ARTICLES

# Fertility Desires and Intentions of HIV-Positive Men and Women

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**Context:** *HIV-positive men and women may have fertility desires and may intend to have children. The extent of these desires and intentions and how they may vary by individuals' social and demographic characteristics and health factors is not well understood.*

**Methods:** *Interviews were conducted from September through December 1998 with 1,421 HIV-infected adults who were part of the HIV Cost and Services Utilization Study, a nationally representative probability sample of 2,864 HIV-infected adults who were receiving medical care within the contiguous United States in early 1996.*

**Results:** *Overall, 28–29% of HIV-infected men and women receiving medical care in the United States desire children in the future. Among those desiring children, 69% of women and 59% of men actually expect to have one or more children in the future. The proportion of HIV-infected women desiring a child in the future is somewhat lower than the overall proportion of U.S. women who desire a child. The fertility desires of HIV-infected individuals do not always agree with those of their partners: As many as 20% of HIV-positive men who desire children have a partner who does not. Generally, HIV-positive individuals who desire children are younger, have fewer children and report higher ratings of their physical functioning or overall health than their counterparts who do not desire children, yet desire for future childbearing is not related to measures of HIV progression. HIV-positive individuals who expect children are generally younger and less likely to be married than those who do not. Multivariate analyses indicate that black HIV-positive individuals are more likely to expect children in the future than are others. While HIV-positive women who already have children are significantly less likely than others both to desire and to expect more births, partner's HIV status has mixed effects: Women whose partner's HIV status is known are significantly less likely to desire children but are significantly more likely to expect children in the future than are women whose partner's HIV status is unknown. Moreover, personal health status significantly affects women's desire for children in the future but not men's, while health status more strongly influences men's expectations to have children.*

**Conclusions:** *The fact that many HIV-infected adults desire and expect to have children has important implications for the prevention of vertical and heterosexual transmission of HIV, the need for counseling to facilitate informed decision-making about childbearing and childrearing, and the future demand for social services for children born to infected parents.*

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Fertility issues for HIV-positive men and women are becoming increasingly important. Advances in treatment, such as zidovudine and other antiretroviral drugs, have decreased transmission from infected mothers to their children to about 2%.[1] Furthermore, as effective therapies have improved the prognosis for women and men who get infected with HIV, these individuals are more frequently considering childbearing and parenthood.[2] To address these issues, we examine here the fertility desires and intentions of HIV-infected men and women using a nationally representative sample of HIV-infected adults in treatment.

Despite the growing importance of fertility issues for HIV-infected men and women, little is known about their actual fertility desires and intentions. Among the few studies in the United States, the prevalence of pregnancy after diagnosis in convenience samples of infected women ranges from 18% to 40%.[3] A recently published study using the nationally representative HIV Cost and Services Utilization Study (HCSUS) sample found that 12% of all women and 26% of women younger than 30 had children after HIV diagnosis.[4] However, that study did not address whether the pregnancies were intentional, nor did it include information about the desires and intentions of HIV-infected men and women to have children in the future. Given the dramatic recent advances in treatment, fertility desires and intentions in late 1998 are likely to foreshadow future fertility behavior more closely than the fertility histories of HIV-infected adults as of 1996 and early 1997, when highly active antiretroviral therapy had only recently become widely available.

Although this research indicates that some women have children even after HIV diagnosis, very little is known about their desires to have children, and to our knowledge there have been no studies of HIV-positive men's desire to have chil-

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dren. The majority of studies have examined childbearing and women's choice to continue a pregnancy. They provide only limited information about fertility desires and intentions, however, because they exclude women who are not pregnant and include some women who got pregnant unintentionally.[5]

Choices to continue pregnancy are also confounded by feelings about abortion. Studying fertility desires and intentions directly is essential to focus on the subset of HIV-infected men and women who are most likely to become pregnant by choice. This is an important subpopulation whose counseling and service needs differ substantially from those of women who experience unwanted pregnancy.

The desire of HIV-infected persons to have children in the future has significant implications for the transmission of HIV to sexual partners and newborns. Although the risk of transmission of HIV from mother to infant can be decreased with prophylactic treatment, maternal transmission accounts for almost all new HIV infections in children.[6] The risk of HIV transmission among individual couples is likely to increase as more infected individuals choose to have children with their HIV-negative partners. In addition, many children of infected parents are likely to need social services, including income supplementation, housing, child care and, for those who lose one or both parents, bereavement support, foster care or adoption.[7] An accurate description of fertility desires and intentions among infected individuals is necessary to aid infected individuals who desire and expect children to do so without sacrificing the health and well-being of their newborns, their partners and themselves. As a benchmark for gauging the fertility-related counseling and service needs of HIV-infected adults, it is useful to compare their desires and intentions with those of non–HIV-infected adults; in this study, we make such comparisons for the U.S. population of women using data from the National Survey of Family Growth.

This study is the first to use a representative sample to describe the desire for and intentions to have children among HIV-positive men and women. Our weighted sample represents the national population of HIV-positive adults receiving medical care in the United States in 1996. We separately analyze desires for and expectations about having children, and examine how desires and intentions are associated with a range of social and demographic, health and HIV-related factors.

## Methods

### *Sample Description*

The sample for this study was drawn from a larger sample of participants in the HCSUS. This was a multistage national probability sample of 2,864 persons at least 18 years old with known HIV infection who made at least one visit for regular or ongoing care to a nonmilitary, nonprison medical provider other than an emergency department in the contiguous United States during a specified period in the first two months of 1996. HCSUS baseline interviewing began in January 1996 and ended 15 months later. Full interviews had been conducted with 2,864 of 4,042 eligible persons (71%). Full details of the HCSUS design[8] and other published HCSUS results are available elsewhere.[9]

The Risk and Prevention Study sample on which our analyses are based consisted of 1,421 persons from the HCSUS sample. Eligible members of the HCSUS sample were those who were interviewed in English at HCSUS baseline, whose gender was unambiguous based on HCSUS data, and who participated in a second, follow-up HCSUS interview between August 1997 and January 1998 (N=2,205).

