that in 1989 12.7 percent of 1,652 tested partners of hemophiliacs were HIV infected; in 1990 11.6 percent of 1,981 tested partners were positive.

HIV can be transmitted from an infected woman to her fetus in utero or during birth. According to a National Hemophilia Foundation (*10*) and a CDC (*9*) survey, 280 of 2,276 sex partners of hemophiliacs (12 percent) were pregnant during 1985–87, and of those tested, 13 percent (22 of 170) were HIV positive. Of the tested infants born to HIV seropositive women, 69 percent (9 of 13) were HIV seropositive.

Proper use of latex condoms is recommended to reduce the possibility of an HIV-infected sex partner transmitting the virus to an uninfected partner (*16*). Condom use is advised when both partners are HIV positive to reduce the likelihood of transmission of other sexually transmitted diseases (STD) that could contribute to compromising the partner's immune system (*17*). Although heterosexual transmission of HIV can be reduced by discontinuing high-risk behaviors, including unprotected intercourse, safer sex guidelines are not adhered to by all at-risk persons, and seroconversion as a result of heterosexual exposure is increasing among women (*2*).

*'The partners of hemophiliacs in our study had a higher condom use rate than other sexually active nonhemophilic groups at risk for the heterosexual transmission of HIV. . .'*

Despite extensive safer sex education efforts by the National Hemophilia Foundation and comprehensive care hemophilia centers, surveys published by hemophilia centers in 1988 showed that the proportion of sexually active hemophiliacs (HIV positive, negative, and untested) who practiced regular use of condoms was fewer than one-half, by one report (*10*), and fewer than one-third, by another (*18*). Similarly, Overby and coworkers (*19*) found that only one of the eight (12.5 percent) sexually active hemophilic adolescents responding to their survey always used condoms, and the remainder did sometimes. A survey of 935 hemophiliacs in the Netherlands revealed that 9 percent used condoms (*20*). However, within studies, condom use by HIV-positive hemophiliacs was higher than that for untested or seronegative hemophiliacs (*20–22*).

Research studies published or presented in the period 1988–90 concerning condom use by HIV-positive hemophilic adults and their sex partners in the United States showed varying results. Lawrence and coworkers (*11*) found that condoms were used in about 25 percent of sexual encounters and that only 18 percent (7 of 38) of their sample nearly always used condoms, with the remainder using condoms sometimes or never. Ragni and coworkers (*14*) reported that 40 percent (8 of 20) of their subjects used condoms all of the time. In a study by Smiley and coworkers (*12*), 50 percent (9 of 18) of participants reported no condom use and the remainder reported regular use. Parish and colleagues (*22*) surveyed 351 hemophiliacs and found that 68 percent of those who were sexually active and HIV positive reported using condoms all of the time. Similarly, 66 percent of 321 HIV-positive hemophiliacs engaging in intercourse claimed to use condoms always, as did 64 percent of 250 partners of seropositive hemophiliacs, according to another survey (*21*).

We studied a small group of women who were

the sex partners of male HIV-positive hemophiliacs. We investigated their frequency of sexual intercourse, the extent of their use of condoms, and their reasons for not using condoms. We analyzed the interrelationships and effects of such variables as

- the couple's frequency of condom use,
- the couple's frequency of sexual intercourse,
- the actual HIV serostatus of both partners,
- the woman's perception of the status of both partners,
- the woman's knowledge of AIDS and HIV infection risk-reduction practices,
- the extent of her worry in general about the possibility of getting AIDS,
- the extent of her worry about HIV infection through heterosexual transmission from her partner,
- her perception of the negative impact of AIDS on various aspects of the couple's lives, and
- her mood, age, education, and parenthood.

## Methods

**Subjects.** Fifteen women participated who were involved in long-term, monogamous relationships with HIV-positive hemophilic men. According to blood tests conducted 5 months before the study, 11 of the women were HIV negative and 4 were positive. All of the women had been told of their own and their partner's HIV status. All participants were white. They ranged in age from 20 to 53 years, with a mean of 34.4 years. Eleven of the women were employed. All but two were married, and they married their partners after the data were collected. The mean education level of the group was 12th grade, with a range of grade school through college. All of the women and their partners received psychosocial services (*23*) from the Hemophilia Center of Central Pennsylvania.

