

Washington University School of Medicine Digital Commons@Becker

Open Access Publications

2013

Strategies and outcomes of HIV status disclosure in HIV-positive young women with abuse histories

Gretchen A. Clum

Tulane University

Lauren Czaplicki

The Louisiana Public Health Institute

Katherine Andrinopoulos

Tulane University

Kathryn Muessig

Johns Hopkins University

L Hamvas

Washington University School of Medicine

See next page for additional authors

Follow this and additional works at: http://digitalcommons.wustl.edu/open_access_pubs

Recommended Citation

Clum, Gretchen A.; Czaplicki, Lauren; Andrinopoulos, Katherine; Muessig, Kathryn; Hamvas, L; and Ellen, Jonathan M., "Strategies and outcomes of HIV status disclosure in HIV-positive young women with abuse histories." *AIDS Patient Care and STDs*.27,3. 191-200. (2013).

http://digitalcommons.wustl.edu/open_access_pubs/4766

This Open Access Publication is brought to you for free and open access by Digital Commons@Becker. It has been accepted for inclusion in Open Access Publications by an authorized administrator of Digital Commons@Becker. For more information, please contact engeszer@wustl.edu.

Authors

Gretchen A. Clum, Lauren Czaplicki, Katherine Andrinopoulos, Kathryn Muessig, L Hamvas, and Jonathan M. Ellen

Strategies and Outcomes of HIV Status Disclosure in HIV-Positive Young Women with Abuse Histories

Gretchen A. Clum, PhD,¹ Lauren Czaplicki, MPH,² Katherine Andrinopoulos, PhD,¹ Kathryn Muessig, PhD,³ L. Hamvas, MPH,⁴ Jonathan M. Ellen, MD,⁵ and the Adolescent Medicine Trials Network for HIV/AIDS Interventions

Abstract

Young women with HIV and histories of physical and/or sexual abuse in childhood may be vulnerable to difficulties with disclosure to sexual partners. Abuse in childhood is highly prevalent in HIV-positive women, and has been associated with poorer communication, low assertiveness, low self worth, and increased risk for sexual and other risk behaviors that increase the risk of secondary transmission of HIV. HIV disclosure may be an important link between abuse and sexual risk behaviors. Qualitative interviews with 40 HIV-positive young women with childhood physical and/or sexual abuse were conducted; some women had also experienced adult victimization. Results suggest that HIV-positive women with abuse histories use a host of strategies to deal with disclosure of HIV status, including delaying disclosure, assessing hypothetical responses of partners, and determining appropriate stages in a relationship to disclose. Stigma was an important theme related to disclosure. We discuss how these disclosure processes impact sexual behavior and relationships and discuss intervention opportunities based on our findings.

Introduction

ADVANCEMENTS IN ANTIRETROVIRAL DRUG treatment have enabled persons living with HIV/AIDS (PLWHA) to live longer, healthier lives with increased opportunity for engaging in intimate relationships. An ongoing challenge to secondary prevention of HIV is understanding and intervening with factors influencing continued engagement in unprotected sex with new and existing partners.¹⁻³ HIV-positive women with childhood abuse histories, including both physical and sexual abuse in childhood, have been identified as a particularly vulnerable population, with higher rates of unprotected sex, greater numbers of partners, and additional health risk behaviors, such as substance use, and poorer adherence than their counterparts without abuse histories.⁴⁻⁹ One potentially relevant mechanism linking abuse and engagement in unprotected sex is disclosure of HIV status. Women with childhood abuse histories report less assertive behavior, greater interpersonal distress, increased shame, and more difficulty with interpersonal communication.¹⁰⁻¹⁴ Young women with HIV diagnosis and prior experiences of

physical and/or sexual abuse in childhood may be particularly vulnerable to difficulties disclosing their HIV status to partners, which may play an important role in risk behaviors.

