Sex Without Disclosure of Positive HIV Serostatus in a US Probability Sample of Persons Receiving Medical Care for HIV Infection

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It is difficult to identify a more charged issue in AIDS prevention than that of nondisclosure of positive HIV status to sexual partners. Seropositive individuals who do not disclose their status to sexual partners are often portrayed as dangerous pariahs.[1] As of 1999, 31 states had statutes making sexual contact without disclosure a criminal offense.[2] Public health researchers, responding to data reporting sexual contact without disclosure by HIV-positive persons, have called for interventions to promote increased sexual responsibility and to increase rates of consistent safer sex among HIV-positive persons.[3,4]

Public discourse on this topic is heavily influenced by a few well-publicized cases in which individuals who knew they were HIV positive reportedly infected a series of unsuspecting partners. The public health significance of nondisclosure, however, depends on both its prevalence and the riskiness of the behaviors that occur without disclosure—that is, the extent to which sex without disclosure is unprotected sex between serodiscordant partners. Previous studies show that not disclosing positive HIV serostatus to at least some sexual partners is common,[5–7] that HIV-positive persons are more likely to disclose their status to steady partners than to nonsteady partners,[8–10] and that unprotected sex without disclosure occurs within both types of partnerships.[5,9] Much of the previous research on this topic focused on specific subpopulations, such as gay and bisexual men,[9,11] men in general,[12] or women.[7,13,14] Studies that included both sexes or multiple risk groups[8,10,15] generally did not use sufficiently large sample sizes to support detailed group comparisons. Nor did previous studies examine whether and how individuals' behavior varies according to their partners' HIV status and condom use.

We report data from the Risk and Prevention Study subset of the nationally representative probability sample of the HIV Cost and Services Utilization Study (HCSUS). We describe (1) the extent to which Americans in treatment for HIV have sex without disclosure, (2) the extent to which this population has *unprotected* sex without disclosure, and (3) the extent to which unprotected sex without disclosure occurs within serodiscordant sexual partnerships. To the best of our knowledge, this is the first study to report data on the extent of sex without disclosure from a probability sample of HIV-positive adults in the United States and the first to provide comparative data across risk groups. Because data were collected on partnerships, we can examine disclosure at both the dyad and individual levels. We hope that this analysis will help inform policy and intervention debates on the best ways to encourage disclosure among HIV-positive persons and safer sex practices among the broad range of Americans infected with HIV or at risk of infection.

Objectives. We estimated the proportion of HIV-positive adults who have any sexual contact without disclosure and the proportion of their sexual partnerships that involve unprotected sex without disclosure.

Methods. We drew participants from the HIV Cost and Services Utilization Study (n=1421). Interviews assessed disclosure and sexual activities with up to 5 recent partners.

Results. Overall, 42% of the gay or bisexual men, 19% of the heterosexual men, and 17% of all the women reported any sex without disclosure, predominately within nonexclusive partnerships (*P*<.001). Across all groups, 13% of serodiscordant partnerships involved unprotected anal or vaginal sex without disclosure, with no significant difference between groups.

Conclusions. Risky sex without disclosure of serostatus is not uncommon among people with HIV. (*Am J Public Health.* 2003;93:949–954)

METHODS

Sample Description

Respondents were participants in the HCSUS, a national probability sample of 2864 persons aged 18 years or older with known HIV infection who made at least 1 visit to a nonmilitary, nonprison medical provider other than an emergency department in the contiguous United States during the first 2 months of 1996. Full details of the HCSUS design are available elsewhere.[16,17]

The Risk and Prevention Study subset used for our study consisted of 1421 HCSUS participants. Eligible members of the HCSUS sample were those who were interviewed in English at the HCSUS baseline interview, whose sex was unambiguous on the basis of HCSUS data, and who participated in the second follow-up HCSUS interview, conducted from August 1997 through January 1998 (n=2205). We drew 1794 individuals from this group, sampling randomly after stratifying by primary HCSUS sampling unit, type of health care provider, age, ethnicity, and self-described sexual orientation. We randomly sampled one third of eligible White gay men aged 40 years, 44% of eligible White gay

men aged 39 years and younger, and 100% of all other groups. We conducted interviews from September through December 1998. The completion rate was 79%, and the response rate after adjustment for known mortality was 84%.