The sample was taken from a group of partners of HIV-positive hemophiliacs participating in a study at the center in collaboration with the National Cancer Institute to investigate HIV transmission among household members. Eighteen women met the criteria of living with a hemophilic partner at the time of data collection and having been informed of her and her partner's HIV status. One eligible subject was not included because her partner's illness precluded usual activities of daily living, and her partner died a week after the study began. Sexual activity with the partner was not required for inclusion, although none of the participants who qualified for the study was abstaining. All eligible women approached agreed to participate. Three of the 18 women were excluded because of time constraints during their partners' clinic appointments, leaving 15 participants.

Information on AIDS and HIV infection risk-reduction counseling, including the need to use condoms by those engaging in intercourse, had been provided each of the 15 participants as part of the original household HIV transmission study begun in 1984. Counseling was provided by the center's hematologists, nurse coordinator, or social workers, in a mean of 8.2 sessions per subject (range of 5 to 10). Safer sex counseling was provided whenever applicable during the hemophilic patients' routine 6-month-interval clinic visits, during hospital visits for medical care, and other visits or calls, which averaged at least one per month. Counseling at the center was based on the recommendations of the Public Health Service's Surgeon General, CDC, and the National Hemophilia Foundation, and emphasized maintaining as normal a sexual relationship as possible while taking protective measures. One-third of the subjects were in an HIV education-support group at the center at the time of the study.

**Materials.** In January 1988, participants completed a questionnaire consisting of a modification of the Hemophilia and AIDS Risk Reduction Survey: Partner Form (HARRS) (*24*) and the Profile of Mood States (POMS) (*25*). HARRS is a test of the participant's knowledge of AIDS and AIDS risk-reduction practices; the participant's feelings, thoughts, and reactions about AIDS, rated according to the degree to which they apply; the participant's HIV status and that of her partner; their sexual practices; their reasons for not using condoms; and demographic data. HARRS was modified to include an addendum focusing on the extent to which the AIDS threat had negatively affected various aspects of the participant's life, rated on a 5-point scale from "no effect" to "extreme." The AIDS knowledge portion of HARRS was revised to convert all questions to a true-false format. Questions were eliminated that were believed by the four hematologists at the center to be possibly confusing or if they disagreed on the correct answer.

POMS yields a Total Mood Disturbance (TMD) score and six factor scores (tension-anxiety, depression-dejection, anger-hostility, vigor, fatigue, and confusion-bewilderment). These are based on a respondent's 5-point ratings ("not at all" to "extremely") of the degree to which 65 terms apply,

such as tense, unhappy, angry, energetic, and forgetful.

We continue to follow the study participants and interview them at 6-month intervals regarding condom use. Followup data from 1991 were compared with the original 1988 survey data.

**Data analyses.** Subgroup comparisons were performed using independent *t*-tests, correcting for the number of comparisons made using the Dunn table. For categorical data, Fisher's exact probability estimate was applied to ascertain the significance of differences between cell frequencies. Pearson correlation coefficients were calculated to investigate interrelationships among study variables. When two variables were significantly related to each other and to another common variable, partial correlations were used to control for the possible confounding effects of the third variable. The sign (binomial) test was used to explore the pattern of scores across the POMS subscales. All tests of significance were two-tailed. To determine if HIV status influenced the findings, all data analyses were repeated, excluding data on the four HIV-positive women. Unless otherwise specified, changes in the pattern or significance of findings were not seen. Data were complete with the exception that two participants failed to indicate frequency of intercourse. Results need to be interpreted cautiously in view of the small sample size.

## Results

**Condom use related to frequency of intercourse and knowledge of AIDS.** None of the 15 partners of HIV-infected hemophiliacs was abstaining from sexual intercourse. According to the responses, 60.0 percent always used condoms, 13.3 percent did so most of the time, 26.7 percent did sometimes, and none never used condoms. During the 4 weeks preceding the survey, condoms were used an average of 70.1 percent of the times the partners had intercourse (range none to 100 percent). Frequency of sexual intercourse during the prior 4 weeks ranged from 2 to 20 times (mean of 6.2) and was not significantly related to condom use ($r = 0.18$, $P = 0.556$).

