



WOMEN LIVING WITH HIV: DISCLOSURE, VIOLENCE, AND SOCIAL SUPPORT

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ABSTRACT This paper describes the frequency of women's disclosure of their HIV status, examines the extent to which they experience adverse social and physical consequences when others learn they are infected, and analyzes correlates of these negative outcomes. There were 257 HIV-positive women between the ages of 18 and 44, recruited from HIV/AIDS primary care clinics and from community sites, who completed a face-to-face interview. Women in the sample were 33 years old on average; 92% were African-American; 54% had less than 12 years of education; 56% had used intravenous drugs; and 30% knew they were HIV positive for 5 or more years. There were 97% who disclosed their HIV status; 64% told more than 5 people. Negative consequences associated with others knowing they were HIV-positive were reported by 44%, most commonly the loss of friends (24%), being insulted or sworn at (23%), and being rejected by family (21%). There were 10 women (4%) who reported being physically or sexually assaulted as a result of their being HIV positive, and 16% reported having no one they could count on for money or a place to stay. Violence was widespread in this sample, with 62% having experienced physical or sexual violence, including sexual abuse or rape (27%), being beaten up (34%), and weapon-related violence (26%). Logistic regression analysis indicated that women with a history of physical and sexual violence were significantly more likely to experience negative social and physical consequences when their infection became known to others, adjusting for age and the number of people women had disclosed to, both of which were only marginally significant. Partner notification policies and support programs must be responsive to the potential negative consequences associated with others learning that a woman is HIV positive. The high rates of historical violence in the lives of women living with HIV underscore the need for routine screening and intervention for domestic violence in all settings that provide health care to HIV-positive women.

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INTRODUCTION

People with HIV generally are encouraged to inform appropriate others of their infection status, including, for example, sexual partners who may be at risk, as well as friends and family who might provide assistance with medical and complicated medication regimens. Yet, disclosure has been identified as an important psychological stressor for HIV-positive women.¹ Fear of abandonment and rejection, public ignorance and stigma, loss of children and housing, and potential violence have all been reported as barriers to disclosure.²⁻⁴ Nevertheless, it appears that most women eventually do disclose their status to others. Three prior studies³⁻⁵ of HIV-positive women have reported disclosure rates in the range 72%–98%. A study of 20 HIV-positive women who were tested during pregnancy found that 65% had not disclosed to any friends, and 25% had not disclosed to family members, but this somewhat discrepant finding may be due to the very small sample size or the short time between when women learned they were positive and the interview (6–36 months).²

Others may learn of a woman's HIV status either through her specific disclosure or through word of mouth when her status becomes known to friends and family.⁴ Very little is known about the impact on women of both intended and unintended disclosure to others. Lester et al.² compared 20 HIV-positive and 20 HIV-negative postpartum women and found that HIV-positive women were more depressed and anxious and reported more discrimination by health care providers and more social isolation. Gillman and Newman³ found that disclosure was associated positively with receiving more emotional and personal support, although 8% of women who disclosed to more than 10 people reported receiving no support, and 8% reported receiving support from only 1 person. Our own previous study⁴ found that just over one-quarter of a sample of 50 HIV-positive women experienced negative consequences when others learned of their status; the consequences included rejection or abandonment (22%) and verbal or physical assault (4%). Rothenberg et al.⁶ reported that, among 136 HIV/AIDS health care providers, 24% had at least 1 female patient who experienced violence as a result of HIV disclosure. Vlahov and colleagues⁷ recently reported that in a cross-sectional survey of HIV-positive women, the rate of physical or sexual attack as an adult did not differ by disclosure of test results to sexual partners, although these results are somewhat difficult to interpret because the question about violence was a cumulative measure of abuse during adulthood by any perpetrator. Nevertheless, in this sample, rates of violence during adulthood were quite

high: 66% reported having been abused physically, and 46% reported having been abused sexually or raped.⁷ Thus, whether violence is a substantial risk of disclosure remains an open question. Understanding the risks to women and their experiences when others learn of their HIV status is critical to formulating sound partner notification policies, as well as to developing appropriate interventions for women living with the disease.

