

# Women's Lives After an HIV-Positive Diagnosis: Disclosure and Violence

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*Objectives:* This research addresses four questions: (1) What role do health care providers play in women's disclosure to others of their HIV-positive status? (2) What are women's concerns and experiences with disclosure? (3) What violence do women living with HIV experience? (4) How is the violence related to their diagnosis and disclosures? *Methods:* Participants were 310 HIV-positive women enrolled in an HIV primary care clinic in an urban teaching hospital. Women were interviewed once using both quantitative and qualitative methods. *Results:* Women had known they were HIV-positive for an average of 5.8 years; 22% had an HIV-positive partner; 58% had disclosed their status to more than 10 people; and 68% had experienced physical abuse and 32% sexual abuse as an adult. Fifty-seven percent of the sample reported that a health care provider had told them to disclose to their sex partners. Women who were afraid of disclosure-related violence (29%) were significantly more likely than those who were not to report that a health care provider helped them with disclosure (21% vs. 10%). Although 4% reported physical abuse following a disclosure event, 45% reported experiencing emotional, physical, or sexual abuse at some time after their diagnosis. Risk factors for experiencing abuse after diagnosis were a prior history of abuse, drug use, less income, younger age, length of time since diagnosis, and having a partner whose HIV status was negative or unknown. *Conclusions:* Identifying women at risk for abuse after an HIV-positive diagnosis is important for those who provide HIV testing and care. Routine screening for interpersonal violence should be incorporated into HIV posttest counseling and continuing primary care services.

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**KEY WORDS:** HIV/AIDS; disclosure; partner notification; females; intimate partner violence; sexual abuse; physical abuse.

## INTRODUCTION

HIV/AIDS has become an increasingly important public health problem for women; an estimated 51,447 women in the United States are now living with the disease (1). Women currently account for 32% of all adults with HIV, and African American women account for approximately 62% of all AIDS

cases among women in the United States. The CDC currently estimates that among cumulative AIDS cases in African American women, 37% were infected through heterosexual contact and 43% through injecting drug use (1).

Notification of a positive HIV test result can profoundly affect a woman's psychological and physical well-being (2, 3). The stigma associated with HIV can cause women to experience feelings of isolation and shame (4). HIV-infected people often fear rejection and abandonment following disclosure of their status (5–7). These concerns keep some women from disclosing to others even when they would like to, and for some, disclosure has in fact led to negative consequences, including violence (7–10).

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Public health authorities, however, seek to make it routine practice for health care providers to counsel HIV-positive women to disclose their status to sex partners. The three primary mechanisms by which partner notification occurs are (1) health-care-assisted disclosure, (2) contact tracing programs, and (3) self-disclosure (11–16). The assisted notification option depends on the health care provider's offer and the infected person's acceptance of assistance during disclosure to a sex partner. Contact tracing programs, which exist in at least 30 states (13), require health care providers to ask people found to be HIV-positive for the names of current and past sexual and/or needle-sharing partners. This information is then provided to state public health departments, which, in turn, locate and assist contacts in assessing their own HIV status. Serious questions about patient confidentiality have been raised about these programs (16). Although health authorities participating in contact tracing programs are forbidden to disclose the identity of the index patient to contacts, in some situations, such as with monogamous couples, not providing the name of the infected patient does not guarantee anonymity. North and Rothenberg (8) make a compelling argument that the public health need for partner notification requirements must be balanced against the potential harms women may experience as a result of their status disclosure. A solid understanding of the process and consequences of disclosure is needed both to inform the discussions of policy options for partner notification and to offer appropriate posttest counseling.

Current research on disclosure by HIV-infected women suggests high rates of disclosure (5, 17–20). However, little is known about delays in disclosure, which may increase exposure to the virus through continued high-risk behavior, or about the consequences of disclosures on women's lives and relationships. Although women frequently report serious concerns about disclosing their HIV status, the weight of the evidence suggests that the vast majority of women do eventually disclose their status to partners, family members, and friends. Kalichman and Nachimson's study (17) of disclosure to sex partners found disclosure rates among women below 50%, but in this study the disclosure question was restricted to disclosures in the 6 months before the interview. Simoni *et al.*'s (18) study among HIV-positive women ( $n = 65$ ) found that 87% had disclosed their status to their sexual partners and 78% had disclosed to friends. Seventy-six percent of the 107 HIV-positive women in Carter's study (19) had disclosed their sta-

tus to their primary sex partner. Similarly, 78% of the women in Stein *et al.*'s study (20) had disclosed their HIV status to all of their sexual partners. Gillman and Newman's study (5) found that 72% of 67 HIV-positive women interviewed had disclosed their status to more than 10 people and that disclosure was positively associated with increased emotional and personal support.