Scores on the AIDS and risk reduction knowledge test were relatively high (mean of 88.0 percent correct, range 76.5 to 100 percent) and were not significantly associated with condom use in general ($r = 0.11$, $P = 0.690$) or use during the preceding 4 weeks ($r = -0.09$, $P = 0.744$). Agreement with the statement "I am satisfied that I am taking all necessary precautions against AIDS infection when we have sex" increased with increases in the frequency of condom use in general ($r = 0.60$, $P = 0.018$) and use during the prior 4 weeks ($r = 0.62$, $P = 0.014$). The questions and the correct answers for the AIDS knowledge test are shown in the accompanying box.

**Condom use related to HIV status.** All participants reported that they believed that there was a chance that they or their partners had HIV infection. However, some understated their or their partner's actual HIV status, even though both had received the information. Three of the four HIV-positive women (75.0 percent) were "certain" they were HIV infected, whereas the other thought her chance of seropositivity was "50–50." None of the 11 HIV-negative women ranked her likelihood of infection as "certain," which differed significantly from the HIV-positive women (Fisher's $P = 0.009$). Seven HIV-negative participants rated their chances of infection as "fairly low," three as "50–50," and one as "fairly high." Nine of the women (60.0 percent) felt "certain" their partner was HIV positive, whereas two rated the likelihood of their partner's infection as "fairly high" and four as "50-50."

Nonsignificant relationships were found between condom use during the past 4 weeks and each subject's perception of her own HIV status ($r = -0.21$, $P = 0.464$) and that of her partner ($r = -0.09$, $P = 0.752$). Subjects who always used condoms and those who sometimes did not both reported a mean of a "50-50" chance of HIV positivity in themselves and a "fairly high" to "certain" likelihood for their partners. Of the 11 HIV-negative women, 54.5 percent reported using condoms 100 percent of the time, and 75.0 percent of the four positive women (Fisher's $P = 0.604$) reported so doing.

**Condom use related to worry about becoming infected.** Overall condom use was not significantly related to the extent of general worry about acquiring HIV ($r = -0.44$, $P = 0.098$). The four who worried "rarely" about acquiring AIDS reported a condom use rate of 100 percent during the previous 4 weeks. The 11 subjects who said they worried "occasionally" reported a condom use rate of 59.2 percent ($t = 2.87$, $P = 0.017$, Dunn $> 0.05$). The correlation between worry about acquiring AIDS heterosexually and condom use during the preceding 4 weeks was -0.08 ($P = 0.782$). The correlation between worry about acquiring AIDS heterosexu-

**Questions, Correct Answers, and Percent of Incorrect Responses to the AIDS Knowledge Test[1], by 15 Women Who Were Sex Partners of HIV-Infected Hemophiliacs, 1988**

1. The AIDS virus can be spread through drinking water systems. (F) None
2. The AIDS virus can be spread by sexual activity between a man and a woman. (T) None
3. There is no known case where AIDS was spread by sneezing. (T) None
4. AIDS is a disease that has been found to affect only men. (F) None
5. More people carry the HIV virus than get sick. (T) 20 percent
6. People are contagious if they have the HIV virus even if they have no symptoms. (T) 27 percent
7. AIDS may be spread from an infected woman to her newborn child. (T) None
8. It is possible to spread AIDS by normal household contact such as hugging and using the same dishes and silver. (F) None
9. Safer sex practices are recommended to reduce the risk of transmitting the AIDS virus. (T) None
10. Avoiding any contact with an infected person is recommended to reduce the risk of transmitting the AIDS virus. (F) 40 percent
11. Recommended safer sex practices include use of condoms for oral, anal, or vaginal intercourse. (T) 7 percent
12. Recommended safer sex practices include reducing the number of sexual partners. (T) None
13. A positive result on an HIV blood test means one has been infected but will not definitely get AIDS. (T) 17 percent
14. The National Hemophilia Foundation recommends that hemophilia patients assume they have been exposed to the AIDS virus. (T) 57 percent
15. It is estimated that 90 percent of persons with severe hemophilia have been exposed to the AIDS virus. (T) 37 percent
16. Safe disposal and handling of infusion equipment includes placing it in containers before discarding. (T) None
17. There is no way to disinfect the AIDS virus on infusion equipment. (F) None

[1] Reference *24*.

ally and condom use in general was $-0.06$ ($P = 0.822$). The nine women who did and the six who did not always use condoms worried, on the average, "occasionally" about developing AIDS as a result of sexual activity, with a range of "rarely" to "frequently."