We drew a subsample of 1,794 from this group, sampling randomly after stratifying by primary sampling unit, type of health care provider, age, ethnicity and self-described sexual orientation. Eligible white gay men aged 40 and older were sampled with a one-third probability, eligible white gay men aged 39 and younger were sampled with a four-ninths probability and all others were sampled with a probability of one. Interviews were conducted from September through December 1998. The completion rate was 79%; the response rate after allowing for known mortality was 84%. The resulting sample of 1,421 was weighted to represent a reference population of 197,063 adults receiving HIV care in the 48 contiguous states in early 1996 who survived and were eligible to be interviewed in 1998.

For this analysis, we restricted the sample to bisexual and heterosexual men aged 20 and older and all women aged 20–44 at the time of the Risk and Prevention Study. We excluded men who identified themselves as exclusively gay. The unweighted sample consisted of 361 men and 377 women. Weighted sample sizes were 53,177 men and 34,833 women.

### *Survey Instrument and Procedures*

Risk and Prevention Study participants were contacted directly, using information that they provided at earlier interview waves. The survey covered sexual activities, attitudes and beliefs related to HIV transmission and its prevention, and fertility and contraception attitudes and behavior. All interviews were conducted in person, using a combination of computer-assisted self-interviewing and computer-assisted personal interview methods. Interviewers asked questions and entered responses for most of the interview using a laptop computer.

### *Hypotheses*

We developed four hypotheses for this study.

- First, because of the risks of transmission to the newborn,[10] the potential health risks for HIV-infected women to have children[11] and concerns regarding childrearing, we hypothesized that HIV-infected women would desire and expect fewer children than the general U.S. population.
- Our second hypothesis was that many HIV-infected individuals would expect not to have children because of the potential risks of having children, the physical inability to have children or the unwillingness of their partner.[12]
- Additionally, the recent finding that 12% of women but only 2% of men in the HCSUS sample conceived a child after HIV diagnosis suggests that fertility desires and intentions may differ by sex, with women desiring and expecting more children in the future than men.[13]
- Finally, we hypothesized that fertility desires and intentions would vary by age, risk group, fertility history, health status, relationship status and HIV status of the primary partner, in accordance with previous studies of reproductive decisions.[14]

### *Variables*

The majority of the variables that we examine here were collected during the Risk and Prevention Study interview. The outcome variables were fertility desire and fertility intention. Fertility desire was defined by the response to a question asking whether the respondent would like to have children in the future. Women who were trying to get pregnant were not asked if they desired children in the future, but we included them by imputation in the "desire children" category. Of respondents who indicated they would like to have children in the future, fertility intention was defined by a separate question asking how many children the respondent expected to have in the future. Since women who were pregnant at the time of the interview were not asked if the pregnancy was wanted or if they desired

**Table 1. Percentage distribution of HIV-positive men and women, by fertility desires and expectations**

| Characteristic | Men (N= 53,177) | Women (N= 34,833) | p |
|---|---|---|---|
| FERTILITY DESIRES | | | .72 |
| **Desires children in the future** | | | |
| Yes | 28 | 29 | |
| No | 70 | 69 | |
| Do not know | 0 | 1 | |
| Response missing | 1 | 1 | |
| FERTILITY EXPECTATIONS | | | |
| **No. of children expected*** | | | .001 |
| 0 | 41 | 31 | |
| 1 | 24 | 56 | |
| ≥2 | 35 | 13 | |
| **Partner would like to have child†** | | | .0007 |
| Yes | 33 | 46 | |
| No | 65 | 45 | |
| Do not know | 2 | 5 | |
| Response missing | 0 | 4 | |
| **Likelihood of having abortion if pregnant‡** | | | na |
| Definitely would | na | 31 | |
| Probably would/50% chance/probably would not | na | 30 | |
| Definitely would not§ | na | 37 | |
| Do not know | na | 2 | |
| Response missing | na | 1 | |
| Total | 100 | 100 | |

*Among those desiring children. †Asked only of respondents who were currently married or with a heterosexual partner. (Unweighted sample sizes were 182 males and 255 females; weighted sample sizes were 27,885 males and 23,167 females.) ‡Asked only of female respondents. §Includes those who were trying to become pregnant. *Notes:* Ns shown represent weighted sample sizes. The unweighted sample sizes are 361 males and 377 females. na=not applicable, either because it was not asked or because category was excluded as a result of sample restrictions.

children in the future, we treated those women as missing responses with respect to both fertility desires and intentions.

Predictor variables included demographic, relationship, fertility history and health variables, as well as other indicators that were expected to be associated with fertility desire or intention. The likelihood of abortion was examined through the use of the question: "If you were to become pregnant now, how likely would you be to have an abortion?" Those who were trying to become pregnant were included in the category of "definitely would not abort." Women who were pregnant and expecting to carry to term were treated as missing in the abortion question, which they were not asked.

The variable "partner's desire to have children" was defined only for respondents who had a spouse or an opposite-sex partner. For those who had such a partner and were trying to get pregnant, partner's desire to have children was coded "yes." Women who were currently pregnant and men whose partner was pregnant were coded as missing, since the partner may or may not have desired the pregnancy.

Tubal ligation status was asked only of women who had an opposite-sex partner in the six months preceding the Risk and Prevention Study interview. Participants self-reported their current number of children in response to the question: "How many children do you have?" Total number of births expected was a derived variable that combined the number of children and the number of children expected from the question: "How many (more) children do you expect to have?"

Relationship status combined marital status and current relationship to classify respondents in the following categories: married; nonmarried partner; separated or divorced; or widowed or never-married. Marital status was determined by the question: "What is your legal marital status?" Current relationship status was determined by the question: "Do you currently have a male relationship partner (boyfriend), or a female relationship partner (girlfriend)?" The primary partner or spouse's HIV status was based on the respondent's report, as were the respondent's lowest-ever CD4 count* and the importance of religion in the respondent's life.