In 1991, the Centers for Disease Control and Prevention began a multisite demonstration project of behavioral interventions to promote reproductive health in women at risk and HIV-positive women. At our site, baseline interviews were conducted with a sample of HIV-positive women at the time they enrolled in the intervention trial. The purposes of this paper are to (1) describe the frequency of women's disclosure of their HIV status and (2) examine the extent to which they experience adverse social and physical consequences as a result of being HIV positive. To understand better the context of women's lives in which these events occur, we also describe women's social support network, their history of interpersonal violence, and the relationship between these experiences and negative consequences of being HIV positive. We hypothesized that women who disclosed to more people, had less social support, and had a history of interpersonal violence would be more likely to experience negative social and physical consequences of being HIV positive.

METHODS

SAMPLE RECRUITMENT

A total of 322 HIV-positive women were recruited between April 7, 1993, and June 21, 1995, from both clinic and community sites in Baltimore, Maryland. The majority of subjects were recruited from two hospital-based clinical settings—one adult outpatient HIV clinic ($n = 213$, 66%) and one pediatric outpatient clinic serving children of HIV-positive women ($n = 59$, 18%). The remaining women were referred from a community-based outpatient HIV treatment clinic ($n = 11$, 3%) or were referred informally by other project participants or by outreach workers employed by the project ($n = 39$, 12%). The HIV status of all participants was confirmed either by medical records or, if records were unavailable, by an HIV test.

Women were eligible for the study if they were between 18 and 44 years old, not currently pregnant, and mentally and physically healthy enough to participate (as judged by the attending physician, charge nurse, or the recruiter). A study interviewer screened all potential participants for study criteria, described the

study, and obtained signed informed consent. The study was approved by the hospital's institutional review board.

To protect patients' confidentiality, names of women who declined to participate were not retained in study records. These women, particularly those identified in the clinics, therefore were likely to be approached more than once over the course of the 2-year recruitment period. Because the names of the women who were approached and declined and the number of times they were approached are not recoverable information, a true refusal rate could not be calculated. To assess the degree to which our sample was representative of the clinic population, we compared the sample distribution with that of the primary recruiting clinic for the same time period by examining 95% confidence intervals (CIs) around the point estimates for each variable in each distribution. Overlapping CIs indicated that our sample was no different from the clinic population as a whole on age and intravenous drug use history. Nonoverlapping CIs indicated that the sample included proportionally more African-American women and women with less than a 9th grade education and proportionally fewer women with more than a 12th grade education.

MEASURES

Women were paid \$10 for completing the baseline interview and \$5 for transportation. Interviews were conducted in a private office, and child care was available. Interviews lasted 40 to 90 minutes and included numerous topics, such as information related to HIV and reproductive health, HIV risk behaviors and beliefs, disclosure, violence, and social support. The subset of items relevant to the specific research questions of this paper are presented here.

Demographic and clinical characteristics Age, education, ethnicity, and number of children living with the woman were collected for all participants. HIV-related clinical information obtained from the women included the length of time they reported knowing they were HIV positive, history of intravenous drug use, and partner's HIV status.

Disclosure Women were asked how many people, besides doctors and nurses, they had told that they were HIV positive. Answer options were categorized as no one, 1 person, 2-5 people, or more than 5 people.

Social support We selected three domains of social support that we believed would be most relevant to women in our samples. *Social network* was measured by asking women how many relatives and how many friends they felt close to

and summing the responses. *Confidant* was measured by asking women if there was anyone in particular they could confide in or talk to about themselves or their problems. *Instrumental support* was measured by summing affirmative responses to two questions that asked women if they had someone they could count on to (1) lend or give them money and (2) take them in if they needed a place to stay.