**Condom use related to the impact of AIDS.** The extent to which AIDS had negatively affected various aspects of respondents' lives ranged from "no effect" to "a lot," with a mean of "somewhat." Coefficient absolute values (independent of the signs) were low (0.00 to 0.18) and nonsignificant ($P = 1.00$–$0.512$) when overall condom use was correlated with degree of negative AIDS impact on the respondent's life in general, psychological well-being, and personal enjoyment of life.

**Condom use related to mood, age, education, and parenthood.** Correlations were nonsignificant between the POMS TMD score and condom use in general ($r = 0.29$, $P = 0.290$) and condom use during the past 4 weeks ($r = 0.30$, $P = 0.274$). Similarly, none of the six POMS subscale scores correlated significantly with condom use, with coefficient absolute values ranging from 0.01 ($P = 0.962$) to 0.42 ($P = 0.114$). The correlation between age and condom use during the preceding 4 weeks was $-0.02$ ($P = 0.944$), and the correlation between age and condom use in general was $-0.01$ ($P = 0.978$).

The corresponding correlations for condom use and educational attainment were 0.22 ($P = 0.442$) and 0.33 ($P = 0.232$). In contrast to these nonsignificant findings, all of the six couples not using condoms all of the time had children living at home. Of the nine couples who always used condoms, a third had children at home (Fisher's $P = 0.028$). Only 1 of the 15 participants reported at the time of the survey that she was trying to become pregnant.

**Reasons for not using condoms.** Of the six women not always using condoms, one declined to provide the reasons for not using them, three said that condoms interfered with mutual sexual pleasure, and two indicated that condoms interfered with the man's pleasure, but did not indicate the same for the woman. One of these women said that her husband refused, against her wishes, to use condoms and instead relied on withdrawal, although they had previously been informed this was not a safer sex option. Two women provided additional rea-

sons for not using condoms. Both claimed condom use was an unwanted reminder of AIDS, and one believed she was at minimal risk for acquiring HIV.

**Frequency of intercourse related to other variables.** Frequency of sexual intercourse during the 4 weeks before the survey did not correlate significantly with any of the study variables, including AIDS knowledge ($r = -0.02$, $P = 0.950$), the woman's estimation of her chances of being HIV infected ($r = 0.02$, $P = 0.946$), her perception of her partner's likelihood of seropositivity ($r = 0.45$, $P = 0.120$), worry about acquiring AIDS in general ($r = 0.03$, $P = 0.932$), worry about contracting HIV infection heterosexually ($r = 0.25$, $P = 0.412$), overall perceived negative impact of AIDS ($r = 0.07$, $P = 0.824$), POMS subscale and TMD score ($r = 0.03$, $P = 0.934$), and education ($r = -0.09$, $P = 0.780$). Although there was a tendency for frequency of intercourse to decrease with increasing age in the sample of 20- to 53-year-old partners of hemophiliacs, the relationship was nonsignificant ($r = -0.46$, $P = 0.114$). Frequency of intercourse was similar for the 11 HIV-negative and 4 HIV-positive women, with respective mean frequencies of 6.1 and 7.0 during the prior 4 weeks.

**AIDS knowledge related to other variables.** Performance on the AIDS knowledge test did not differ significantly between the group of 11 women who tested HIV negative prior to the study (mean 88.8 percent correct test score) and the 4 who tested positive (mean 86.0 percent) ($t = 0.48$, $P = 0.641$). Further, a question-by-question analysis of the AIDS knowledge test did not reveal differences between HIV-positive and negative respondents. Knowledge test scores were not significantly related to respondents' perceptions of whether they were infected ($r = -0.40$, $P = 0.136$), perception of their partner's serostatus ($r = 0.08$, $P = 0.776$), worry in general about acquiring AIDS ($r = 0.15$, $P = 0.604$), worry about contracting HIV infection heterosexually ($r = -0.15$, $P = 0.582$), POMS TMD score ($r = 0.40$, $P = 0.140$), education ($r = 0.35$, $P = 0.202$), and age ($r = -0.15$, $P = 0.600$). Although the perceived AIDS effect was not significantly related to AIDS knowledge for the total group ($r = 0.44$, $P = 0.102$), an increase in knowledge was significantly associated with more negative perceptions of the AIDS impact for the 11 HIV-negative respondents ($r = 0.85$, $P = 0.002$). This significant relationship was maintained when the analysis was repeated controlling for age (partial $r = 0.73$, $P = 0.018$).