Disclosure has been associated with greater adherence to HIV care and regimens, and improved mental and physical health.¹⁵ Several factors appear to influence disclosure of HIV status. Persons living with HIV or AIDS who report low self-efficacy to disclose their status are more likely to never or infrequently disclose their HIV status to a sexual partner.^{16,17} HIV stigma has also been shown to be negatively related to the decision to disclose across studies.¹⁸ Exposure to heightened levels of HIV stigma are associated with increased feelings of negative self-image—including shame and guilt—and a subsequent decrease in confidence to disclose HIV status.¹⁹⁻²¹ PLWHA are more likely to disclose their HIV status to primary sex partners compared to casual partners²²⁻²⁴ and several studies have found higher rates of disclosure in established relationships lasting longer than 6 months.^{3,25} Frequency of contact with an individual, and female gender has also been shown to be associated with time to disclosure in women with HIV.²⁶ The association between relationship

¹Tulane University School of Public Health and Tropical Medicine, New Orleans, Louisiana.

²The Louisiana Public Health Institute, New Orleans, Louisiana.

³Johns Hopkins School of Public Health, Baltimore, Maryland.

⁴Washington University, St. Louis, Missouri.

⁵Johns Hopkins School of Medicine, Baltimore, Maryland.

length and status disclosure, and differences in status disclosure by partner type are potential ways PLWHA attempt to mitigate the social risk of revealing one's serostatus.^{27,28} Strategizing disclosure may be particularly important for women with abuse histories who may already have experienced stigma and shame due to the abuse, and who may be more likely to internalize feelings of low self-worth or feelings of powerlessness.^{29,30}

HIV-positive women with abuse histories have numerous abuse-related sequelae that are relevant to disclosure of HIV status and sexual behaviors. For example, a qualitative study of women with sexual abuse histories included reports that consideration of disclosure of abuse was associated with feelings of powerlessness, fears of additional victimization ensuing, and thoughts related to their own responsibility (self blame) for the abuse.³¹ Similar to the difficulty of disclosing abuse status, women with abuse histories may have fears or difficulty disclosing their HIV status to partners. This hypothesis is underscored by the fact that discomfort with intimacy, and avoidance of intimacy have also been described in HIV positive women with abuse histories.¹⁰ Other studies report emotional distress linked to abuse in HIV positive women, which may also play a role in disclosure and sexual behavior, for example, PTSD related avoidance may heighten the likelihood that women will not disclose HIV status.¹⁰

Research has shown that women with abuse histories are more likely to engage in HIV risk behaviors relevant to both primary and secondary transmission, including higher rates of unprotected sex and an increased likelihood of having risky sexual partners.^{10,12,32} Research also demonstrates that women with an abuse history are less likely to successfully negotiate condom use than those without an abuse history, with this effect stronger for minority women.^{8,33} Women with abuse histories have also been shown to engage in less sexual communication in general, which in turn has been identified as an important mediator between abuse and sexual risk behavior.^{4,34} Sexual communication specific to sexual history, as well as condom use, has demonstrated strong associations with condom use.³⁵ Thus, in HIV-positive populations, disclosure of sexual history, including HIV status, may be an important factor in condom use and may be particularly challenging for those women with abuse histories with poorer communication skills and more abuse-related distress. However, while several studies have demonstrated increased consistency of condom use as a consequence of disclosure,³⁶⁻³⁸ other studies show inconsistent condom use after disclosure within sexual partnerships.^{2,3,39,40}

Given the potential vulnerability of women with abuse histories to having greater difficulty with disclosure through abuse-related sequelae such as low assertiveness, increased shame, poor self worth, and powerlessness, and the increased potential for stigma, investigation of disclosure in this population is needed. The aims of this study are to explore disclosure strategies in young HIV-positive women with histories of childhood sexual and/or physical abuse, examine factors influencing those strategies, and to examine outcome associated with disclosure. Greater understanding of the dynamics of disclosure communication in young women with abuse histories may provide targets for intervention to facilitate status disclosure or inform strategies for communication in the absence of disclosure that will reduce the likelihood of

unprotected sex and reduce risk for secondary transmission of HIV in this high risk group.

Methods

The specific methods of our interview approach and interview development are described in detail in Clum and colleagues.¹⁰ We utilized a naturalistic, inductive approach to explore the experience of sexual and physical abuse on the lives of young HIV-positive women. We adapted the method of the Life Story Interview,⁴¹ using audio-recorded one-on-one in-depth interviews. Descriptive demographic data and trauma related symptoms were also assessed. Saturation was determined by consensus of the primary interviewer and authors who reviewed transcripts as interviews were completed.