Our quality-of-life variables consisted of self-reported overall health, physical functioning and emotional well-being.[15] For each scale, the average of the items was placed on a 0–100 range, with higher scores representing better health, functioning and well-being. Overall health was a self-rating of current health. Physical functioning was based on the SF-36† and is composed of self-ratings of the extent to which the following activities are limited: engaging in vigorous activities; climbing stairs; walking more than one mile; walking more than one block; bathing or dressing; doing housework; shopping; getting around; and feeding yourself. Emotional well-being was composed of self-ratings of the extent to which the respondent experienced the following states in the previous four weeks: calm and peaceful; downhearted and blue; happy; very nervous; sad; anxious or worried; and depressed. Five of these items were drawn from the SF-36.

Age was based upon the respondent's age at the time of the Risk and Prevention Study interview. Ethnicity, education, employment, income, HIV risk group and sexual orientation were all self-reported and taken from the HCSUS baseline interview.

### *Weighting and Data Analysis*

The Risk and Prevention Study analysis weight for each respondent is the multiplicative product of the respondent's HCSUS second follow-up weight, a Risk and Prevention Study sampling weight and a Risk and Prevention Study attrition weight. This analysis weight is equivalent to an estimate of the number of persons in the Risk and Prevention Study target population represented by that respondent. The HCSUS weights are fully described elsewhere.[16] The Risk and Prevention Study sampling weight adjusts for the differential probabilities of selection; the Risk and Prevention Study attrition weight adjusts for second follow-up respondents who were eligible for the study but were not successfully interviewed. To adjust standard errors and statistical tests for the differential weighting and complex sample design, we used linearization methods in Stata.[17]

We first describe the social and demographic characteristics and fertility desires and intentions of the sample members by gender. Weighted Pearson's chi-square tests were performed to compare characteristics and fertility intentions between men and women. We then compare the total number of births expected for the HCSUS Risk and Prevention Study women with those of the 1995 National Survey of Family Growth (NSFG), the most recent wave of a large nationally representative sample of women aged 15–44 in the civilian noninstitutionalized U.S. population.[18] Conducted by the National Center for Health Statistics, the NSFG provides data on factors affecting pregnancy and women's health.

We then examine the social and demographic characteristics of men and women according to their desire to have children. Predictor variables were tested separately for men and women using the weighted Pearson's chi-square test. Among men and women who desired children, we examine the associations of selected variables with the expectation of having children.

We constructed a multivariate logistic regression model separately for men and women, using as outcomes first the desire for, and then the expectation of, children.

*The CD4 count, an indicator of the clinical progression of HIV infection or AIDS, is the number of CD4 immune cells, the cells that modulate host immune defenses to infection.

†SF-36 is a 36-item short-form survey designed to measure health status by assessing health concepts, using multi-item scales.

**Table 2. Percentage distribution of study participants and mean values, by selected characteristics, according to sex**

| Characteristic | Men (N= 53,177) | Women (N= 34,833) | p |
|---|---|---|---|
| **Age** | | | .0000 |
| 20–29 | 3 | 16 | |
| 30–34 | 8 | 26 | |
| 35–39 | 20 | 32 | |
| 40–44 | 20 | 26 | |
| ≥45 | 49 | na | |
| **Race/ethnicity** | | | .4317 |
| Non-Hispanic white | 33 | 28 | |
| Non-Hispanic black | 51 | 52 | |
| Hispanic/Latino | 14 | 18 | |
| Other | 2 | 3 | |
| **No. of children** | | | .4593 |
| 0 | 27 | 24 | |
| 1 | 19 | 24 | |
| 2 | 21 | 19 | |
| ≥3 | 33 | 34 | |
| **Education** | | | .0013 |
| Some high school | 32 | 42 | |
| High school graduate | 33 | 32 | |
| Some college | 25 | 23 | |
| College graduate | 11 | 3 | |
| **Currently employed** | | | .9253 |
| Yes | 27 | 27 | |
| No | 73 | 73 | |
| **Annual income** | | | .1179 |
| <$5,000 | 23 | 28 | |
| $5,001–10,000 | 31 | 34 | |
| $10,001–25,000 | 26 | 27 | |
| >$25,000 | 20 | 11 | |
| **HIV risk group** | | | .0001 |
| Heterosexual contact | 25 | 60 | |
| Injection drug use | 41 | 25 | |
| Bisexual contact | 22 | na | |
| Other | 12 | 15 | |

| Characteristic | Men (N= 53,177) | Women (N= 34,833) | p |
|---|---|---|---|
| **Sexual orientation** | | | .0000 |
| Straight/heterosexual | 81 | 92 | |
| Lesbian | na | 3 | |
| Bisexual | 19 | 4 | |
| Other | na | 1 | |
| **Mean health ratings** | | | |
| Overall health | 73.0 | 73.3 | .8684 |
| Physical functioning | 79.9 | 82.7 | .0958 |
| Emotional well-being | 66.7 | 64.8 | .3546 |
| **Lowest CD4+ count ever** | | | .1579 |
| 0–49/mm$^3$ | 27 | 21 | |
| 50–199/mm$^3$ | 33 | 30 | |
| 200–499/mm$^3$ | 34 | 43 | |
| ≥500/mm$^3$ | 6 | 6 | |
| **Viral load** | | | .0128 |
| Detectable | 39 | 49 | |
| Undetectable | 27 | 18 | |
| Do not know | 6 | 4 | |
| Response missing | 27 | 29 | |
| **Relationship status** | | | .0000 |
| Married | 29 | 19 | |
| Nonmarried partner | 29 | 51 | |
| Separated/divorced | 18 | 7 | |
| Widowed/never-married | 24 | 23 | |
| **HIV status of primary partner/spouse*** | | | .8407 |
| Positive | 26 | 27 | |
| Negative | 52 | 54 | |
| Unknown | 22 | 20 | |
| **Importance of religion** | | | .0081 |
| Very | 52 | 65 | |
| Somewhat | 33 | 28 | |
| Not very | 9 | 2 | |
| Not at all | 6 | 5 | |
| Total | 100 | 100 | |

*Includes only respondents who had a primary partner or spouse. (Unweighted sample size is 250 males and 305 females; weighted sample represents 37,497 males and 27,476 females.) *Notes:* Ns shown represent weighted sample sizes. The unweighted sample sizes are 361 males and 377 females. na=not applicable, either because it was not asked or because category was excluded as a result of sample restrictions.