**HIV serostatus related to AIDS worry and AIDS impact.** No significant differences in frequencies were found between subjects grouped according to the woman's estimate of her own and her partner's HIV serostatus and her degree of worry about acquiring AIDS in general or becoming HIV-infected through sexual activity (Fisher's $P \geq 0.103$). The actual HIV status of the women was not related to AIDS worry. Both HIV-positive and HIV-negative respondents worried from "rarely" to "occasionally" about AIDS in general. All 4 of the HIV-positive and 8 of the 11 HIV-negative women worried at least occasionally about the possibility of contracting the AIDS virus through sexual activity (Fisher's $P = 0.516$). The overall degree of negative AIDS impact reported did not differ significantly between women dichotomized according to their perceived chance of HIV infection in themselves ($t = 0.41$, $P = 0.688$) and in their partner ($t = 2.69$, $P = 0.019$, Dunn $> 0.05$). The mean of reported degrees of overall negative AIDS impact on their lives was "somewhat" among both the HIV-negative and HIV-positive women.

**HIV status related to mood, education, and age.** Variations in mood (as measured by the POMS subscales) were not significantly related to the woman's estimation of her likelihood of infection or that of her partner. Similarly, the correlation between the POMS TMD score and each woman's perceived chance of HIV positivity in herself was -0.48 ($P = 0.074$), and the correlation between TMD and her perception of the chance of HIV infection in her partner was -0.25 ($P = 0.374$). The four HIV-positive women scored more favorably, but not significantly so, than the 11 HIV-negative women on five of the six POMS subscales (sign test $P = 0.218$). The HIV-positive women earned a mean TMD score of 13.8 (SD 8.4), compared to a somewhat less favorable score of 31.1 (SD 21.2) for the HIV-negative women ($t = 1.56$, $P = 0.143$).

Education beyond high school was not significantly related to the respondents' actual HIV status or perceived chance of HIV seropositivity of herself or her partner (Fisher's $P \geq 0.560$). No significant age differences were found between the HIV-positive and HIV-negative women ($t = 0.19$, $P = 0.851$), or between respondents grouped according to their perceived chance of HIV infection ($t = 0.08$, $P = 0.934$). However, the nine respondents who felt "certain" of their partner's HIV-

seropositive status were significantly younger (a mean age of 28.2 years) than the six respondents who rated their partner's chance of positivity as "50–50" to "fairly high" (a mean age of 43.7 years) ($t = 3.97$, $P = 0.002$, Dunn $< 0.05$).

**AIDS worry, AIDS impact, mood, age, and education.** Respondents grouped according to worry about acquiring AIDS in general and heterosexually did not differ significantly in terms of perceived negative AIDS impact ($t = 1.24$, $P = 0.237$ and $t = 1.07$, $P = 0.304$), POMS TMD score ($t = 0.25$, $P = 0.806$ and $t = 0.60$, $P = 0.562$), age ($t = 0.90$, $P = 0.385$ and $t = 2.70$, $P = 0.018$, Dunn $> .05$), and education (Fisher's $P = 0.560$ and 1.000). The TMD score was not significantly associated with age ($r = 0.07$, $P = 0.798$), education ($r = -0.06$, $P = 0.830$), and perceived AIDS impact ($r = 0.29$, $P = 0.302$). The five respondents with educations beyond high school did not report a greater negative AIDS effect than the 10 who completed high school or had less education ($t = 0.40$, $P = 0.699$). However, younger women claimed to have experienced a significantly greater negative AIDS impact than older women ($r = -0.68$, $P = 0.006$).

**Condom use in 1991.** Reassessment at 6-month intervals from 1988 through February 1991 indicated a nonsignificant mean change in condom use. Eleven of the 15 participants were still engaging in sexual intercourse with their hemophilic partner 2.5 to 3 years after the initial study. On a 4-point scale of condom use from "never" to "always," five maintained their 1988 level of condom use, three increased condom use by an average of 1 scale point, and three decreased condom use by a mean of 1 point. Of the remaining four subjects, one was divorced from her hemophilic partner, the partner of another died from AIDS-related disease, one developed AIDS herself and was seriously sick, and the other engaged primarily in fondling because of the declining health of her spouse and as a safer sex option.