History of physical and sexual violence Women were asked whether, as an adult, they had ever been (1) pushed, grabbed, or slapped; (2) kicked, bit, or hit; (3) beat up; (4) threatened with a knife or gun or had a knife or gun used against them; and (5) sexually abused or raped. Items 1–4 were adapted from the Conflict Tactics Scale, in which Items 2–4 are considered severe physical violence,⁸ and Item 5 measures sexual violence. The number of affirmative responses to the severe violence items (2–5) were summed to construct the history of violence scale score, which ranged from 0 to 4.

Negative consequences Two measures were used to construct the negative consequences variable. First, if a woman responded that she had experienced any of the five violent events described above, she was asked if she thought it happened because she was HIV positive. If she answered yes, it was counted as HIV-related violence and was included in the dependent variable as a negative consequence, but excluded from the history of violence independent variable (described above) to avoid double counting the same event and to disentangle background violence from that related to others learning that the woman was HIV positive. Second, all women were asked the following: "I'd like to ask you about some bad consequences that some women have experienced because they are HIV positive. Have any of the following things happened to you that you think were caused by your being HIV positive?" Have you been insulted or sworn at; had trouble getting or keeping a job; lost some of your friends; been turned out of your home; had your boyfriend/husband reject you; had other family members reject you. A summary score was calculated across all questions to reflect the total number of negative consequences women reported having experienced because of their HIV status.

ANALYSES

We first describe the sample characteristics and women's experiences of disclosure, social support, violence, and negative consequences. Bivariate comparisons relevant to the study aims are presented using Pearson r , t test, and Fisher exact tests. Logistic regression analysis was used to examine the extent to which demographic and clinical characteristics, disclosure, social support, and a history

of violence are related to whether women experience negative social and physical consequences of being HIV positive.

RESULTS

SAMPLE

Of the 322 women recruited, the first 65 (20%) were not asked questions about the negative consequences and therefore were excluded from this analysis. When the demographic and clinical characteristics of the remaining 257 women were compared to the 65 women not included, no statistically significant differences were found.

DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

The average age of participants was 32.7 years. Most women were African-American (92%), and more than one-half (54%) had less than a 12th grade education (Table I). A majority were never married (62%) and living with at least one child (60%). Over one-half of the women had used intravenous drugs, and 19% were currently with an HIV-positive male partner, although 45% did not have a main partner at the time of the interview. Of the women, 30% reported knowing they were HIV positive for 5 years or more.

DISCLOSURE

Only 8 women (3%) had not told anyone of their HIV status at the time of the interview (Table I); 6 of these women had known they were positive for 12 months or less. A majority of the sample (64%) reported having disclosed their HIV status to five or more people. The correlation between the length of time (in months) a woman knew she was positive and the reported number of people told was Pearson $r = 0.142$, $P = .023$.

SOCIAL SUPPORT

Most women reported having a confidant (89%) and numerous people who they felt close to in their social networks (mean = 8.1) (Table I). There were 68% who reported having someone they could count on for money and a place to stay, although 16% reported having no one they could count on for either. We compared the women with no instrumental support to the remainder of the sample on demographic and clinical characteristics and on their disclosure history. The absence of instrumental support was associated only with the average number of months women knew they were positive; women with no instrumental support had known they were positive for an average of 29 months, compared to 44 months for the remainder of the sample ($t = 3.1$, $P = .002$).

TABLE 1 Sample Characteristics, 257 Women Living with HIV, Baltimore, Maryland, 1993–1995

Study Variables	Percentage*	Study Variables	Percentage*
Demographics		Social support	
Age		Social network (# of people)	
<30	30	0	3
30–34	32	1–5	50
≥35	39	>5	47
Ethnicity		Confidant	
African-American	92	No	11
Other	8	Yes	89
Education (years)		Instrumental support score	
<12	54	0	16
12, GED	32	1	16
≥13	14	2	68
Marital status		Violence history	
Never married	62	Kicked, bit, or hit	
Married	8	No	65
Divorced/separated	24	Yes	35
Widowed	6	Beaten up	
Main partner status		No	66
HIV+	19	Yes	34
HIV–	25	Threatened with or used a knife or gun	
HIV unknown	10	No	74
No main partner	45	Yes	26
Years HIV positive		Sexually abused or raped	
<3	43	No	73
3–4	27	Yes	27
≥5	30	Total violence scale score (# of types)	
Ever used IV drugs		0	38
No	44	1	28
Yes	56	≥2	34
Disclosure			
Number of people told status			
0	3		
1–4	33		
≥5	64		

*May not add to 100% due to rounding.