Participants

Young women with behaviorally acquired HIV were recruited from three Adolescent Trials Network Sites (ATN) in Miami, New York City, and Philadelphia. During enrollment, all young women attending the clinic were approached with information about the study. Forty women met the inclusion criteria of age from 18 to 24 years, a reported history of physical or sexual abuse prior to the age of 18, and heterosexual sexual activity in the past 4 months, defined as vaginal or anal sex. We stratified recruitment to include substance users, with the result that 23 of 40 (57.5%) participants reported greater than minimal use of alcohol, marijuana, or other illicit drugs in the last 4 months.

Study participants received study information from nurse coordinators during a clinic visit; interested participants gave informed consent for eligibility screening. Of 84 women approached for the study, 8 women were not interested or left care prior to screening, thus a total of 76 women completed the screen. Of these, 34 were ineligible based on study inclusion requirements and two declined to participate. Interviews were scheduled within 60 days of initial contact, and conducted by one of three trained interviewers.

Interviews lasted from 60 to 90 min and began with a semi-structured interview reviewing abuse events, age and frequency of abuse, PTSD symptoms, and sexual behaviors, followed by the interview based on the Life Story Interview. All interviewers were trained to administer the interview and be sensitive to psychological issues during the course of the interview. The primary interviewer was a trained Adolescent Medicine physician unaffiliated with the clinics. Additional interviewers included a clinical psychologist and a doctoral level graduate student in public health proficient in qualitative research methods, neither of whom were professionally affiliated with the clinics. All participants were debriefed regarding potential psychological reactions to the interview, and were made aware that assistance was immediately available at the clinic site, or would be available if the need arose later. All young women were also provided with referrals for care within the community in addition to clinic contacts. Interviews were transcribed word for word and the original recordings were destroyed. Interviews were reviewed by three authors as received. All participants received compensation for time, transportation, and child care, as determined by their local site standards. Approval from each study site's and the first authors Institutional Review Board was obtained.

Measures

Abuse. Participants were assessed for abuse histories prior to the age of 18 years. A modified version of a standardized traumatic event assessment method⁴² utilized in the National Survey of Adolescents⁴³ was used. Abuse was defined by endorsement of at least one behaviorally specific description of an event of physical or sexual abuse occurring prior to age 18. Examples of specific items include: "Has a boy or man ever put his penis inside your vagina or rear end or inside your mouth when you didn't want them to?" and, "In your lifetime, has anyone, including family members or friends, ever attacked you with a gun, knife, or some other weapon, regardless of whether you ever reported it or not?"

Post-traumatic stress disorder assessment. PTSD symptoms were assessed with an interviewer administered Posttraumatic Diagnostic Scale⁴⁴ based on the DSM-IV diagnostic criteria. The scale provides a severity score (17 items) and assessment of functional impairment (9 items yes/no) in the past month. Item anchors ranged from 0 (Not at all or only 1 time) to 3 (5 or more times a week/almost always). The PDS has demonstrated high internal consistency, test-retest reliability, good sensitivity and specificity, and diagnostic agreement with the Structured Clinical Interview for DSM-IV-TR (SCID).

The Life Story Interview. A modified version of the Life Story Interview⁴¹ was used to guide the interview. Participants identified different life chapters and followed up these chapters with details regarding their significant life events. A question guide with probes in areas such as the impact of abuse, coping, and sexual behavior was available to interviewers to facilitate the discussion and encourage elaboration on certain themes and topics as interviews progressed. These themes were chosen based on prior literature examining abuse and its sequelae in HIV positive and nonpositive women^{8,45,46}

Analyses

Grounded theory was utilized to guide our analysis.⁴⁷ The analysis process included conventional and directed content analysis.⁴⁸ Each transcript was reviewed in its entirety. Codes were developed to capture concepts that were important to the research questions. Transcripts were then broken down into text segments that represented an important domain, concept, or theme, labeled with the appropriate code⁴⁹ and catalogued using Atlas.ti 5.0 software.⁵⁰ One primary coder, not affiliated with the interviews or clinics, performed all the coding. A second coder reviewed the coding scheme and coded 25% of the interviews. A minimum of 80% inter-rater reliability was achieved; any discrepancies were reviewed by three authors of the study and discussed until agreement was obtained. Codes were clustered based on overlapping concepts. The relationship among codes and important themes emerging through the clustering of concepts was discussed among two of the co-authors. Identified themes were synthesized for presentation. Results are focused on the themes of sexual communication including disclosure, condom use negotiation, and factors influencing these themes. Segments taken directly from interview transcripts are included as illustrations of how the theme is expressed by participants.