## Discussion

In spite of the number and scope of variables analyzed, few significant interrelationships were found. Younger women were more certain that their partner was seropositive and they perceived a greater negative AIDS effect than did older women. Perhaps the older the participant, the less likely she is to change her thinking, alter her perceptions, or be affected by AIDS, owing to her age and the length of her relationship with her partner. In the subgroup of HIV-negative women, subjects who reported the most negative AIDS impact earned higher AIDS knowledge test scores, independent of age. This can be interpreted in at least two ways: those with the most knowledge had more reason for concern, and those most affected negatively by the threat of AIDS had a high AIDS interest level and a strong motivation to learn about AIDS.

Although sexual activity was not a criterion for participation in the study, all of the partners of HIV-positive hemophiliacs were continuing to engage in sexual intercourse in 1988. During the 4 weeks prior to the study, the women had intercourse with their partners a mean of 6.2 times. These findings are consistent with a previously published study (*11*) of female heterosexual partners of HIV-positive hemophiliacs that indicated a mean frequency of intercourse of 8 times per month and abstinence from intercourse by 1 of the 56 subjects (1.8 percent). In contrast, a 1990 national survey (*21*) of HIV-positive hemophiliacs 16 years of age and older and partners of hemophiliacs, married or unmarried, showed that 36 percent of 464 hemophiliacs and 12 percent of 279 partners did not have sexual intercourse during the preceding 12 months.

There are many possible reasons for the difference in the frequency of sexual intercourse between the general population of seropositive hemophiliacs and their partners and our sample. Some sexually inactive hemophiliacs in the general population may abstain for safer sex reasons. Others may not yet be sexually active. Still others may not be involved in a relationship, may lack the opportunity to engage in sexual activity, may not desire heterosexual relations, or may have HIV-related or other problems interfering with the drive or ability to have intercourse.

By report, 60.0 percent of the women in our study used condoms every time they had intercourse, 13.3 percent did so most of the time, 26.7 percent did sometimes, and none never used condoms. Overall, condoms were used 70.1 percent of the times the women had intercourse during the 4 weeks preceding the 1988 survey. These results are similar to those of a 1990 national hemophilia survey (*21*). Of 321 HIV-positive hemophiliacs engaging in intercourse, 66 percent always used condoms, 12 percent did so most of the time, 9 percent did some of the time, 5 percent rarely used condoms, and 7 percent never used condoms. The

corresponding percentages for 250 partners of HIV-positive hemophiliacs were 64 percent (always), 12 percent (most), 8 percent (some), 6 percent (rarely), and 9 percent (never). These findings are consistent with a 1988 survey (*22*) showing that 68 percent of HIV-positive hemophiliacs in California reported using condoms with all intercourse. However, earlier studies of HIV-infected hemophiliacs published in 1988 and 1989 reported considerably lower levels of condom use by sexually active, HIV-positive hemophiliacs (*11, 12, 14*), with only 18 to 50 percent regularly, nearly always, or always using condoms. The differences in findings may reflect regional attitudes, sample selection, biased reporting, variations in safer sex counseling from one hemophilia treatment center to another, or an improving trend over time.

The partners of hemophiliacs in our study had a higher condom use rate than other sexually active nonhemophilic groups at risk for the heterosexual transmission of HIV, including adolescents (*26–28*), undergraduate students (*29, 30–32*), and heterosexual patients at STD clinics (*33, 34*). Greater condom use by partners of HIV-positive hemophiliacs, in comparison to other at-risk groups, may be because of the known HIV-positive status of the hemophilic partner and the extensive safer sex counseling provided to hemophiliacs and their partners through comprehensive care centers.

Followup data on our subjects indicated no increase in overall condom use for the 11 participants who still engaged in intercourse 2.5 to 3 years after the initial 1988 survey. The only difference was that one subject no longer had vaginal intercourse because of both her spouse's declining health and for reasons of safer sex. Of the remaining three women, one was divorced, one had AIDS and was seriously sick, and one was widowed when her spouse died of AIDS-related illness.