Predictor variables were restricted to those significantly related to at least one of the two outcomes at the bivariate level. The final model included these variables: age; age squared; race and ethnicity; number of children; tubal ligation status; overall health; physical functioning; relationship status; and the HIV status of the respondent's primary partner or spouse.

## Results

### *Fertility Desires and Intentions*

Twenty-eight percent of HIV-positive heterosexual or bisexual men and 29% of HIV-positive women who receive medical care in the United States desire children in the future (Table 1), but fewer expect to have children in the future. Of those desiring children, 31% of women and 41% of men do not expect to have any. Among those who desire children, about one-quarter of men and about half of women expect to have one child, while about one-third of men and 13% of women expect to have two or more children. Thus, although a similar percentage of HIV-positive men and women desire children, fewer men expect to have children in the future.

Among individuals who were married or had a heterosexual partner, 46% of women and 33% of men have partners who desire children in the future. Almost one-third of HIV-positive women in the total sample definitely would have an abortion if pregnant, and a little more than a third definitely would not.

### *General Sample Characteristics*

Three-quarters of the respondents previously had children, with one-third having three or more (Table 2). Overall, sample respondents were generally black or Hispanic and of lower socioeconomic status. Women in the sample were younger, less-educated, more often Hispanic, of lower socioeconomic status and more likely to have a nonmarital partner than were men. Women were most commonly infected through heterosexual contact (60%), while injection drug use was the most common risk group for men (41%). More than 50% of respondents had had CD4 counts of less than 200 per mm$^3$, while 27% of men and 18% of women had an undetectable viral load. More than half were married or in a relationship, and 26% of men and 27% of women had an HIV-positive partner. Most were somewhat or very religious, with women being more religious than men.

### *Comparison with U.S. Women*

The percentage of HIV-positive women desiring children in the future (29%, Table 1) was less than the 36% of women in the U.S. population who desired children in the future.[19] Similarly, the percentage of HIV-positive women who were expecting children was slightly less than the percentage among women in a sample of the U.S. population across all age-groups (Table 3). The percentages of HIV-infected women who expected at least one child ranged from 82% to 89% across age-groups, compared with 85–94% among U.S. women as a whole. The percentages of women who were expecting two or more children were also consistently and substantially lower among the HIV-infected, ranging from 57% to 65% across age-groups compared with 68–81% among U.S. women in general.

### *Who Desires Children?*

Three-quarters or more of HIV-positive men and women who desired children in the future had partners who would like to have

**Table 3. Percentage distribution of HIV-positive women and U.S. women overall, by total number of births expected, according to age**

| Age | HIV-positive* | | | All† | | | Total |
|---|---|---|---|---|---|---|---|
| | 0 | 1 | ≥2 | 0 | 1 | ≥2 | |
| 20–29 | 10 | 25 | 64 | 6 | 13 | 81 | 100 |
| 30–34 | 15 | 20 | 65 | 8 | 16 | 76 | 100 |
| 35–39 | 18 | 23 | 59 | 11 | 16 | 73 | 100 |
| 40–44 | 16 | 28 | 57 | 15 | 17 | 68 | 100 |

*From the Risk and Prevention Sample of the HIV Cost and Services Utilization Study. Total number of births expected is the sum of the number of children ever born and the number of births expected in the future. †From the 1995 National Survey of Family Growth (NSFG). Total births expected is the sum of the number of children ever born and the additional number of births expected. *Notes:* Weighted Ns are 34,833 for HIV-positive women and 44,578 for NSFG respondents. Some percentages may not add to 100% because of rounding.

**Table 4. Percentage distribution of study participants and mean values, by selected characteristics, according to sex and desire for children in the future**

| Characteristic | Men | | | Women | | |
|---|---|---|---|---|---|---|
| | Do not desire children (N= 37,295) | Desire children (N= 15,115) | p | Do not desire children (N= 23,953) | Desire children (N= 10,235) | p |
| **Partner would like to have child*** | | | .0000 | | | .0000 |
| Yes | 17 | 75 | | 27 | 78 | |
| No | 82 | 19 | | 69 | 6 | |
| Do not know | 1 | 5 | | 4 | 7 | |
| Response missing | 0 | 0 | | 0 | 8 | |
| **Likelihood of having abortion if pregnant** | | | na | | | .0000 |
| Definitely would | na | na | | 42 | 8 | |
| Probably would/50% chance/probably would not | na | na | | 30 | 30 | |
| Definitely would not† | na | na | | 27 | 59 | |
| Do not know | na | na | | 1 | 2 | |
| **Woman has had/partner has had tubal ligation‡** | | | .3190 | | | .0367 |
| Yes | 12 | 17 | | 40 | 22 | |
| No | 77 | 78 | | 57 | 71 | |
| Do not know | 5 | 0 | | 0 | 0 | |
| Response missing | 6 | 5 | | 3 | 7 | |
| **No. of children** | | | .0804 | | | .0020 |
| 0 | 22 | 38 | | 17 | 37 | |
| 1 | 18 | 22 | | 23 | 24 | |
| 2 | 23 | 16 | | 20 | 19 | |
| ≥3 | 37 | 24 | | 39 | 20 | |
| **Age** | | | .0002 | | | .0014 |
| 20–29 | 2 | 5 | | 11 | 27 | |
| 30–34 | 5 | 14 | | 24 | 30 | |
| 35–39 | 15 | 33 | | 34 | 28 | |
| 40–44 | 20 | 19 | | 31 | 15 | |
| ≥45 | 58 | 29 | | na | na | |
| **Race/ethnicity** | | | .6957 | | | .2087 |
| Non-Hispanic white | 33 | 32 | | 24 | 35 | |
| Non-Hispanic black | 51 | 51 | | 54 | 47 | |
| Hispanic/Latino | 14 | 16 | | 19 | 16 | |
| Other | 3 | 1 | | 3 | 2 | |
| **Education** | | | .4365 | | | .4972 |
| Some high school | 33 | 28 | | 41 | 47 | |
| High school graduate | 32 | 34 | | 34 | 24 | |
| Some college | 27 | 21 | | 22 | 26 | |
| College graduate | 8 | 16 | | 3 | 2 | |
| **Currently employed** | | | .6003 | | | .2704 |
| Yes | 26 | 29 | | 24 | 30 | |
| No | 74 | 71 | | 76 | 70 | |
| **Annual income** | | | .7882 | | | .4205 |
| <$5,000 | 24 | 23 | | 29 | 27 | |
| $5,001–10,000 | 31 | 29 | | 36 | 29 | |
| $10,001–25,000 | 23 | 29 | | 26 | 28 | |
| >$25,000 | 21 | 20 | | 9 | 16 | |