TABLE 1. DEMOGRAPHIC AND SOCIOBEHAVIORAL VARIABLES IN YOUNG HIV-POSITIVE WOMEN (N=40)

Variable	Percent	Mean (SD)
Employed	35.0	
In school	45%	
Long-term relationship	45%	
Race/ethnicity		
Black	87.5	
Hispanic	5.0	
Other	12.5	
Child abuse > 18 years		
Sexual	75%	
Physical	80%	
Both	55%	
PTSD symptoms		20.75 (10.18)
Impact of PTSD		
Sexual relationships	67.5	
General life satisfaction	57.5	
Family relationships	52.5	
Friend relationships	50.0	
Leisure activities	45.0	
Recent sexual partners		
0	2.5	
1	57.5	
2	20.0	
3 or more	20.0	
Unprotected sex last 6 months	42.5	
Recent substance use	57.5	

Results

Demographics and abuse history

Demographic and behavior data are presented in Table 1. Young women were between the ages of 18 and 24 years. Thirty-five of 40 participants were Black (87.5%), 5 reported "other" status. Two of 40 women (5%) indicated they were of Hispanic ethnicity. Thirty five percent reported they were currently working, 45% reported they were in school, and 45% reported they were in a long-term relationship of 1 year or more. A detailed report of participants' trauma exposure and symptoms is available in Clum et al.¹⁰ Briefly, young women reported histories of sexual (75%) and physical (80%) abuse histories, with 55% reporting the occurrence of both physical and sexual assault. Post-traumatic stress disorder symptoms were, on average, in the moderate to severe range as assessed by the PDS (20.75, SD 10.18) and the impact of symptoms across several life areas were reported, including the impact on sexual relationships (67.5%), general life satisfaction (57.5%), family (52.5%), and friend (50%) relationships, and leisure activities (45%). Unprotected sex in the past 6 months was reported by 17 of 39 women (42.5%). Women reported a range from 0 to 50 partners, 2.5% ($n = 1$) reporting 0, 57.5% reporting 1, 20% reporting 2, 20% reporting 3 or more.

Overview of results

Results are organized by themes and subthemes that include (1) disclosure strategies, with subthemes of (a) disclosure avoidance/delay, and post delay disclosure strategies, (b) strategies used to disclose after delay occurred; (2) relationship factors influencing disclosure with subthemes of (a) intimacy/

timing, (b) anticipated partner reactions, (c) stigma, (d) emotional costs, and (e) moral obligations. Finally, themes around (3) partner reactions to disclosure and (4) links between disclosure and condom use are discussed.

Disclosure strategies

Disclosure avoidance/delay. The desire to avoid or delay disclosure of HIV status among study participants was common and influenced by myriad personal and relationship factors that led to decreased communication regarding HIV status. One young woman, with a reported history of both childhood sexual and physical abuse, had a difficult time accepting her own HIV status. This impacted her decision to not disclose to her partner of 3 years that she was HIV positive. She said, "He doesn't know yet, I have to tell him, so-. I know. I told you that I'm a quiet person. And plus, I don't think about it. In my eyes, I don't have it."

Several other women felt that their HIV status was a private matter, one that was only shared with select family members and health care providers. Another woman, who selectively disclosed to some partners but not all, struggled with what she saw to be the moral issue of disclosure, "I would never purposely look for people to just, you know, 'I'm going to give this to as many people as I can,' but if I'm in a relationship with someone, and I don't know how to address the situation, I normally ignore it." In these situations, avoidance plays an important role in the disclosure process, making it difficult for young women to communicate with partners.

Other women avoided or delayed disclosure out of a concern that disclosure could result in loss of their partner. One participant stated: "But the thing that really was bothering me was that how I'm going to tell the person that I really love without him wanting to leave." This young woman felt that disclosure could result in termination of her relationship, and because of her investment in "really loving" him, felt the risk of disclosure was greater than the benefits of disclosure. Another participant delayed disclosure until she was sure of the strength of her partner's feelings. "But when I tell them, I find it easier to wait until they already fall in love with you. That's what it is. Because if they're not, then I don't know what they would do. But if I really like them, then I would rather for them to be already in love with me before I tell them." In these situations, the intensity of feeling or love for a partner drives these women's decision to ultimately disclose their HIV status.