HISTORY OF VIOLENCE

A history of physical and sexual violence was widespread in this sample (Table I), including 26% who had been threatened with a knife or gun or had one used against them, and 27% who had been raped. In total, 62% reported having

experienced at least one event; 28% experienced one type; and 34% reported two or more types of violent events.

NEGATIVE CONSEQUENCES

When asked specifically about negative consequences of being HIV positive, women most frequently reported the loss of friends (24%), followed closely by reports of being insulted (23%) and being rejected by family (21%) (Table II). In total, 56% reported experiencing no negative consequences, 16% reported one, 11% reported two, and 17% reported experiencing three or more.

There were 10 women (4%) who reported experiencing violence that they thought was attributable directly to their HIV status. The violence reported by these women included being pushed, grabbed, or slapped ($N = 4$); kicked, bit, or hit ($N = 1$); beaten up ($N = 1$); threatened with knife or gun or had one used against them ($N = 3$); and raped ($N = 1$). We compared these 10 women with the remainder of the sample on all study variables, and the two groups appeared similar on all measures with the following exceptions. Women who experienced HIV-related violence appeared more likely to have less than 12 years of education (90% versus 52%, $P = .022$) and to report experiencing more other negative consequences, including having trouble getting or keeping a job (40% versus 9%, $P = .013$); losing their home (50% versus 10%, $P = .002$); and being rejected by their families (70% versus 19%, $P = .001$).

RELATIONSHIP BETWEEN NEGATIVE CONSEQUENCES, DISCLOSURE, VIOLENCE, AND SOCIAL SUPPORT

Logistic regression was used to examine the probability of experiencing any negative consequences as a function of all of the study variables. Instrumental social support was dichotomized to compare women who had both types of support versus all others. All study variables were entered first into the model,

TABLE II Negative Consequences of Living with HIV
Among 257 Women, Baltimore, Maryland,
1993–1995

Type of Negative Consequence	Percentage
Physical violence or rape	4
Insulted or sworn at	23
Trouble getting or keeping a job	10
Lost friends	24
Turned out of home	11
Rejected by boyfriend/husband	9
Rejected by other family members	21

and those that were significant at $P \leq .10$ were retained and entered into the final model (Table III).

A history of physical or sexual violence was associated positively with experiencing negative consequences attributable to being HIV positive (OR = 1.4, 95% CI 1.11–1.74). There was a marginally statistically significant relationship between experiencing negative consequences and both having disclosed one's HIV status to more people and being younger.

DISCUSSION

In this sample of women, the majority of whom knew they were HIV positive for less than 5 years, almost all (97%) had disclosed their status to others, which is consistent with our previous qualitative study⁴ and higher than other reports from smaller samples of HIV-positive women¹⁻³ and from another large sample recently reported.⁷ Disclosure was not related to reported levels of social support, which were generally quite high in this sample. However, 16% reported having no one they could count on for money or a place to stay if they needed it.

Violence during adulthood was widespread in this sample, with 62% having experienced some form of severe physical or sexual violence, including sexual abuse or rape (27%), being beaten up (34%), and experiencing weapon-related violence (26%). These rates generally are consistent with two existing studies of HIV-positive women. In a study of 90 HIV-positive pregnant women, 53% reported ever having experienced domestic violence.⁹ Zierler et al.¹⁰ found that 35% of 74 HIV positive women reported having been raped as an adult. These rates among HIV-positive women appear higher than other studies of violence against women living in low-income urban areas, which have reported rates of physical violence of 25% to 34% and rates of 20% for sexual abuse by a partner.¹¹⁻¹³