The Risk and Prevention Study subsample was weighted to represent a target population of 197063 HIV-positive adults receiving medical care in the 48 contiguous states of the United States in 1996 and surviving until 1998. The analytic weights take into account differential selection probabilities, nonresponse, multiplicity, and attrition.[18] Men who identified themselves as "gay," "bisexual," or "heterosexual" and all women were included in the analysis reported in this article. Men who specified "other" or who did not report their sexual orientation were excluded (n=24). Tables show proportions weighted to represent the population, as well as unweighted sample sizes.

Survey Instrument and Procedures

The Risk and Prevention Study covered sexual activities, attitudes, and beliefs related to HIV transmission. Interviews were conducted in person. Interviewers asked questions and entered responses for most of the interview using a laptop computer. The computer was turned over to respondents for the section of the survey concerning sexual behavior and disclosure. Studies have found the use of such techniques to result in more accurate reporting of sensitive and socially undesirable behaviors.[19]

Sexual behavior was assessed for 6 months before the interview date. The interview defined oral, anal, and vaginal sex for respondents. Those who reported engaging in any of these categories of sexual activity during the 6-month period answered a set of questions regarding each (of up to 5) of their most recent partners in the past 6 months. Some respondents had a spouse or primary relationship partner with whom they were sexually active over the 6-month interval but who was not among their 5 most recent partners. These participants described their behavior with their primary partner in a final set of questions, which resulted in the assessment of 6 partners for these respondents. The questions covered partner HIV status; frequency of engaging in oral, anal, and vaginal sex; consistency of condom use with each activity; disclosure; and timing of sexual activity relative to disclosure.

Measures

Sexually active respondents were those reporting any oral, anal, or vaginal sex in the preceding 6 months; all others were considered abstinent. Aggregating across partners, we classified each active respondent into 1 of 2 mutually exclusive categories reflecting behavior in the past 6 months: (1) had sex only after disclosure, and (2) had any sex without disclosure. Respondents who refused to answer whether there had been any sex before disclosure were classified as missing data (n=7); those who said they didn't know or who were otherwise missing data were treated as having had sex only after disclosure (n=45).

Within partnerships, we first combined the "sex without disclosure" variable with consistency of condom use ("always" vs any other response) for anal and for vaginal sex and then aggregated across partners to create the variable "any unprotected sex without disclosure" in the past 6 months. Disclosure was not assessed for specific sexual activities. In addition, because timing specifically of unprotected sex was not assessed in relation to timing of disclosure (we asked about timing of any sex, not timing of unprotected sex), it is possible that some respondents had unprotected sex only after disclosing their positive status. However, we consider this sequence unlikely with serodiscordant partners, who are the focus of our analyses of this variable.

We classified respondents as having an exclusive partnership if they reported having sex with only 1 partner in the past 6 months and described this partner as a primary relationship partner or spouse.

We classified partnerships as serodiscordant if a partner was reported to be HIV negative (n=576), the partner's HIV status was unknown to the respondent (n=696), or the respondent refused to answer (n=1).

Analysis

We conducted analyses at both the respondent level and the partnership level. We used the full analysis sample of 1397 respondents to examine the prevalence of abstinence, sex only with disclosure, any sex without disclosure, and any unprotected anal or vaginal sex without disclosure by risk group. To adjust standard errors and statistical tests for the differential weighting and complex sample design, we used linearization methods[18,20] available in the statistical package Stata (Stata Corp, College Station, Tex).

Analyses at the partnership level focused on 1273 serodiscordant partnerships, examining the prevalence of unprotected anal and vaginal sex within these partnerships. Results for the multiple partners of a respondent might be correlated. In a sensitivity analysis, we adjusted for this design effect by treating each individual and his or her associated partners as a primary sampling unit and by using the same analytic weights. Because the sensitivity analysis yielded the same conclusions as our original analysis, which did not account for the correlation among partners, and because the sensitivity analysis reduced our statistical power owing to the design effect, we present only our original analysis results in this article.