Post delay strategies. Among women who delayed disclosure, patterns of delay were influenced by several factors. For example, some women negotiated their delay in disclosure by not fully expressing the truth about the timing of their HIV diagnosis. As one woman explains, "I was in a relationship with him for a year prior to finding out. So how was I going to tell him? I said, 'you gave me HIV.' No he didn't. I know he didn't. And he know he didn't, but he went and got tested anyway." Similarly, another young woman described: "And then the second guy, I didn't tell him immediately, but when I finally told him, I told him as if I had just found out." These women adopted a strategy to address disclosure that allowed them to disclose their status but also allowed them to withhold information from their partner, in this case timing of HIV diagnosis, that they were not comfortable communicating.

Relationship factors

Intimacy/timing. Several women discussed the effect of contextual factors within a relationship on their decision to disclose, such as how they perceived their relationship with a current partner would develop. For example, one woman based her decision to disclose on both her perceived future with her partner and whether her partner potentially got sick in the immediate future. "Depends, if I think that we're going to be together for awhile, then I will say something to him. But if I don't think we're going to be together for awhile, then I'll probably just [not]. Not unless he went to the doctor or something and something was wrong with him, then I would explain to him, but now I wouldn't." Another woman said that she did not expect to have to disclose her status saying "I don't know. That's the last thing, I won't ever be close to nobody." The stage of the relationship and level of intimacy were thus important to disclosure.

Anticipated partner reactions. Women reported that they would gauge partner reactions based on hypothetical situations involving HIV. One woman described how she expected to handle disclosure, "Oh, [if it is] the right person for me to tell my business to like that. If I see that it's going somewhere, then I'll just sit down and tell him. And I'll talk to him. First, I'll like figure out what you think about it. I ain't going to come out and say, okay, yeah, you know, but first give an opinion on what you think. From that, I'll just figure out what I'll do."

Another woman similarly explained her strategy for finding out how a partner might react to knowing she had HIV. As one woman explains: "Well, when the subject of sex would come up, my partners, the guy will usually talk about, oh, they don't want to catch anything.... We start talking about it, and then I will be like, 'Oh, what if you...?' I remember telling my way of saying it, 'Well what would you do if I was sick?' And they would be like, well, they would say this and that but they never change their words and they completely wouldn't want to like deal with it. So I'm like 'Okay.'"

Another woman employed a similar strategy: "It's hard. You know, we watch shows. If it comes on, I'll be like, 'How would you react if-?'...I asked them that for a couple of months, just to see what they would say. And if I feel like I'm comfortable to tell them—you know everybody's different. I feel like if they can't take it I'll break up with them. Then I'll tell them, 'It's for your best.'" By testing the hypothetical response of their partner when determining whether or not to disclose to them, these women were protecting themselves against possible negative and stigmatizing reactions.

Disclosure and stigma. Lack of disclosure was, in fact, associated with a fear of incurring stigmatizing beliefs about HIV from others, particularly gossip and potential rejection by partners. One participant described how HIV-related stigma and her assessment of the particular partner she was with influenced her disclosure decisions: "My new boyfriend, he don't know. My ex-boyfriend didn't. You can't tell everybody because everybody have a different reaction when they don't know the real story or the real concept of the disease. So I don't tell my partner." She went on to say of her other partners "the other two, no. They're too 'hood'. They're too 'in-the-street'. So it's like, 'I'm not telling you. I know my

distance." Another woman linked the subtheme of intimacy/timing to the subtheme of stigma. She described how the length of time she has known her partner is important to her decision to disclose her status. She felt that early disclosure was potentially problematic and could lead to public exposure and stigmatization: "Well, I really look at it as a time issue. If I see I've been dealing with this person for so long, I'll tell them. But I always wait a grace period because I don't want to tell any and everybody because people are so prejudiced...And everybody knows everybody, and I don't want to be walking around and they're like 'Oh, that's – she right there.'

These young women thus made situation specific decisions regarding disclosure based on a character assessment of her partners, with HIV-related knowledge and stigma playing a role in that assessment process.