| Characteristic | Men | | | Women | | |
|---|---|---|---|---|---|---|
| | Do not desire children (N= 37,295) | Desire children (N= 15,115) | p | Do not desire children (N= 23,953) | Desire children (N= 10,235) | p |
| **HIV risk group** | | | .3357 | | | .1366 |
| Heterosexual contact | 26 | 24 | | 58 | 63 | |
| Injection drug use | 40 | 43 | | 28 | 19 | |
| Bisexual contact | 20 | 26 | | na | na | |
| Other | 14 | 8 | | 14 | 18 | |
| **Sexual orientation** | | | .4133 | | | .1323 |
| Straight/ heterosexual | 82 | 77 | | 90 | 96 | |
| Lesbian | na | na | | 4 | 1 | |
| Bisexual | 18 | 23 | | 5 | 3 | |
| Other | 0 | 0 | | 1 | 0 | |
| **Mean health ratings** | | | | | | |
| Overall health | 72.6 | 74.5 | .4496 | 70.2 | 80.5 | .0002 |
| Physical functioning | 78.1 | 84.0 | .0258 | 82.6 | 83.1 | .8221 |
| Emotional well-being | 66.7 | 67.1 | .8542 | 64.1 | 67.1 | .2042 |
| **Lowest CD4+ count ever** | | | .1019 | | | .4783 |
| 0–49/mm$^3$ | 28 | 23 | | 24 | 17 | |
| 50–199/mm$^3$ | 36 | 27 | | 29 | 32 | |
| 200–499/mm$^3$ | 30 | 45 | | 42 | 44 | |
| ≥500/mm$^3$ | 6 | 5 | | 5 | 7 | |
| **Viral load** | | | .6369 | | | .2194 |
| Detectable | 38 | 45 | | 54 | 39 | |
| Undetectable | 27 | 28 | | 16 | 23 | |
| Do not know | 6 | 5 | | 3 | 5 | |
| Response missing | 29 | 22 | | 27 | 33 | |
| **Relationship status** | | | .1171 | | | .0042 |
| Married | 30 | 25 | | 15 | 29 | |
| Nonmarried partner | 29 | 32 | | 49 | 55 | |
| Separated/divorced | 21 | 12 | | 8 | 4 | |
| Widowed/ never-married | 20 | 31 | | 27 | 12 | |
| **HIV status of primary partner/spouse§** | | | .4765 | | | .0197 |
| Positive | 28 | 21 | | 28 | 22 | |
| Negative | 53 | 52 | | 58 | 46 | |
| Unknown | 19 | 27 | | 14 | 32 | |
| **Importance of religion** | | | .2448 | | | .0869 |
| Very | 49 | 58 | | 68 | 62 | |
| Somewhat | 36 | 27 | | 28 | 28 | |
| Not very | 8 | 10 | | 2 | 2 | |
| Not at all | 7 | 4 | | 2 | 9 | |
| Total | 100 | 100 | | 100 | 100 | |

*Includes only respondents who were currently married or had a heterosexual partner. (Unweighted sample size is 181 males and 247 females; weighted sample represents 27,687 males and 22,691 females.) †Includes those who were trying to become pregnant. ‡Among respondents who had sex with an opposite-sex partner within the last six months. (Unweighted sample size is 172 males and 243 females; weighted sample represents 25,645 males and 22,744 females.) §Among respondents who had a primary partner or spouse. (Unweighted sample size is 247 males and 296 females; weighted sample represents 36,923 males and 26,832 females.) *Notes:* Ns shown represent weighted sample sizes. The unweighted sample sizes are 107 males and 109 females who desire children and 249 males and 259 females who do not desire children. na=not applicable, either because it was not asked or because category was excluded as a result of sample restrictions.

a child, but nearly 20% of men who desired children had a partner who did not (Table 4). Seventeen percent of men who desired children and who had had sex within the last six months had a partner with a tubal ligation, and 22% of women who desired children and had had sex within the last six months had a tubal ligation.

More than half of women who desired children said they definitely would not have an abortion if they were to become pregnant, while 8% definitely would have an abortion if pregnant. Importantly, 27% of those who did not desire children also said they would definitely not have an abortion. Men and women who desired children had fewer children than those who did not desire children. In fact, almost 40% of those who desired children had had no previous children.

HIV-positive men and women who desired children were younger than those who did not. The percentage who had had a tubal ligation was significantly lower

among women who desired children (22%) than among those who did not (40%), but men who desired children were as likely to have a partner with a tubal ligation as were those who did not desire children. In terms of health, men who desired children had higher self-ratings of physical functioning and women who desired children had higher self-ratings of overall health than their counterparts who did not desire children. However, the desire for children was not significantly related to HIV progression (either the lowest CD4 count or viral load) in either men or women, nor was it significantly related to emotional well-being.

Women who desired children were more likely either to be married or to have a partner (84%) than were those who did not (64%). Men who desired children were no more likely to have had an opposite-sex partner than were men who did not desire children. The percentage of men who identified themselves as bisexual was somewhat greater among those who desired more children (23%) than among those who did not (18%), although this difference was not statistically significant. Women who desired children were more likely to have a partner of unknown HIV status (32%) than were women who did not desire children (14%).