RESULTS

The demographic characteristics of the sample differed significantly according to sexual risk group (Table 1). Gay or bisexual men more often were White, resided in the western region of the United States, and had higher levels of education and higher incomes compared with the other 2 groups. Heterosexual men were by and large older, of African American descent, and of lower education and income than the gay or bisexual men. Women, similar to heterosexual men, were often from the South and of lower income and education but tended to be younger than both men's groups, with one third being younger than age 35 years. A higher proportion of heterosexual men than of women or of gay or bisexual men reported injecting drugs before their HIV diagnosis, compared with women and gay or bisexual men. Compared with the other risk groups, gay or bisexual men had been HIV positive significantly longer and were more likely to have progressed to AIDS.

TABLE 1—Demographic Characteristics by Risk Group[a]

Characteristic	All Groups	Gay/Bisexual Men	Heterosexual Men	Women	P
Sample size	1397	606	287	504	
Target population	197 063	109 132	42 920	45 011	
Age, %					<.0001
20–39 y	47	49	30	57	
≥ 40 y	53	51	70	43	
Ethnicity, %					<.0001
African American	32	15	53	55	
Hispanic	13	10	15	16	
White	51	70	31	26	
Other	3	5	1	2	
Education, %					<.0001
< 12 y	24	10	38	43	
12 y	28	25	32	30	
13–15 y	27	30	23	22	
≥ 16 y	21	34	7	4	
Income ($), %					<.0001
0–10 000	44	32	56	62	
10 000–25 000	25	24	26	27	
≥ 25 000	31	44	19	11	
History of injection drug use prior to HIV diagnosis, %	20	11	41	24	<.0001
AIDS indicator condition, %	42	46	38	34	.0143
Mean days since tested HIV positive (95% confidence interval)	2668 (2573, 2764)	2929 (2797, 3061)	2376 (2266, 2487)	2311 (2194, 2427)	.0514

[a]Percentages are weighted to represent the population of HIV-positive individuals who received medical care in the United States in 1996 and survived to 1998.

Abstinence rates for all 3 risk groups were fairly high and were significantly higher among heterosexual men than among gay or bisexual men (*P*=.007 for heterosexual men vs gay or bisexual men) (Table 2). Rates of any sex without disclosure differed according to sexual risk group. Forty-two percent of gay or bisexual men reported any sex without disclosure, compared with 19% of heterosexual men and 17% of women (*P*<.001). Among gay or bisexual men, most sex without disclosure occurred within nonexclusive partnerships, whereas the rates of nondisclosure within exclusive partnerships were relatively low. Thirty-five percent of gay or bisexual men reported any sex without disclosure in a nonexclusive partnership, compared with 9% of heterosexual men and 9% of women

(*P*<.001). Among those who had engaged in sex without disclosure, gay or bisexual men were much more likely to be involved in a nonexclusive rather than an exclusive partnership, whereas heterosexual men and women were equally likely to be in either type of partnership.

The risk that sexual activity would lead to transmission varied by type of activity. Among gay or bisexual men who reported any sex without disclosure in a nonexclusive partnership, 42% engaged only in oral or receptive anal sex (not shown). Gay or bisexual men were more likely than the other 2 groups to report unprotected anal or vaginal sex without disclosure than the other 2 groups (*P*<.001). However, although 16% of gay or bisexual men reported such behavior, far fewer—3.2%—reported unprotected anal

insertive sex to ejaculation without disclosure in the past 6 months.

Sexually active members of our sample reported sex within 1273 serodiscordant partnerships in the past 6 months. Approximately half of the sexually active gay or bisexual men (58%), heterosexual men (46%), and women (47%) had any serodiscordant sexual partners during the 6 months before the interview. Almost one third of the gay or bisexual men (30%) had 2 or more serodiscordant partners, whereas fewer women (10%) and heterosexual men (9%) had 2 or more serodiscordant partners (*P*<.001).

Table 3 shows the percentage of serodiscordant partnerships involving unprotected sex without disclosure. There were no statistically significant differences between risk groups overall. Among gay or bisexual men who had serodiscordant partnerships, nearly all of the unprotected anal and vaginal sex without disclosure occurred in nonexclusive partnerships. Gay or bisexual men's relationships were significantly more likely to involve unprotected sex without disclosure with a nonexclusive partner of unknown or negative serostatus than were women's relationships (*P*<.001). Five percent of women reported not disclosing their HIV-positive status in serodiscordant exclusive partnerships, compared with 1% to 2% of all men (*P*=.065).