Emotional costs of disclosure. Other women reported that disclosures resulted in relationship termination and status exposure. As one woman expressed: "I have seen people that got treated so bad because they told the person they thought that loved them, and they turned around, and they just turned their back on them, told everybody in the streets their business. So that's why I say make sure that person is the right person." Much like the women who chose to delay disclosure based on their partner's reaction to a disclosure scenario, these young women approached each relationship with a strategy for disclosure that was based on an assessment of potential stigmatizing reactions and whether or not they perceived their partner and relationship as "right" for them.

It was evident in several narratives that the emotional cost of engaging in HIV status disclosure was high. One woman described a phenomenon related to disclosure that she thought was relevant to other women that she knew. She said that the cost of engaging in the disclosure process was so great that once you have disclosed to a partner, it is difficult to want to move on to another partner and have to go through the disclosure process again. She explained that this led to remaining in relationships that were detrimental: "I think like, for my friends, a lot of my friends, that most of them rather, that they stay in relationships that they don't want to be in mostly with their partner that knows because the fact that they're afraid to start over again."

She also directly linked stigma associated with HIV to remaining in bad relationships: "And most of the times it's bad relationships because the partner uses it as, you know, nobody else is going to want you because you got that or things like that. And that's really hard to know that you have to start all fresh and have to go through the whole process of telling your partner and all that. That's hard. So I have friends stuck in situations you don't want to be in because you don't want to start over."

This perception reflects several important themes, including the stigma of living with HIV and the links between stigma, disclosure, and increased vulnerability to "bad relationships" that might include emotional or other forms of abuse.

Moral obligation. Some women eventually disclosed their status to a sexual partner. One primary motivation appeared to be feelings of guilt over not disclosing sooner and a sense of moral obligation to disclose. As one woman described: "In the beginning [of the relationship] I just used protection. And then it just was eating me up inside. I just had to tell him."

Another woman stated: "I think it should be a moral obligation to tell even if you might make a mistake. Some women feel as though after it's done, it's done, and then just go on repeating the same mistake. They have sex with a guy and then leave him alone because they're so afraid that he's going to find out, or they just never ever really able to tell him, or if you—just because a mistake is made doesn't mean you can't clean it up."

However, she herself was still unable to tell some of her partners in spite of her belief that she had an obligation to do so. She adds: "I have gone back and told people, and I have people that I need to tell, but I don't just dismiss it, you know." She struggled with what she felt was a moral obligation to disclose and the reality of actually disclosing, but was clear that her decision making was not taken lightly.

Partner reactions to disclosure

Women who disclosed their status, reported partner reactions to HIV disclosure that were varied, including positive, negative and neutral responses. Some women reported men who were shocked and upset, but eventually accepted the diagnosis and maintained the relationship. One woman who waited to tell her sexual partner about her status felt fortunate in his decision to stay involved with her: "About 6 months to a year, then I told him. I wouldn't say he was okay. I can't say it didn't bother him, but he didn't turn his back; he didn't leave. He stayed. I was lucky."

Other women said that their partner "didn't care" about the diagnosis. Several women mentioned that when they did disclose their status to partners, partner reactions included a willingness to risk acquisition of HIV. As one woman who made selective assessments regarding which partners to disclose to stated: "I only told one partner after my baby's father, and he understood it. He didn't care. He didn't care. He's like, 'I'm with you. I don't care' or whatever. 'If we get it, we get it together.'" It appeared that her partner's attitude toward acquiring HIV represented a gesture of intimacy. She continued: "Even before he went and got tested he said, 'I don't care. I love you. Oh well, we're going to get it together.'" Another woman reported that she and her partner had not used condoms during their sexual relationship even after her disclosure, and she saw his HIV diagnosis as an eventual certainty: "And we haven't [used a condom], and he gets tested, and so, far so good. I'll face that road when we get to it because, of course, eventually, he'll most likely—he'll eventually get it or something."

Partner reactions to disclosure also demonstrated a lack of education about HIV. As one participant described her partner's response to her disclosure: "It went off pretty well [the disclosure] because he don't believe that I have it...He got tested (after unprotected sex). And he's like, 'I really don't believe you because I'm good now and it don't say positive.' So he don't believe me." In this case, her partner's lack of knowledge regarding HIV transmission influenced his reaction to her disclosure, and potentially her ability to communicate effectively about risk for transmission and motivate her partner to engage in safe sex strategies.