In a multivariate analysis (not shown), women with at least one child were less likely to desire children than were women with no children (odds ratio, 0.77; 95% confidence interval (CI)=0.6, 0.9; p<.05). Women with better overall health were more likely to desire children (odds ratio, 1.03; 95% CI=1.01, 1.04; p<.05). However, women with better physical functioning were less likely to desire children (odds ratio, 0.98; 95% CI=0.97, 0.99; p<.05). Women whose partner's HIV status was negative (odds ratio, 0.33; 95% CI=0.15, 0.74; p<.05) or positive (odds ratio, 0.38; 95% CI=0.15, 0.98; p<.05) were less likely to desire children than were women whose partner's HIV status was unknown. There were no significant multivariate predictors of desire for children among men.

**Table 5. Percentage distribution of respondents who desired more children, by selected characteristics, according to sex and whether they expect to have children in the future**

| Characteristic | Men | | | Women | | |
|---|---|---|---|---|---|---|
| | Expect no children (N=6,168) | Expect ≥1 children (N=8,946) | p | Expect no children (N=3,188) | Expect ≥1 children (N=7,047) | p |
| **Age** | | | .3510 | | | .1258 |
| 20–29 | 3 | 6 | | 19 | 31 | |
| 30–34 | 10 | 16 | | 19 | 35 | |
| 35–39 | 26 | 38 | | 42 | 21 | |
| 40–44 | 20 | 19 | | 19 | 13 | |
| ≥45 | 41 | 21 | | na | na | |
| **Race/ethnicity** | | | .0795 | | | .3684 |
| Non-Hispanic white | 46 | 23 | | 48 | 28 | |
| Non-Hispanic black | 38 | 59 | | 36 | 52 | |
| Hispanic/Latino | 14 | 18 | | 15 | 17 | |
| Other | 2 | 0 | | 0 | 3 | |
| **Has children** | | | .2142 | | | .3229 |
| No | 28 | 46 | | 30 | 41 | |
| Yes | 72 | 54 | | 70 | 59 | |
| **Lowest CD4+ count ever** | | | .0383 | | | .9030 |
| 0–49/mm$^3$ | 40 | 12 | | 15 | 18 | |
| 50–199/mm$^3$ | 33 | 23 | | 38 | 30 | |
| 200–499/mm$^3$ | 23 | 59 | | 41 | 45 | |
| ≥500/mm$^3$ | 4 | 6 | | 7 | 8 | |
| **Viral load** | | | .9269 | | | .1633 |
| Detectable | 43 | 46 | | 47 | 35 | |
| Undetectable | 28 | 27 | | 29 | 20 | |
| Do not know | 7 | 4 | | 8 | 4 | |
| Response missing | 22 | 22 | | 15 | 41 | |
| **Relationship status** | | | .1765 | | | .8447 |
| Married | 33 | 20 | | 35 | 26 | |
| Nonmarried partner | 27 | 34 | | 49 | 58 | |
| Separated/divorced | 19 | 7 | | 5 | 4 | |
| Widowed/never-married | 20 | 39 | | 11 | 12 | |
| **HIV risk group** | | | .4343 | | | .3988 |
| Heterosexual contact | 29 | 21 | | 72 | 59 | |
| Injection drug use | 47 | 40 | | 12 | 23 | |
| Bisexual contact | 18 | 30 | | na | na | |
| Other | 6 | 9 | | 16 | 19 | |
| **HIV status of primary partner/spouse*** | | | .5212 | | | .1798 |
| Positive | 17 | 24 | | 19 | 24 | |
| Negative | 59 | 46 | | 36 | 51 | |
| Unknown | 23 | 30 | | 45 | 25 | |
| **Woman has had/partner has had tubal ligation†** | | | .6789 | | | .2254 |
| Yes | 21 | 14 | | 30 | 18 | |
| No | 77 | 79 | | 68 | 72 | |
| Response missing | 3 | 7 | | 2 | 9 | |
| Total | 100 | 100 | | 100 | 100 | |

*Includes only respondents who had a primary partner or spouse. (Unweighted sample size is 78 males and 97 females; weighted sample represents 11,213 males and 9,427 females.) †Includes only respondents who had had sex with an opposite-sex partner within the last six months. (Unweighted sample size is 56 males and 83 females; weighted sample represents 8,015 males and 7,941 females.)
*Notes:* Ns shown represent weighted sample sizes. The unweighted sample sizes are 42 males and 32 females who expect to have no children and 65 males and 77 females who expect to have at least one child. na=not applicable, either because it was not asked or because category was excluded as a result of sample restrictions.

### *Who Intends to Have Children?*

Among HIV-positive men and women who desired children, the percentage of those younger than 40 who actually expected to have children was almost always greater than the percentage who did not (Table 5). The percentage of respondents or their partners who had had a tubal ligation was smaller among those who expected to have children than among those expecting no more children. Moreover, respondents who expected children in the future were less likely to be married than were those who did not.

The percentage of women who expected to have children and who had a partner who was HIV-negative was greater than that among comparable women who did not expect to have children, but this pattern did not hold among men. Eighteen percent of women and 12% of men who expected to have children had a lowest-ever CD4 count of less than 50 per mm$^3$, but 20% and 27%, respectively, had an undetectable viral load (Table 5).

Eighteen percent of women and 14% of men who desired and expected to have children had had a tubal ligation or had a partner with a tubal ligation. Women who expected to have children were younger, more likely to be from the injection drug use risk group and more likely to have a

partner whose HIV status they knew than were women not expecting to have a child. Similarly, men who expected to have children were younger, were more likely to be unmarried and were more likely to be from the bisexual risk group than were those who did not expect to have a child.

In multivariate analysis (data not shown), women with at least one child were less likely to expect children than were women with no children (odds ratio, 0.78; 95% CI=0.6, 0.95; p<.05). Women with an HIV-negative (odds ratio, 11.0; 95% CI=2.7, 44.4; p<.05) or HIV-positive (odds ratio, 5.3; 95% CI=1.3, 22.0; p<.05) partner were more likely to expect children than women who did not know their partner's HIV status. Health seems more strongly related to men's expectations than women's, as men with better overall health appear somewhat more likely to expect children in the future (odds ratio, 1.02; 95% CI=1.0, 1.04; p<.10). Just as with black men (odds ratio, 4.9; 95% CI=1.2, 21.0; p<.05), black women (odds ratio, 3.0; 95% CI=0.87, 10.0; p<.10) appear more likely to expect children than women who were not black.