Across risk groups, most unprotected sex without disclosure in serodiscordant partnerships appeared to involve mutual nondisclosure (i.e., with a partner of unknown HIV serostatus). Among gay or bisexual men who had serodiscordant partnerships, most of the unprotected sex without disclosure occurred in nonexclusive partnerships with partners of unknown HIV status. Of the 13.8% of serodiscordant gay or bisexual partnerships in which there was unprotected sex without disclosure, more than three quarters (10.9% of all) involved nonexclusive partners whose HIV status was unknown, as opposed to partners known to be HIV negative.

The percentage of partnerships in which unprotected sex occurred without disclosure was similar in seroconcordant and serodiscordant partnerships. We saw no differences across risk groups.

TABLE 2—Respondent-Level Analyses: Disclosure of HIV-Seropositive Status to Sexual Partners[a]

	Gay/Bisexual Men (n = 606), Weighted % (95% CI)	Heterosexual Men (n = 287), Weighted % (95% CI)	Women (n = 504), Weighted % (95% CI)
Unweighted (N = 1397)			
Abstinent	28 (22, 33)	39 (34, 44)	34 (30, 38)
Sex only with disclosure	29 (24, 35)	41 (36, 47)	48 (42, 54)
Any sex without disclosure	42 (34, 49)	19 (14, 23)	17 (13, 20)
Nonexclusive partnerships	35 (29, 41)	9 (6, 12)	9 (5, 12)
Exclusive partnerships	6 (3, 9)	10 (7, 13)	8 (5, 11)
Unprotected anal or vaginal sex without disclosure	16 (10, 21)	5 (2, 7)	7 (4, 9)

Note. CI = confidence interval.
[a]Sex is defined to include vaginal and insertive and receptive oral and anal sex unless otherwise stated.

TABLE 3—Partnership-Level Analysis: Unprotected Anal or Vaginal Sex Without Disclosure in Serodiscordant and Seroconcordant Partnerships Within the Past 6 Months

	Weighted % (95% Confidence Interval)		
	Partnerships of Gay/Bisexual Men	Partnerships of Heterosexual Men	Partnerships of Women
Serodiscordant Partnerships Analysis			
Unweighted number of serodiscordant partnerships	n = 796	n = 167	n = 310
(n = 1273), weighted % (95% confidence interval)			
Unprotected anal or vaginal sex without disclosure	13.8 (10.4, 17)	8.8 (1.6, 15.9)	9.5 (4.7, 14.3)
With HIV-negative partner	2.5 (1.1, 4.0)	0.9 (0, 2.6)	3.8 (0.1, 7.5)
With HIV-unknown partner	11.3 (8.4, 14.2)	7.9 (0.9, 14.9)	5.7 (3.3, 8.1)
Nonexclusive partnerships	12.5 (9.4, 15.6)	6.7 (0.2, 13.2)	4.5 (2.8, 6.2)
With HIV-negative partner	1.6 (0.5, 2.6)	0 (0, 0)	1.3 (0, 2.9)
With HIV-unknown partner	10.9 (8.0, 13.9)	6.7 (0.2, 13.2)	3.2 (1.1, 5.2)
Exclusive partnerships	1.3 (0, 2.6)	2.1 (0, 5.3)	5.0 (0.6, 9.3)
With HIV-negative partner	1.0 (0, 2.2)	0.9 (0, 2.6)	2.4 (0.1, 4.8)
With HIV-unknown partner	0.4 (0, 0.9)	1.2 (0, 3.8)	2.5 (0.1, 4.9)
Seroconcordant Partnerships Analysis			
Unweighted number of seroconcordant partnerships	n = 303	n = 64	n = 101
(n = 468), weighted % (95% confidence interval)			
Unprotected anal or vaginal sex without disclosure	13.0 (6.5, 19.6)	6.1 (0.1, 12.1)	5.1 (1.3, 9.0)
Nonexclusive partnerships	10.8 (4.4, 17.3)	2.8 (0, 6.5)	2.2 (0, 4.9)
Exclusive partnerships	2.2 (0.3, 4.1)	3.3 (0, 6.6)	2.9 (0, 5.8)

DISCUSSION

The results of this study indicate that sex without disclosure of HIV status is relatively common among persons living with HIV. The rates of sex without disclosure found in our sample of HIV-positive individuals translate into 45 300 gay or bisexual men, 8000 heterosexual men, and 7500 women—all HIV-infected—engaging in sex without disclosure in our reference population of individuals who were in care for HIV in early 1996 and who survived until follow-up and were eligible to be interviewed in the fall of 1998. Because the reference population is smaller than the entire population receiving care in early 1996 and does not include those who began receiving HIV care between early 1996 and late 1998, these numbers should be considered a lower-bound estimate.