TABLE III Odds Ratios of Experiencing Any Negative Consequences of Living with HIV Among 257 Women, Baltimore, Maryland, 1993–1995: Multiple Logistic Regression Results

Variables Included in Final Model	Odds Ratio	95% Confidence
		Interval
History of violence	1.39	1.11, 1.74
Number of people told	1.66	1.01, 2.72
Age	0.95	0.91, 0.99
Instrumental support (both vs. other)	0.58	0.33, 1.02

In a study comparing rates between HIV-positive and sociodemographically similar HIV-negative women, Vlahov et al.⁷ found that rates of adult violence did not differ between 764 HIV-positive women and 367 HIV-negative women (66% vs. 69%, respectively). HIV-positive women experienced significantly lower rates of recent physical or sexual violence in the 6 months preceding the interview (5% vs. 8%, respectively).⁷ Given the differences in sampling methods, time frames, questions, and perpetrators in this small body of literature, further research seems warranted.

Particular attention needs to be paid to measures of violence. A limitation in our study, as in others, is that simply counting violence as present or absent does not represent frequency and severity of the violence or its potential harm adequately. We tried to address this limitation by counting the number of different types of violence women experienced rather than simply using a dichotomous variable. Because of the substantial rates of violence in these women's lives, it may be that women experience the same violence after seroconversion as before, but after seroconversion, they attribute it to their HIV status. A longitudinal design comparing HIV-positive and HIV-negative women's violence experience over time would help address this limitation.

Regardless of the actual comparative risk, it is also relevant and important to describe the experiences and needs of women living with HIV. In that regard, we found substantial evidence that HIV-positive women experience social harms when others learn they are positive. Negative consequences associated with being HIV positive were widespread, with 44% of the sample reporting at least one problem, and almost one-quarter of the sample reporting that they lost friends, were rejected by their family, or had been insulted by others because they were HIV positive. Although the adverse consequences related to HIV reported here represent the women's perceptions, this should not undermine the validity of the findings. Rather, these results can be interpreted as indicating that there remains substantial stigma associated with being a woman infected with HIV.

Logistic regression analysis indicated that women who had experienced a history of severe physical or sexual violence were at increased risk for negative consequences, adjusting for age and the number of people the women had disclosed to, both of which were marginally significant. Interestingly, other socio-demographic characteristics, length of time since diagnosis, partner characteristics, and social support variables did not contribute significantly to experiencing negative consequences. This suggests that there is no simple profile of women at greatest risk for negative consequences, such as women with a history of intravenous drug use or with HIV-negative partners. Future studies should re-

examine the influence of social support because, due to time constraints on the interview, we were restricted in the number of items we could choose.

Fortunately, very few women in our sample (4%) reported experiencing violence that they thought was attributable directly to others learning they were HIV positive. It is troubling, however, that this last group of women also reported disproportionately more other negative consequences of being HIV positive, such as losing their jobs and their homes and being rejected by their family. These data suggest that there may be a core group of HIV-positive women who are particularly badly affected by others learning of their status. This group also had a smaller proportion of women who graduated from high school, which may leave them with limited opportunities and resources to overcome such negative experiences.

Because our sample closely mirrored the recruiting clinic's population of HIV-positive women, results should be generalizable to other HIV-infected women receiving care in inner-city teaching hospitals. Nonetheless, it is important to note that these women may not be representative of HIV-infected women who are not receiving care.

As symptoms of HIV disease become manifest, women eventually will come into contact with the medical care system. Thus, health care providers can use the results of this study in several ways. First, partner notification policies must acknowledge and be responsive to the potential negative consequences associated with others learning that a woman is HIV infected. Young women, those who disclose to more people, and those with a history of physical or sexual violence appear to be at increased risk for negative social consequences such as losing friends, jobs, and housing and being rejected by family. Screening women for these risk factors may help individualize recommendations about disclosure. Second, support services and programs should be available to ameliorate the negative consequences that appear to be widespread among HIV-infected women. Finally, the high rates of historical violence in the lives of these women underscore the need for routine screening and intervention for domestic violence in all settings that provide health care to women living with HIV.

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