In our 1988 survey, condom use was not significantly related to the majority of study variables, consistent with other research findings. The nonsignificant relationship between condom use and knowledge about AIDS and HIV infection risk reduction found in our study had been previously reported for sexually active undergraduate students (*30*), randomly selected single adults (*35*), women at a contraception clinic (*36*), and heterosexual adults at STD clinics (*33, 34*). Studies have shown high mean levels of AIDS knowledge and low levels of condom use in sexually active singles (*19, 30, 32, 33, 36*). In two studies, adolescents agreed about the importance and value of using condoms, but the percentages of subjects always using condoms were approximately 4 percent (*26*) and 12.5 percent (*19*).

Apparently, knowledge about AIDS and HIV infection risk reduction may be necessary but not sufficient to insure adequate levels of condom use. The absence of a significant relationship between condom use and AIDS knowledge may be a consequence of high knowledge levels in the general public, thus creating a truncated range. The vast majority of those at risk for acquiring HIV through heterosexual activity now may be relatively well informed regarding AIDS and recommendations for condom use. Publications overwhelmingly indicate good knowledge performance by study participants (*19, 30, 32, 33, 36–38*). Thus, for already informed at-risk persons, variables other than AIDS knowledge are likely to influence whether or not condoms are used.

As in this study, perceived risk of HIV infection was not significantly related to condom use in samples of undergraduate students (*30*) and STD clinic patients (*34*). However, a significant association between condom use and personal worry or concern about AIDS was reported in two studies of single adults (*30, 35*). Consistent with our study is the reported absence of a significant relationship between condom use and demographic data among attendees at contraception clinics (*36*) and STD clinics (*34*).

In a study of undergraduate students (*30*), it was supposed that condom use was infrequent because few, if any, of the subjects actually had witnessed effects of the AIDS epidemic. However, in this study of partners of HIV-positive hemophiliacs, relatives, friends, and acquaintances of the participants have suffered and died from AIDS. In spite of this, 40 percent of the subjects did not always use condoms. Furthermore, CDC (*34*) found a nonsignificant difference between condom use by STD clinic patients who knew someone with AIDS and those who did not.

Lack of knowledge, denial of risk, or absence of worry does not explain why some women partners of HIV-infected hemophiliacs in our study did not always use condoms. All women were informed of their own and their partner's HIV status, were repeatedly counseled regarding risk reduction, and acknowledged that HIV can be transmitted by sexual intercourse and that condoms are advised to diminish this risk. Further, as degree of condom use increased, agreement with the statement, "I am satisfied that I am taking all necessary precautions against AIDS infection when we have sex" also increased. All partners of hemophiliacs reported at

least some chance of HIV positivity in their partners and themselves. Thus, partners who did not use condoms all of the time did not totally deny their risk of HIV infection. Failure to always use condoms was not because some partners were already HIV positive and believed that further exposure did not matter, because more seropositive partners than negative partners used condoms all of the time. Finally, all partners of hemophiliacs admitted to some degree of worry (a mean of "occasionally") about acquiring AIDS as a result of sexual activity, with a nonsignificant difference between those who did and did not always use condoms.

The presence of children in the home did not serve to promote condom use by HIV-positive hemophiliacs and their partners. One might expect that the nine couples with dependent children at home would be less likely than the five childless couples and the one with grown children living away from home to risk the mother's exposure to HIV infection and the possibility of both parents dying. However, the opposite was found. All couples not using condoms 100 percent of the time had children at home, whereas only 33.3 percent of the couples always using condoms had children at home. The results depict what would be anticipated in the absence of extenuating circumstances, like AIDS: couples who did not use condoms were more likely to have children than couples who used condoms. Lastly, only one of the participants said she was trying to get pregnant at the time of the survey. Thus, this does not explain why more couples were not consistently using condoms.

The identification of determinants of condom use has been problematic, and studies for the most part have delineated noncontributing factors. However, some variables influencing the choice not to use condoms are evident. All partners of hemophiliacs who explained why they did not always use condoms indicated that condoms interfered with pleasure. Several other studies have revealed respondents' dislike of condoms, with complaints that condoms reduced feeling and were unpleasant, uncomfortable, inconvenient, and not romantic (*32-34*). Valdiserri and coworkers (*36*) found that attitudes about condoms were significant predictors of condom use. Like seat belts, condoms can serve a potentially life-saving function, but many people dislike and choose not to use them. In fact, seat belt and condom use were significantly correlated with each other in a study of college students (*30*).