When we focus more narrowly on the people with the greatest risk of transmission—that is, those who report having unprotected anal or vaginal sex without disclosure—our results suggest that 17 400 gay or bisexual men, 2000 heterosexual men, and 2900 women engaged in this behavior during the 6-month reporting period. These estimates may be high because our variable would misclassify anyone who engaged in protected sex before disclosure and unprotected sex after disclosure during the 6-month interval. Among those with seroconcordant partners (most often gay or bisexual men), this pattern is not unlikely. Nevertheless, these numbers are large enough to suggest that substantial numbers of new HIV infections could occur among partners of HIV-positive persons who do not disclose their status.

The evidence that disclosure increases use of condoms with serodiscordant partners is mixed.[12] Still, prevention efforts designed to promote disclosure in addition to reducing unsafe sex among HIV-positive persons may yield important public health benefits. For example, the increasing availability of postexposure prophylaxis makes it possible for HIV-negative partners who know they are at risk to obtain treatment in the case of condom failure during sex.

Our results reveal substantially higher rates of sex (including protected and oral sex) without disclosure among gay or bisexual men than among heterosexual men or women. This suggests that the norms regarding disclosure may be quite different among gay or bisexual men than they are among the other risk groups. Within the gay community, the prevalence of HIV infection is substantially higher than it is among heterosexuals, providing a basis for HIV-positive gay or bisexual men to assume that their partners are aware of HIV transmission risk even if they do not disclose their serostatus. Moreover, public health messages urging gay men to "act as if every partner is HIV positive" may have contributed to norms that make disclosure optional. Among heterosexual men and women, the perceived and actual risk that a partner is

seropositive is quite low unless the person is an injection drug user. In view of these generally low risks, it cannot fairly be assumed that one's partner is aware of and accepts HIV transmission risk unless there has been explicit disclosure.

The proportions of people who engage in sex without disclosure differ not only by risk group but also according to the types of partnerships they have. Gay or bisexual men who have sex without disclosure are much more likely to be in nonexclusive than in exclusive partnerships. Exclusive relationships are likely to involve substantial commitment, and individuals may feel a greater responsibility to disclose to their partners in such relationships. Such relationships may align more with the traditional heterosexual relationship model than with casual relationships of gay or bisexual men. Together, these factors may account for the higher prevalence of unprotected sex in nonexclusive partnerships in this risk group. Among women and heterosexual men who have sex without disclosure, the proportions do not differ significantly by type of partnership.

In all 3 risk groups, most of those who reported engaging in sex without disclosure also reported having only protected sex or oral sex, both of which pose less risk of transmission than unprotected anal or vaginal sex. This suggests that people who do not disclose their HIV status often take steps to reduce HIV transmission risk to their partners—or that they consider that disclosure is not necessary, given that they have taken these steps. However, because these lower-risk activities still carry some risk of transmission (e.g., from condom failure), they are of public health concern. Moreover, use of unilateral risk reduction strategies is ethically indefensible, in that such strategies do not allow one's partner the opportunity of exercising informed choice about what level of risk is acceptable.[21–23]

It is frequently reported in the prevention literature that the majority of unprotected sex among male couples occurs within monogamous relationships.[24–26] However, when issues of disclosure and HIV serodiscordance are taken into account, most of the unprotected sex without disclosure among these men occurs within relationships that do not meet our definition of exclusivity. Conse-

quently, nonexclusive partnerships—which often may be short-term relationships in which assumptions about the other person's serostatus can easily be erroneous—may be those in which the greatest risk for HIV transmission lies. Preventive approaches for gay or bisexual men that focus on more enduring relationships as the source of HIV transmission may miss the subpopulations at greatest risk for HIV transmission.