In a qualitative study with 50 HIV-positive women, experiences following disclosure included both positive (acceptance, understanding) and negative consequences (rejection, abandonment, verbal abuse, physical assault), reported by 75% and 25% of the sample, respectively (7). North and Rothenberg (8) described anecdotally the experience of two women who were shot as result of disclosing that they were HIV-positive. Vlahov *et al.* (10) found that 85.3% of HIV-positive and 98.3% of the HIV-negative women with main partners ( $n = 835$ ) reported disclosing their test results to those partners. Although disclosure rates were no different for women with and without a history of abuse, it was not possible to link either the timing or perpetrator of the violence with the testing and disclosure. Thus, the potential for violence to be a consequence of disclosure remains an important question to address empirically.

In addition to disclosure-related violence, evidence is increasing that abuse and HIV risk are interrelated in other important ways. In a study of sexual violence among HIV-positive women, 35% reported having been raped as an adult, which was associated with a history of multiple high-risk sexual practices (26). Abused women in general have been found to have higher rates of unsafe sexual practices (21, 22) and a host of other reproductive health problems (23–27). In a cross-sectional survey of 764 HIV-positive women, Vlahov *et al.* found rates of 46% for sexual abuse or rape and 66% for physical abuse as an adult; physical abuse in the last 6 months was reported by 5.1% of the sample (10). The negative impact of abuse on women's health may have particularly dire consequences for HIV-positive women, whose health status is already compromised.

Examining only the specific case of violence after disclosure is perhaps too narrow a lens through which to understand the role of violence in the lives of women after an HIV-positive diagnosis. Studies typically treat the issue of disclosure as a series of discrete patient-initiated events and ask about consequences of that event. Results from our previous study suggest that the notion of "disclosure" and its consequences

has broader dimensions that may have a substantial impact on women's lives (7). Women talk about how others "found out" that they were positive. Sometimes it was because a partner asked them directly, or following a patient-initiated disclosure, the recipient of the news then told someone else in the woman's social network. A second limitation of previous studies is how the consequences questions are framed. Reactions to learning that a partner or family member or friend is HIV-positive take shape and change over time; if we ask only about how someone reacted when they first found out, we may miss significant aspects of how women's lives and relationships are affected by living with HIV. Similarly, intimate partner violence is known to be an escalating cycle of events associated with power and control in the relationship (27), so it is quite possible that the abuse associated with disclosure occurs not out of instant anger in reaction to the news, but rather some time later either in the context of an ongoing or new cycle of violence.

We were able to begin to address some of these issues in a study of the relationship between HIV status and violence in a large urban area. HIV-positive women who had known they were positive for at least 6 months were interviewed using both quantitative and qualitative methodology. The following research questions are addressed in this paper: (1) What role do health care providers play in the disclosure process? (2) What are women's concerns and experiences with disclosure? (3) What violence do women living with HIV experience? (4) How is the violence related to their diagnosis and disclosures?

## METHODS

### Sample Recruitment

Data are from Project WAVE, a cross-sectional study of the relationship between violence and HIV risk in which 301 HIV-negative and 310 HIV-positive women were interviewed. The HIV-positive women who form the sample for this analysis were recruited between May 1997 and April 1999 from an outpatient HIV primary care clinic and an outpatient drug treatment clinic, both affiliated with a large urban teaching hospital located in and serving an economically poor inner-city area of Baltimore, Maryland. To maintain patient confidentiality, we were unable to record the names of women we approached for participation who declined to be in the study, so women could

have been approached multiple times, thus making it impossible to calculate a refusal rate. We did, however, compare our enrolled sample with the age and ethnicity distributions of Baltimore City female AIDS patients and found no apparent differences (data available upon request).