*"Health may play a greater role in fertility expectations for men than it does for women, as [HIV-positive] men with better overall health and higher CD4 counts are more likely to expect children."*

## Discussion

Our study is the first to use nationally representative data to examine the fertility desires and intentions of HIV-positive men and women. We found that many HIV-infected men and women desire and expect to have children in the future. Compared with those who do not desire children, these individuals have fewer children, would not abort if they were pregnant and are younger. The men and women who desire children have better overall health, but the women have poorer physical functioning than those who do not desire children.

Our finding that 28% of HIV-positive men and 29% of HIV-positive women desire children in the future translates into 14,900 HIV-positive men and 10,100 HIV-positive women. However, because our sample represents only HIV-positive individuals who were in treatment as of early 1996, the actual number of HIV-positive men and women who desire children is likely to be much greater.

Our second key finding is that fewer HIV-infected men and women actually expect to have children than desire children: Four in 10 men and three in 10 women who desire children do not expect to have any. Compared with respondents who desire but do not expect to have children, infected individuals who expect to have children in the future are most likely to be non-Hispanic black and are somewhat younger. Health may play a greater role in fertility expectations for men than it does for women, as men with better overall health and higher CD4 counts are more likely to expect children. For women, health appears to play a greater role in desire for children, as women with better overall health but poorer physical functioning have a greater desire for children; this relationship does not hold for fertility expectations, nor is there such an effect at the bivariate level. Given the potential health complications associated with childbearing, this is a surprising finding.

Although desires for children are similar among men and women, expectations are not. Men are less likely to expect to have any children, but appear to be more likely to expect two or more if they expect to have any. Men who desire children are more likely than women who do so to have a partner who does not want a child. This does not seem to be explained by partner's serostatus, since men and women are about equally likely to have an HIV-infected partner. It may reflect a disparity in families' economic prospects, with these being worse when the male partner is HIV-infected and unable to work than when the female partner is HIV-infected, but her partner is not.

For both men and women, black race is a predictor of expectation but not of desire for children. Black men are five times more likely and black women are three times more likely than are others to expect to have children, suggesting cultural differences in perceived barriers to parenthood that are not directly measured in this study. For men, in addition to race and ethnicity, better overall health is a predictor of expectation of children. For women, however, having no children is a predictor of both desires and expectations. Interestingly, having a partner whose HIV status was unknown is a predictor for women to desire children compared with women who knew their partner's status, regardless of whether that status was positive or negative. In contrast, having a partner whose HIV status was known is a significant predictor for expectation of children compared with women whose partner's HIV status was unknown. This finding suggests that knowledge of a partner's HIV status may be a proxy for duration, intimacy or other unobserved characteristics of primary relationships that affect whether people desire and expect children.

The discrepancy between fertility desires and expectations most likely reflects a range of additional factors that affect fertility decisions, including the physical inability to have children and the partner's desire for children. One woman in five who desires children and who had sex in the past six months cannot conceive because of a tubal ligation. Moreover, among men who desire children, similar proportions either have a partner who does not desire a child or have a partner with a tubal ligation. Men who desire children but do not expect to have them are less likely than women in this situation to have marital or relationship partners. Marital or relationship status also has effects that are less straightforward. Both men and women who are married are less likely to expect one or more children than are nonmarried individuals with a partner. It is very likely that this finding reflects the effects of other confounding factors, such as age, number of children or partner status.

Our study lacked in-depth measures that would have enabled us to determine with greater specificity why HIV-positive individuals desire or expect children or why they may desire but not expect to have children. The medical and social concerns of people managing their HIV infection compound a complex array of reasons for desiring children that may include cultural value systems, personality traits, life-cycle factors and situational factors.[20] The desire for children is likely associated with economic or cultural backgrounds that link parenthood to adult identity or to regard for one's race.[21] For example, black parents may value children more than other parents do as sources of immortality, companionship or economic utility.[22] For individuals in nonwhite communities, childlessness may be a serious concern,[23] and therefore the loss of ability to bear children because of HIV infection may be an unthinkable option. Childbearing may also be a method of coping

with a recent loss or with the complexities of a life caught up in disease or poverty.[24] For some individuals, pregnancy may be a time of high self-esteem and motivation to live a "normal" life.[25] These motivations and the threat of childlessness may become more compelling as HIV disease advances, perhaps explaining why women with poorer physical functioning have a greater desire for children.

A smaller proportion of HIV-infected women desire children in the future than does the general population of women in the United States. Fewer women in our sample expected to have at least one total birth in their lifetime than did respondents to the 1995 NSFG, and HIV-positive women expect fewer total births as well. This comparison is crude, however, since HIV-infected women differ from women in the general population on a number of demographic characteristics, and a controlled multivariate comparison is beyond the scope of this study.

Nevertheless, our results are consistent with the conclusion that being infected with HIV dampens but does not come close to eliminating individuals' desires and intentions to have children. Factors such as race, number of children, health status and partner's HIV status are predictors of fertility desires or expectations. Some of these factors presumably account for the dampening effect of HIV infection on fertility desires and expectations. This effect is therefore much more modest than some might expect, especially given the advanced stage of HIV illness to which many in our sample had progressed. However, its modest nature is consistent with reports from other countries comparing pregnancy rates of HIV-infected and other women.[26]

An obvious implication of our findings is the potential for transmission of HIV from mother to child. While recent studies have shown that maternal transmission of HIV can be reduced to about 2%,[27] the possibility of vertical transmission still exists. Our results are of concern because nearly half of women in our sample who desire or expect to have children had previously had a lowest-ever CD4 count below 200 per $mm^3$, well within the range recommended for antiretroviral therapy. These low CD4 counts would place women at risk for near-term clinical progression,[28] which would further increase the risk of perinatal transmission.