Because we collected detailed information on sexual risk behavior and disclosure for each individual partner, we were able to conduct analyses at both the dyad and the individual level. Across risk groups, 13% of serodiscordant partnerships involved unprotected anal or vaginal sex without disclosure; no significant differences were found between groups overall. The partners of HIV-positive gay or bisexual men represent a much larger portion of the population of partners of persons with HIV. Thus, targeting interventions to this class of relationships should have a greater impact. However, among the serodiscordant partners of persons with HIV, the partners of gay or bisexual men do not appear to be at higher relative risk of unprotected sex without disclosure.

Although our study does not examine individual reasons for nondisclosure, significant disincentives to disclosure exist at the sociocultural level. As we enter the third decade of the AIDS epidemic, the stigma related to HIV-positive status continues to influence the behavior of persons living with HIV and AIDS.[2,27] Disclosure is undoubtedly complicated by perceived fears of rejection,[28] discrimination,[29] and violence from partners and others.[30,31] Women especially may fear retribution for disclosure of positive serostatus.[13,14,30,32] Among gay men, HIV status has become a defining characteristic that creates social barriers between individuals of differing serostatus. Interventions to reduce stigma at the community or societal level deserve further attention.

This study had several limitations that should be kept in mind when interpreting the results. First, the study focused only on HIV-positive persons who were receiving medical care. The reference population did not include HIV-positive persons who did not know they were infected or those who had been di-

agnosed but were not receiving medical care for HIV. Moreover, the people we studied had all been receiving care for at least 2.5 years. Because many individuals do not seek treatment until they begin having symptoms, this study represents those whose HIV disease is more advanced, on average, than would be found in the population of all diagnosed HIV-positive persons. Patterns of disclosure and sexual behavior may well differ between people with early-stage HIV illness who have not yet sought care and the people represented in our study.

In addition, as a study of people receiving medical care, our study underrepresents those with poor access to care, including the uninsured, minorities, and persons with low incomes. Also, all data were self-reported. Some HIV-positive persons may have been reluctant to admit that they engage, without informing their partners, in sexual behaviors that may transmit HIV; accordingly, the behavioral estimates reported here may be considered lower-bound estimates. However, our sample had already been interviewed several times, establishing a relationship with the larger HCSUS study, and we used computer-assisted self-interviewing methods, which have been shown to improve the accuracy of data obtained from self-report.[33] These factors may have reduced underreporting to some extent. In addition, because the "timing of disclosure" variable and the sexual activity variables were ascertained separately, we do not know the specific (i.e., whether high- or low-risk) sexual activities that occurred before disclosure. Finally, we acknowledge that no clear relationship exists between disclosure and unprotected sex.[12]

Many intriguing questions remain. What is the relationship between partner selection, on the basis of serostatus, and disclosure? To what degree are HIV-positive persons making sexual risk decisions on the basis of their partners' disclosure or lack thereof? Is it unethical to have sex without disclosing one's status when one's partner also does not disclose? Whose responsibility is it to disclose? Is the ethical obligation to disclose greater for the HIV-positive person? The data reported here suggest that these questions should be in the forefront of HIV prevention interventions for HIV-positive populations.

Such interventions should focus on specific relationships and contexts in which disclosure is most likely to affect behavior. Further analyses of sexual risk, HIV-positive status, and disclosure among HIV-positive persons have the potential to make such interventions more effective. ∎

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Contributors
D.H. Ciccarone contributed to the interpretation of the analyses and led the writing of the article. D.E. Kanouse and R.L. Collins contributed to the conception and design of the study and the interpretation of the analyses and made substantial contributions to all sections of the article. A. Miu led the analyses, contributed to the interpretation of the data, and made substantial contributions to the Methods and Results sections. J.L. Chen contributed to the interpretation of the analyses and made substantial contributions to the Results and Discussion sections. S.C. Morton contributed to the study design (including development of the weighting methods) and interpretation of the analyses and made substantial contributions to the Methods section. R. Stall contributed to the study design and interpretation of the analyses and made substantial contributions to the Introduction, Results, and Discussion sections.

Human Participant Protection
The study protocol was approved by the RAND and local health care provider institutional review boards.

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