Women were eligible for the study if they were aged  $\geq 18$  years, not currently pregnant, and were mentally and physically healthy enough to participate (as judged by the clinic staff). Recruitment was done in person, except for 74 (24%) of the women from the primary care clinic who had participated in a prior study of the investigators and who were recruited for this study by letter. 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 institutional review board. Women were paid \$20 for completing the interview and \$5 for transportation.

### Measures

Data were obtained through a quantitative interview that lasted 60 min on average. In addition, 43 of the women who reported current or recent intimate partner abuse were randomly selected and asked to complete an additional in-depth qualitative interview, which took an average of 25 min to complete. All interviews were conducted in a private study office.

### Quantitative Survey

#### *Demographic and HIV-Related Characteristics*

Women were asked their age, education (less than high school, high school, greater than high school), per capita monthly household income (total household income divided by the number of people living in the household), ethnicity, and history of ever having used hard drugs (cocaine, crack, heroin). We also asked women about their main partner and his HIV status, which was coded into a single variable: partner status unknown or HIV-negative, partner HIV-positive, or no partner. We also recorded the date (month and year) when the woman reported being diagnosed HIV-positive and constructed the length of time since diagnosis as  $\leq 4$  years or  $> 4$  years.

### *Role of the Health Care Provider*

A series of yes/no questions was asked about women's experiences with health care providers, defined for women as doctors, nurses, social workers, or counselors. Women were asked, "Did a health care provider ever do any of the following things: tell you that you had to tell your sex partners about your status? offer to help you tell a sex partner about your status? help you tell a sex partner about your status? tell you that they were going to notify your sex partners of your status?"

### *HIV Disclosure*

Women were asked how many people, besides doctors and nurses, they had told about their HIV-positive status. Based on the frequency distribution of responses, answers were categorized as 0–5, 6–10, and more than 10 people. We also asked, "Were you ever afraid to tell someone because you thought they would get violent or physically attack you?" And "Did anyone ever get violent or physically attack you when they found out that you were HIV-positive?" Women who answered yes to this latter question were asked what happened.

### **Violence Before and After HIV Diagnosis**

Women were asked three separate questions about whether, as an adult, they had a partner or ex-partner (defined as husband, boyfriend, or male or female partner) do any of the following things to them: (1) repeatedly called you names or yelled at you, belittled you in public or controlled your social life (Emotional Abuse); (2) hit, slapped, kicked, pushed, shoved, or otherwise physically hurt you (Physical Abuse); or (3) forced you into sexual activities (Sexual Abuse). A second series of two questions following the same format asked women whether anyone other than a partner or ex-partner had physically or sexually abused them as an adult. For each positive response, women were asked the approximate date (month and year) of the first time they were abused and the date when they were last abused or whether it was ongoing. Using these starting and ending dates of abuse and the month and year of diagnosis, we constructed a variable to indicate for each type of abuse (and for all types combined) whether the abuse occurred only before, only after,

or both before and after the woman learned she was HIV-positive.

### **Qualitative Interview**

Women who participated in the qualitative component of the study were asked a series of broad, open-ended questions related to their experiences of disclosure, abuse, and HIV. The women were asked to think about the times when they told a sex partner about their HIV-positive status, and using qualitative interviewing techniques such as probing, the interviewers encouraged respondents to describe what the experience was like for them. For example, particular attention was paid to discussions of how they told their partners of their positive status, what their concerns were, exactly how the partner responded, and how their relationship changed following disclosure. They were also asked to talk about their experiences with intimate partner violence, specifically what factors they believed contributed to the violence and how their HIV status affected their relationship decisions.

## **ANALYSIS**

### **Quantitative Analysis**

Univariate statistics were used to describe the sample, women's disclosure-related experiences, and women's experience of violence. Bivariate chi-square analysis was used for assessing factors associated with receiving help with disclosure from health care professionals. Multiple logistic regression was used to identify risk factors for violence after an HIV-positive diagnosis. The outcome variable for the regression was any emotional, physical, or sexual abuse after the time of diagnosis by intimate or nonintimate partners. The independent variables tested included the sociodemographic characteristics (except for ethnicity, which had too little variation), number of people to whom the disclosure was made, whether a health care provider helped with disclosure, time since diagnosis, and a history of violence before the time of diagnosis. All variables were entered into a single model and those that were not significant ( $p > .05$ ) were eliminated in a stepwise fashion to obtain the final, most parsimonious model.