Furthermore, more than two-thirds of those in the HCSUS population most likely to have children—women of childbearing age and heterosexual or bisexual men—are racial and ethnic minorities, for whom access to care often is poor.[29] Many of these people may not be able to access optimal care to reduce the likelihood of transmission to the newborn. In the HCSUS dataset, the proportion of children who tested HIV-positive ranges from 12% to 14% for those born between one year before or nine months after the mother's diagnosis.[30] Although some of these cases may be old, these data may provide a good estimate of mother-to-child transmission risk with current levels of access to prophylaxis.

The finding that a majority of HIV-positive men and women who expect to have children have a primary partner or spouse who is HIV-negative or of unknown status has major implications for the heterosexual transmission of HIV. Anecdotal evidence exists of serodiscordant couples risking HIV transmission to have a child who might not be infected.[31] It is important to determine the extent to which HIV-positive men and women who expect to have children and have HIV-negative or partners of unknown HIV status are aware of the risks of heterosexual transmission of HIV.

*"Our results are consistent with the conclusion that being infected with HIV dampens but does not come close to eliminating individuals' desires and intentions to have children."*

Whether the desires and expectations of HIV-positive individuals to have children in the future will remain stable or increase is an important question. The expectations measured here reflect the cumulative effects of decisions made over time by individuals who may have been diagnosed years previously. The fact that 22% of women who desire more children have had tubal ligations suggests that some HIV-positive people might make different choices now from those they made earlier, when treatment options were more limited. If so, then the proportion of HIV-infected people who expect to fulfill their desire to have children may increase from the levels observed in this study.

HIV-positive men and women who desire children have numerous service needs in addition to planning for a future closely linked to medical care for their infection. To help them make informed choices, HIV-positive individuals will need family planning counseling. Our finding that knowledge of partner's HIV status influences both fertility desires and expectations suggests the need to incorporate partner HIV testing into family planning services. HIV-positive women who become pregnant will need increased access to medical care, as these women are disproportionately from marginalized populations that are less likely to receive prenatal care. In addition, there is a need to assure that treatment guidelines for HIV-positive women during pregnancy are updated and disseminated to obstetricians in a timely manner.[32] HIV-positive women who give birth will need follow-up of the newborn until maternal antibodies disappear and HIV status can be ascertained.

If the desires and expectations of HIV-positive men and women to have children in the future are fulfilled, the number of children with HIV-infected parents will likely increase even further as the HIV epidemic spreads among men and women of childbearing age. The lives of both infected and uninfected children will be significantly affected by their parent's illness. Children of infected parents will need social services and other support to plan for a life with parental illness,[33] including counseling to cope with any stigma of growing up with an HIV-infected parent.

A major strength of our study is the direct measurement of future fertility desires and intentions in a diverse sample of men and women with HIV, rather than assessment of past pregnancies, births or abortions among pregnant HIV-positive women. Our measures of fertility desires and intentions are direct measurements of attitudinal data, rather than derivations of variables describing the timing of the pregnancy, feelings after pregnancy, contraceptive use or decisions about abortion. Our direct approach alleviates any potential confusion with labels such as "intended," "wanted" or "planned" that are derived from survey questions that are both attitudinal and behavioral, and therefore lack consistency across surveys.[34]

Our direct measures of future fertility desires and intentions distinguish between the "desire" and "intention" of having children, both of which are important connections between childbearing motivation and reproductive behavior.[35] In the predominant model of childbearing motiva-

tion, the desire for children is affected by personal and cultural traits, while the intention to have children is affected by timing and situational factors.[36] Better understanding of the source of desires and intentions and how they are affected by HIV infection would lead to more effective strategies to reach infected individuals who desire family planning services.

Our study concerns the potential number of intended and unintended pregnancies for individuals with HIV. Many women become pregnant unintentionally, and this has very different implications for service needs than do intentional pregnancies. Women who become pregnant unintentionally will need services that aid in decision-making to plan the outcome of their pregnancy. This includes services to help cope with unintended pregnancy, explore negative or positive attitudes toward childbearing, consider the consequences of bearing a child[37] or pursue alternatives such as adoption. Those who intend to become pregnant will need services, in addition to prenatal and delivery care, that help plan for a future closely linked to medical and social support, particularly given the competing caregiver responsibility of a parent living with infection.[38] In addition, many women who do not desire children would not have an abortion if they became pregnant unintentionally—in the present sample, more than one-quarter of women not desiring children. This very large number underscores the importance of assessing fertility desires and intentions in HIV-positive samples, just as researchers have long known is necessary for reaching accurate conclusions about fertility in the general population.

Although this article uses the nationally representative HCSUS sample of HIV-positive persons in treatment, the Risk and Prevention Study sample does not fully represent the baseline HCSUS population, but only the surviving members of the 1996 HCSUS cohort, all of whom had been receiving care for two and one-half years or more at the time of the Risk and Prevention Study interview. The fertility-related desires and expectations of persons entering care after 1996 might differ from those of our sample. In addition, our study does not include infected persons who are not in treatment or may not have access to care. However, the HCSUS sampling strategy uses sampling and attrition weights to account for nonresponse and loss to follow-up to the full interview.[39] Another limitation is that the Risk and Prevention Study sample did not include infected individuals younger than 20 or homosexual men, who may have different desires and expectations for children in the future. Sample size also precluded us from further investigating the differences between those who desire or expect one child and those who want two or more.

Our results indicate that many HIV-positive men and women who receive medical care in the United States desire and expect to have children in the future. As these individuals plan their families, they will need counseling and services to minimize the likelihood of HIV transmission to their partners and children and to help them meet the formidable challenges of undertaking parenthood while living with HIV. As the number of HIV-positive individuals who have children increases, the needs of HIV-affected families will become increasingly important. Further research illuminating the fertility decisions of those who are considering parenthood will allow for better counseling and services to aid HIV-infected individuals as they make these critical life decisions.

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*(continued on page 165)*

## Fertility Desires and Intentions…

*(continued from page 152)*

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