Disclosure and condom use

The relationship between disclosure and condom use was also complicated and varied according to disclosure timing,

partner reactions to disclosure, and prior condom use behavior. As is evident from some of the above quotes, some young women did disclose their status to their partners, but this disclosure did not result in safer sex practices. Several women who had not disclosed their status to partners reported that they engaged in unprotected sex with partners, and that the delay in their disclosure made it more difficult to initiate safer sex as time passed. As one participant stated: "We never used protection from day one, which, when I first was with him, I knew; I had found out. I didn't know how to tell him when we were sexually active without protection, before I even told him. And then once I told him, he was so afraid, so he was upset about it because I didn't tell him." Another participant who had not disclosed her status to her partner described her distress at not saying anything about discontinued condom use: "Yeah, we used a condom, but he took it off. He took it off, but I still felt bad because I should have said something." Thus for some women, delay of disclosure appears to be related to difficulty in initiating or maintaining condom use.

However, not all of the women in the study had difficulty negotiating condoms. Here, those women who reported that "they don't negotiate," meaning that condom use was a given and non-negotiable, were consistent with reporting regular condom use in their sexual relationships. Insisting on condom use did not necessarily mean that a woman had disclosed her status; rather, it meant that she had a policy on condom use that she had identified for herself and made clear to her partners. One woman articulated her beliefs regarding condom use and partner reactions to requests for condom use: "And be like if they're not using a condom I'm leaving. That's it. And if they're just going to let you leave like that, then that means they never cared about you."

Other women reported more difficulty with condom negotiation, including justifications for their use in lieu of status disclosure and dealing with negative partner reactions. For example, one woman stated: "Yeah, and I'm like, "But you have to." He's like, "Why"? And then, I don't want to just tell him right there and then, but then at the same time—because once I said, "Oh, well, you might have something, and you don't know it," or something like that, and then he'll get real defensive. So I don't want to bring it up like that, so I try not to just be around it."

Other women made distinctions between condom use with their main partner versus a casual partner, as one woman said: "I mean, if it's just a fly by night—yes, I'm going to use a condom but if it's just my main boyfriend— you know, nn-rrn." Thus, for some women, the decision to use condoms or negotiate condom use is affected by the need to demonstrate intimacy, to imply exclusivity and in some cases to avoid disclosure of HIV status. It was also clear that those women who were more comfortable and assertive with condom negotiation, had partners who accepted condom use, and who were willing to "move on" if partners did not want to use condoms were more likely to engage in safe sex practices.

Discussion

This study provides insight into the complexities surrounding HIV disclosure and safe sex negotiation among HIV positive women with abuse histories. Women with abuse histories may experience sequelae stemming from abuse that

have the potential to affect how they approach disclosure with partners. Increased sense of powerlessness, self blame, shame, and decreased assertiveness associated with prior abuse experiences may impact women's decisions to disclose and the strategies they engage in regarding disclosure and sexual behaviors. While all women in this study had abuse histories, and thus we could not compare their narratives around disclosure with those who have not experienced abuse, several themes emerged that were consistent with abuse sequelae.

Women in this study employed a variety of strategies around disclosure of their HIV status. Some women avoided status disclosure altogether, either because they viewed their HIV status as a private matter that could be problematic in a relationship or had a difficult time accepting their own status. Many delayed status disclosure and struggled with defining the right situation or the right person to tell their status to, and employed strategies such as gauging partner reactions to potential disclosure scenarios or considering the future of their relationship with a sexual partner to determine whether or not to disclose their status. Delay strategies were thus tied to relationship factors that together influenced women's disclosure.

Relationship factors, including fear of partner rejection, fear of stigmatizing reactions from partners, and a sense of moral obligation to notify partners of their HIV positive status were major factors driving the decision to disclose across narratives. These findings are consistent with other qualitative studies where HIV positive youth describe fear of rejection and stigmatizing responses as major drivers in their decision whether or not to disclose their status.^{51,52} These narratives thus suggest an exchange pattern within relationships that may further elucidate motives for lack of disclosure within certain types of relationships, with certain types of partners, and at particular points within the relationship. These exchange patterns align with theories of exchange within sexual relationships including equity theory^{53,54} and investment theory.⁵⁴⁻⁵⁷ Similar to findings from previous research demonstrating increased disclosure of serostatus to primary and longer term partners, women in this study were more likely to disclose their HIV status to longer term partners, choosing to exchange this information with trusted partners with whom they were willing to share a level of intimacy. Intimacy is a valuable resource exchanged in relationships. Disclosing a stigmatized condition is a social risk,²⁷ and sharing this risk creates inequity in the relationship and may also prohibit termination of the relationship because of the investment of intimacy through the sharing of personal information that reveals a vulnerable aspect of their perception of self this resource.^{54,58} Young women in this study described hesitation in leaving a partner, even in scenarios where the relationship did not meet their expectations, given their investment of shared intimacy through status disclosure, and a desire to avoid having to repeat this process again with someone new.