**Qualitative Analysis**

The qualitative interviews were audiotaped and then transcribed. Text sections of the transcripts were coded by pairs of study investigators and research assistants using thematic codes consistent with the study goals and aims. QRS NUD\*IST was used to manage, index, and search the data. Specific codes related to the topic of interest (e.g., disclosure experiences) were then selected and text examined for recurring themes (e.g., delaying disclosure) and to find illustrative quotes to elaborate on specific findings from the quantitative analysis.

**RESULTS**

**Sample**

Most of the women were African American (94%), aged 18–39 years (60%), with at least a 12-grade education (60%), and a per capita monthly household income of less than \$300 (60%) (Table I).

**Table I.** Sociodemographic and HIV-Related Characteristics of the Sample

Variable	N	%
<b>Age</b>		
<30 years	41	13
30–39 years	147	47
≥40 years	122	39
<b>Per capita household income</b>		
<\$300/month	187	60
≥\$300/month	123	40
<b>Ever used hard drugs</b>		
No	30	10
Yes	280	90
<b>Education</b>		
<High school	124	40
High school	139	45
>High school	47	15
<b>Ethnicity</b>		
African American	293	94
Other	17	6
<b>Current main partner</b>		
None	166	54
HIV+	69	22
HIV–/unknown	75	24
<b>Length of time HIV+</b>		
≤4 years	114	37
>4 years	196	63
<b>Number disclosed to</b>		
0–5 people	75	24
6–10 people	54	17
>10 people	181	58

Sixty-three percent of the women reported knowing they were HIV-positive for over 4 years (mean = 5.8, *SD* = 3.2). Fifty-four percent of the women did not have a main partner at the time of the interview; 22% had an HIV-positive partner. At the time of the interview, 58% of the women had told more than 10 people about their HIV status. Few women had disclosed their HIV-positive status to only 1 person (*n* = 9, 3%) or to no one at all (*n* = 5, 2%).

**Role of the Health Care Provider**

Almost one half of the sample (46.5%) reported that a health care provider had offered to help them disclose, 57.1% said they were told they had to disclose to their sex partners, 12.6% were told that the provider would notify their sex partners, and 29.4% reported having been afraid to tell someone because of concerns about violence (Table II). A total of 13.5% of the sample reported that a health care provider had helped them disclose their status to a sex partner. Women whose provider made an offer to help with disclosure were significantly more likely to report that they had actually received help than those whose provider had never made such an offer (26% vs. 3%). Similarly, the proportion of women who reported receiving help with disclosure was significantly greater when health care providers told women they had to tell their sex partners or told them that they

**Table II.** Women’s Reports of Health Care Provider (HCP) Interactions About HIV Disclosure to Sexual Partners and Frequency of Receiving Help with Disclosure

	N	% Total sample	% Received help with disclosure	$\chi^2, p$
<b>HCP offered to help</b>				
No	166	53.5	3.0	33.87, .000
Yes	144	46.5	25.7	
<b>HCP said you have to tell</b>				
No	133	42.9	9.0	4.07, .04
Yes	177	57.1	16.9	
<b>HCP said they will notify</b>				
No	271	87.4	10.0	23.6, .000
Yes	39	12.6	38.5	
<b>Woman afraid of violence</b>				
No	219	70.6	10.5	5.91, .02
Yes	91	29.4	20.9	
<b>Total</b>	<b>310</b>	<b>100</b>	<b>13.5</b>	

were going to notify their sex partners (Table II). Finally, women who were afraid to disclose were significantly more likely than those who were not to have received help from a health care provider (20.9% vs. 10.5%) (Table II).

### Women's Concerns and Experiences with Disclosure

Twelve women (4%) said yes to the specific question about whether anyone had gotten violent or physically attacked them after finding out they were HIV-positive. When asked what happened, women's responses included descriptions of violent events such as "my children's father beat me, he said I was trying to kill him," and "he tried to kill me by hitting me with a car." As illustrated in the following quote from the qualitative interview, women's disclosure to their sex partners could be delayed because of concerns for personal safety:

I was scared to tell him. That's why I waited for awhile. I was gonna send a letter to him so I wouldn't be there cause he done hit me before . . . He gets mad and then says he'll hit me, he get to hollering at me and stuff like that. That scares me cause I know next thing, the next step he would hit me, you know.