Perhaps a universal human biological reproductive drive leads to unprotected sexual intercourse. One might speculate that sexual relations are too important for HIV-positive hemophiliacs and their partners to modify or detract from in any way and that the need to maintain an intimate relationship is more important than avoiding the risk of HIV infection. The women may feel it is their obligation, marital or otherwise, to have unaltered sexual relations with their partner. In fact, of the five women who indicated that condoms interfered with pleasure, three said they interfered with pleasure for both the man and woman, and two said they interfered with pleasure for the man only. One of these said that her husband refused to use condoms, contrary to her wishes. Further, even though 40 percent of the women in the study agreed that "sexual experiences have not been as satisfying since we learned of the threat of AIDS," they continued to engage in intercourse at a frequency similar to that for a local contrast group of nonhemophilic married adults, who participated in another research study by the authors.

A woman partner of an HIV-positive hemophiliac may be reluctant to request that her partner use condoms because she wishes to avoid communicating rejection, adding to the AIDS-related burdens of the partner, or reminding him and herself of her partner's HIV status. Feelings of sympathy and empathy may be so intense that the women are willing to share their partner's fate. For them, having unprotected intercourse may be the ultimate sacrifice and expression of support. Some female partners of hemophiliacs have expressed such thoughts to members of our psychosocial team, including the perception that condoms are an unwanted reminder of AIDS and a lack of caring about what happens to self, given the partner's HIV status.

Several truisms may be applicable in understanding why some of those studied did not always use condoms. People may risk "future pain" for "present gain," and long-standing and pleasurable behavioral patterns are difficult to change. For example, persons with cardiac disease sometimes continue to smoke cigarettes, and patients medically compromised by obesity sometimes persist in overeating. Logic may have little influence on human behavior, and physiological and emotional states may override rational thought. Thus, people may be aware of risks and protective measures, yet not act cautiously.

The finding that 75.0 percent of the 4 HIV-positive women always used condoms, as opposed to 54.5 percent of the 11 HIV-negative women, may suggest that the HIV-negative status of those

not using condoms all of the time was falsely reassuring. Some women have shared this belief with our staff, stating they have remained negative in spite of noncompliance with condom use and thus, do not feel compelled to alter their behavior. In contrast, the HIV-positive women who are confronted with their actual seroconversion may be more likely after the fact to do as initially instructed, similar to the person who stops smoking after lung cancer is diagnosed.

There is a need for further research to investigate relationship variables and other factors that determine whether or not at-risk persons use condoms and for the development of intervention guidelines that will assist realistic efforts to promote condom use and other safer sex practices.

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# Estimating the Prevalence of Chronic Fatigue Syndrome and Associated Symptoms in the Community

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## Synopsis

*Chronic fatigue syndrome is a poorly understood disease characterized by debilitating fatigue and neuromuscular and neuropsychological symptoms. Despite numerous studies on the subject, the epidemiology of the syndrome in the community remains largely unexplored. An estimate of the prevalence in the population is presented, approximating the Centers for Disease Control criteria as well as the prevalence estimates of the fatigue symptom complex that include fatigue, disability, and neuromuscular and neuropsychological symptoms.*

*The study population consisted of a very large, multicenter, stratified, and random sample of a general population health survey known as the Epidemiologic Catchment Area Program. Data used for this study were gathered between 1981 and 1984. The Diagnostic Interview Schedule, a highly structured mental health interview, was used to assess the lifetime prevalence of medical and psychological symptoms.*

*Chronic fatigue was common. A total of 23 percent of the subjects reported having experienced the symptom of persistent fatigue sometime during their lives. Chronic fatigue syndrome, however, as defined by the Centers for Disease Control, appeared to be quite rare in the general population. Only 1 of 13,538 people examined was found to meet a diagnosis of the syndrome with an approximation of the CDC criteria. Fatigue symptom complex was frequently related to medical or psychiatric illness or substance abuse; thus, persons meeting partial criteria of chronic fatigue syndrome were also found to be rare when psychiatric or medical exclusions were applied.*

SINCE THE PUBLICATION of two reports in 1985 that first connected a clinical syndrome of chronic fatigue with unusual serologic responses to Epstein-Barr virus antigens (*1,2*), the chronic fatigue syndrome (CFS) has captured the attention of the media, the public, and also of the medical and scientific communities (*3-5*).

Despite this recent attention, the syndrome of