Even when women were not in an abusive relationship or concerned about violence, their descriptions of the disclosure process show how fear can delay disclosure and increase risk:

We had intercourse a couple of times without protection, and right now today, I'm not sure if he's infected or not, but right now today if he's infected I blame myself, . . . because I told him I was, right, but I didn't tell him as soon as we started the relationship. I didn't come out, I knew I had it, but I didn't come out and tell him straight out. Eventually I did wind up telling him and whatnot because I went somewhere else and got another test done. I told him and he like just stared at me, you know, like in that way, he went into a little shocking look . . . Tears ran down my eyes and he just held me and said, "it's gonna be alright. I'll stick with you. I'll be on your side."

I didn't want to tell him [that I was HIV-positive]. He pulled it outta me. I said, "I got something to tell you, but it's so hard . . . well, I'm HIV-positive and I have been for 10 years." And he looked at me and said, "so?" I wanted to know how he felt about it. He said, "I want to be with you, and if that means that I have to accept that too, then that's okay."

Well, I tried to avoid this thing [disclosing HIV sta-

tus] for maybe about 4 months. We went out on a couple of dates, and then, about the fourth month he wanted to go a little further, and I was like "no." And finally I said that before we can even go further you need to know some things. And I told him. Well, he hugged me and kissed me and said he still wanted to be my guy . . . he's been really good.

Women discussed their troubles disclosing to their family members as well.

Well, I didn't tell everybody until 9 years had passed, I was afraid that my mother and them would stop loving me, or accepting me for myself.

Another woman poignantly expressed the shock and emotion felt by many women.

I just didn't know how to tell my family . . . When I found out [about being infected] I was devastated. When they told me the results and stuff, I was just like in a daze. I didn't wait around to find out if I'm gonna die today, tomorrow, or who I gotta tell about it. I was planning on keeping this thing to myself and not telling nobody.

Others described experiences with discrimination, such as this woman who was ostracized from her social group because they believed she would infect others.

I told my family, they didn't take it well. Didn't nobody take it so well. At first I wouldn't tell nobody, cause in my family they used to separate the dishes cause they didn't understand it. Separate the dishes and stuff. They made me feel like crap.

### Violence Before and After HIV Diagnosis

Two thirds (67%) of the sample experienced some form of emotional, physical, or sexual abuse from a partner or ex-partner as an adult. For 34% of the sample this violence occurred only before their diagnosis; for 16% it occurred only after; for 17% it occurred both before and after the diagnosis (Table III). Additionally, 42% of the sample reported experiencing physical or sexual abuse by someone other than an intimate partner. For 17% of the sample, this violence occurred only before their diagnosis, for 18% only after, and for 7%, the abuse occurred both before and after their diagnosis (Table III). Combining both intimate and nonintimate partner violence, 45% of the sample experienced abuse after learning they were HIV-positive (13% after only and 32% both before and after) (Table III). The qualitative interviews shed light on these experiences:

When my daughter was diagnosed in December with

**Table III.** Frequency of Abuse by Type of Perpetrator and Time of HIV Diagnosis

Perpetrator of abuse	Abuse in relation to time of HIV diagnosis (%)			
	None	Before only	After only	Before and after
<b>Intimate partner</b>				
Emotional abuse ( <i>N</i> = 308)	44	29	15	13
Sexual abuse ( <i>N</i> = 310)	79	13	4	4
Physical abuse ( <i>N</i> = 310)	40	34	15	11
Total partner abuse ( <i>N</i> = 308)	33	34	16	17
<b>Other perpetrator</b>				
Sexual abuse ( <i>N</i> = 309)	82	10	5	3
Physical abuse ( <i>N</i> = 309)	64	14	16	5
Total other perpetrator abuse ( <i>N</i> = 308)	58	17	18	7
<b>Total combined intimate partner + other perpetrator</b>				
Sexual abuse ( <i>N</i> = 306)	68	18	8	6
Physical abuse ( <i>N</i> = 306)	32	28	16	25
Total abuse <sup>a</sup> ( <i>N</i> = 306)	28	27	13	32

Note: Percentages may not total 100 due to rounding.

<sup>a</sup>Emotional abuse, which was measured only for intimate partner, is included in total abuse.

HIV, the abuse started then . . . He didn't want to accept the blame for it and he wanted to throw it on me. So he used to do things mentally to try to make me feel like I was responsible. Then he started disrespecting me in public, especially in front of his family.

He was abusive before I told him I was HIV-positive, and afterwards, well, the beatings got worse and more . . . they happened more regularly. I say that because I remember him making the statement, "I should kill you since you are trying to kill me."

In the logistic regression model of the combined intimate and nonintimate partner violence after time

**Table IV.** Proportion of Women Reporting Abuse by Any Perpetrator After the Time of HIV Diagnosis by Age and Length of Time HIV-Positive (*N* = 306)

Length of time HIV+	Age group (years)	Abused after time of diagnosis	
		<i>N</i>	%
≤4 years ( $\chi^2 = 1.08, p = .30$ )	18–29	28	21
	30–39	55	36
	≥40	29	34
	Subtotal	112	32
>4 years ( $\chi^2 = 13.06, p = .00$ )	18–29	13	76
	30–39	90	63
	≥40	91	39
	Subtotal	103	53
Total		306	45

of HIV diagnosis, we found significant interactive effects of age and length of time since diagnosis (Table IV), and significant direct effects of women's abuse before her HIV diagnosis, use of drugs, partner's HIV status, and per capita household income (Table V). Younger women who had been diagnosed more than 4 years before the interview were at greatest risk for being abused since learning they were HIV-positive. Among women diagnosed more than 4 years ago, the association between age and abuse was statistically significant: 76% of those younger than aged 30 years and 63% of those aged 30–39 years reported abuse, compared with 39% of those aged 40 years and older (Table IV). Adjusted for these effects (age and time since diagnosis), a history

**Table V.** Multiple Logistic Regression: Risk Factors for Abuse by Any Perpetrator After the Time of HIV Diagnosis (*N* = 306)

Variable	Odds ratio <sup>a</sup>	95% CI
<b>Abuse prior to HIV diagnosis</b>		
Yes vs. no	2.37	1.38, 4.09
<b>Ever used hard drugs</b>		
Yes vs. no	3.51	1.30, 9.52
<b>Partner HIV status</b>		
HIV+ vs. no partner	1.55	0.81, 2.96
HIV–/not known vs. no partner	2.07	1.10, 3.90
<b>Per capita household income</b>		
≥\$300/month vs. < \$300/month	0.55	0.32, 0.92

<sup>a</sup>Adjusted for age and length of time HIV-positive.

of abuse before the HIV diagnosis was a significant risk factor for abuse after the diagnosis (OR = 2.37) as was a history of drug use (OR = 3.51) (Table V). The likelihood of experiencing abuse was twice as high for women whose partner's HIV status was negative or unknown relative to women who had no main partner (OR = 2.07) and half as high for women who had more financial resources (OR = 0.55).

## DISCUSSION

Consistent with most previous literature (5, 7, 10, 18, 19), we found high rates of disclosure among our sample of HIV-positive women who had been living with the disease for an average of 5.8 years. Virtually all women (95%) had disclosed to more than 1 person, and 58% had disclosed to more than 10 people. The qualitative data provided examples of how women's delay in disclosure to sex partners was associated with unprotected sex, thus increasing risks to the women and their partners. Health care providers have an opportunity to intervene and an obligation to discuss disclosure when they communicate positive test results. Our quantitative data shed some new light on what this experience is like from the women's perspective. Slightly more than half of the sample (57%) remembered being told by a health care provider that they should disclose to their sex partners. Almost half of the sample (46%) said their health care provider offered to help them disclose their test results, although only 26% of the women who were offered help reported receiving help. Women who reported being afraid of disclosure-related violence were significantly more likely than those who were not afraid to report having received help with disclosure, although the proportions in both groups were low (20.9% vs. 10.5%).

Our data do not allow us to draw conclusions about the quality of the health care provider's discussion of disclosure when it did occur; for example, we cannot know whether women's concerns and risks for violence were assessed. The data do, however, suggest issues for both practitioners and researchers. That a large proportion of women did not report having been told that they should disclose to their sex partners is potentially troubling because of the possibility of high-risk, unprotected sex, which was suggested in our qualitative data on delayed disclosures. Although it was reassuring that women who reported concerns about violence were significantly more likely to report receiving help with disclosure, the overall rates of receiving

help were low, even among women who reported being offered help. Practitioners may want to assess how often and in what context they raise the subject of disclosure with their clients, paying particular attention to when and how they make an offer to help women disclose. More in-depth, patient-provider communication studies seem warranted to better understand the barriers and facilitators to discussions about disclosure from the perspectives of both the health care provider and client.

HIV-positive women report high rates of experiencing intimate partner violence as an adult—56% for emotional, 21% for sexual, and 60% for physical abuse. When abuse by other perpetrators is included, the women in our study reported total prevalence rates of 68% for physical abuse and 32% for sexual abuse. These rates are comparable to those found by Vlahov *et al.* (10) among a sample of sociodemographically similar HIV-positive women, in which 66% reported physical abuse and 46% reported sexual violence or rape during adulthood. Our rate of sexual abuse may be somewhat lower because, unlike the item used in Vlahov's instrument, we did not specify rape in our question. Our rate of physical abuse by an intimate partner among an HIV-positive sample is higher than prevalence rates from other population- and clinic-based samples (28).

The finding that only 4% of women experienced abuse they attributed directly to a disclosure event should be balanced against our finding that 13% of women reported emotional, physical, or sexual abuse that occurred only after they learned they were HIV-positive and an additional 32% of women experienced such abuse both before and after learning they were positive. The qualitative data help capture the meaning of these figures and provide compelling narratives of how reactions to a positive diagnosis, especially by partners, may lead to new or escalating violence only after some period of time.

A limitation in this study is that we relied on women's recall of abusive events and date of HIV diagnosis. Although recall bias is an inherent problem with cross-sectional designs, especially when recall periods are lengthy, we believe that the salience of the events is likely to be high and thus the reporting fairly accurate. The qualitative data add credibility to the findings by providing examples of new and escalating abuse after others learn of the woman's diagnosis. Moreover, it should be emphasized that we are not attempting to define a causal pathway between being diagnosed HIV-positive, disclosure, and experiencing abuse. Rather, we are describing

more broadly dimensions of HIV-positive women's lives that have been previously neglected in the HIV literature. Our data begin to provide a picture of who may be at risk for abuse so that those who care for HIV-positive women can be alert to this aspect of their clients' lives.

The extent to which we can identify women at risk for new or escalating abuse after a positive diagnosis is important for those who provide HIV testing and care for HIV-positive women. Notably, neither the number of people to whom women disclosed nor whether a health care provider helped with disclosure predicted violence after a diagnosis. Caution is required in interpreting this latter result because only a small proportion of the sample reported receiving help with disclosure and the data do not allow us to link who the woman disclosed to (with or without help from the provider) and who abused her. We found that having a history of abuse, a history of drug use, living in a low-income household, and having a main partner whose HIV status was discordant were significant risk factors for abuse after an HIV diagnosis. Also, younger women who had been living with the disease for more than 4 years were at dramatically increased risk, which is counter to the hypothesis suggested by Vlahov *et al.*'s data (10) that as the disease progresses and women become symptomatic, their risk for violence decreases. Perhaps women diagnosed at a very young age have been exposed to conditions that put them at increased risk for both HIV and violence (e.g., child sexual abuse, IV drug use, or poverty). Longitudinal data are needed to properly address the questions raised by Vlahov *et al.* (10) and the present study's results.

Results from this study have implications for care providers. On the one hand, we can reassure HIV-positive women that simply having more people know their status does not necessarily increase their risk for violence. On the other hand, health care providers cannot assume that a history of abuse is the only relevant risk factor for abuse after diagnosis. Our data suggest an additional constellation of factors—drug use, partner status, income, age, and duration of the disease—that can be used to heighten a provider's index of suspicion that a woman may be at risk for abuse. Thus, it seems that an individualized approach to posttest counseling that assesses women's unique situations and risk is warranted. Routine screening and appropriate treatment for interpersonal violence should be incorporated into HIV posttest counseling and continuing primary care services.

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## REFERENCES

- Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Rep* 1999;11(1).
- Abercrombie PD. Women living with HIV infection. *Nurs Clin North Am* 1996;31(1):97–106.
- Semple RR, Moutlon JM, Moss AR. Self-disclosure of HIV-1 antibody test results: The San Francisco General Hospital cohort. *AIDS Educ Prev* 1993;7:116.
- Chung J, Magraw M. A group approach to psychological issues faced by HIV-positive women. *Hosp Commun Psychiatry* 1992;43:891.
- Gillman RR, Newman BS. Psychosocial concerns and strengths of women with HIV infection: An empirical study. *Families Society J Contemp Hum Serv* 1996;131.
- Lester P, Partridge JC, Chesney MA, Cooke M. The consequences of positive prenatal HIV antibody test for women. *J Acquir Defic Synd Hum Retrovirol* 1995;10:341–9.
- Gielen AC, O'Campo P, Faden RR, Eke A. Women's disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. *Women Health* 1997;25(3):19–31.
- North RL, Rothenberg KH. Partner notification and the threat of domestic violence against women with HIV infection. *N Engl J Med* 1993;329:1194–6.
- Rothenberg KH, Paskey SJ, Reuland MM, Zimmerman SI, North RL. Domestic violence and partner notification: Implications for treatment and counseling of women with HIV. *JAMA* 1995;50:97.
- Vlahov D, Wientge D, Moore J, Flynn C, Shumann P, Schoenbaum E, Zierler S. Violence among women with or at risk for HIV infection. *AIDS Behav* 1998;2:53.
- Centers for Disease Control. Partner notification for preventing human immunodeficiency virus (HIV) infection—Colorado, Idaho, South Carolina, Virginia. *MMWR* 1988; 37:393–402.
- West GR, Stark KA. Partner notification for HIV prevention: A critical reexamination. *AIDS Educ Prev* 1997;9(Suppl B):68–78.
- Colfax GN, Bindman AB. Health benefits and risks of reporting HIV-infected individuals by name. *Am J Public Health* 1998;88:876–9.
- Fenton KKA, Peterman TA. HIV partner notification: Taking a new look. *AIDS* 1997;11:1535–46.
- Bayer R, Toomey KE. HIV prevention and the two faces of partner notification. *Am J Public Health* 1992;82:1158–64.
- Kass NE, Gielen AC. The ethics of contact tracing programs and their implications for women. *Duke J Gender Law Policy* 1998;5:89–102.
- Kalichman SC, Nachimson D. Self-efficacy and disclosure of HIV-positive serostatus to sex partners. *Health Psychol* 1999;18:281.
- Simoni JM, Mason HRC, Marks G, Ruiz MS, Reed D, Richardson JL. Women's self-disclosure of HIV infection: Rates, reasons and reactions. *J Consult Clin Psychol* 1995;63:474.
- Carter R. *Disclosure of HIV serostatus to male sexual partners*. Presented at HIV and Women Conference, Washington, DC, 1995, Abstract TP481.
- Stein MD, Freedberg KA, Sullivan LM, Savetsky J, Levenson SM, Hingson R, Samet JH. Sexual ethics: Disclosure of HIV-positive status to partners. *Arch Internal Med* 1998;158:253–7.
- Wingood G, DiClemente R. The effects of an abusive primary

- partner on the condom use and sexual negotiation practices of American-American women. *Am J Public Health* 1997; 87:1016–8.
22. Molina LD, Bassinait C. Revisiting the intersection between domestic abuse and HIV risk. *Am J Public Health* 1998; 88(8):1267–8.
  23. Plichta SB. Violence and abuse: Implications for women's health. In: Falik MM, Collins KS, editors. *Women's health: The commonwealth funds survey*. Baltimore, MD: Johns Hopkins University Press, 1996.
  24. Campbell JC, Pugh LC, Campbell D, Visscher M. The influence of abuse on pregnancy intention. *Women Health Issues* 1995;5:214–3.
  25. Campbell JC. Women's responses to sexual abuse in intimate relationships. *Women's Health Care Int* 1989;8:335–47.
  26. Zierler S, Witbeck B, Mayer K. Sexual violence against women living with or at risk for HIV infection. *Am J Prev Med* 1996;12:304–10.
  27. Campbell J, Rose L, Kub J, Nedd D. Voice of strength and resistance: A contextual and longitudinal analysis of women's responses to battering. *J Interpers Violence* 1998;13:743–62.
  28. Jones AS, Gielen AC, Campbell JC, Schollenberger J, Diememann JA, Kub J, O'Campo PJ, Wynne EC. Annual and lifetime prevalence of partner abuse in a sample of female HMO enrollees. *Women's Health Issues* 1999;9(6):295–305.