Following exchange theory, it is also possible that participant's perceptions of self and self worth as an HIV-positive woman, and as a woman who has experienced abuse, lowered her belief in the ability to find a better partner who would accept her status. Applying an exchange framework, as voiced by the participants in this study, assists in understanding the role of perceived external and internal stigma as a determinant of disclosure. In addition to increasing efficacy and skills related to sexual communication, addressing

underlying perceptions of self-esteem and internalized stigma related to HIV is also important in intervention development.

Women voiced concerns about reactions to disclosure that include stigmatizing responses and relationship termination. Relationship loss and stigmatization as a result of disclosure are real possibilities. Strategies for managing disclosure to minimize stigmatizing reactions, such as partner education regarding living with a partner with HIV, are warranted. Strategies for assisting women with cognitions related to fears of stigmatizing responses and how they might prepare for a variety of possible partner reactions (including positive and negative responses) or loss of partner may also reduce distress associated with actual or imagined disclosure. A recent study found individual variation in disclosure strategies as a method of coping with the stress of HIV diagnosis,⁵⁹ thus tailoring to individual preferences should be considered.

The results of this study also suggest that disclosure and condom negotiation strategies may need to be tailored to the stage of the relationship, as women who delayed disclosure reported concerns about how to disclose after time had passed in a relationship and/or they had engaged in unprotected sex. Women who choose not to disclose or wait to disclose should be equipped with skills to manage their own feelings or distress related to not disclosing, and also strategies for ensuring maximal safety of self and others in their sexual relationships. This may mean introducing or strengthening strategies for negotiation and communication, with a particular emphasis on dealing with partners who are persistent in their desire to not use condoms.

In our study, those women who were clear that they would not have sex without a condom were the most likely to practice safe sex. This is consistent with literature documenting a strong relationship between sexual communication and engagement in protected sex.⁶⁰ Further, less assertive women and those who did not believe they could control condom use in partners were less likely to use condoms.⁶¹ For those women who consistently used condoms in this study, motivations for the safety of self and others appeared to be important. However, there was also evidence of positive esteem for self that was evidenced in those who said they "don't negotiate" and always use condoms. These women did not appear to link intimacy to their use of condoms unless it was to suggest that a partner who won't use condoms is not a good choice for a partner. Further, they had the skills to be assertive and the willingness to "move on" from a partner if needed, perhaps suggesting greater emotional and/or economic independence.⁶² Leveraging these phenomenon, such as motivations for safety of self and others and positive self regard could be useful in promoting safe sex practices and facilitating disclosure.

Another important finding in this study was the reported willingness of male partners to risk HIV acquisition after learning a woman's HIV status. This risk taking appeared to be tied to intimacy for some, to feelings of invulnerability, and perhaps to a lack of education about risks for transmission and what HIV "looks like" in others. HIV-related stigma or lack of education may lead to beliefs that people with HIV look sick, malnourished, and could not appear to be a healthy, functioning young adult woman. A recent qualitative study of HIV-positive women and their serodiscordant partners underscored the findings that intimacy, invulnerability and lack of education may contribute to serodiscordant partners' un-

willingness to use condoms, and also suggested that sexual pleasure and control were important factors.⁶³ The authors also described a "wearing down" process where women's attempts to get partners to use condoms are met with partner resistance and subsequent arguments, resulting in unprotected sex as the outcome.

Strategies for managing partners who are persistent in their negotiations not to use condoms should be considered for this population. Notably, some women experienced ongoing distress with regard to their partner's unwillingness to use condoms, for fear of their eventual HIV infection, which has also been noted in the literature.⁶³ Future research should explore sexual risk taking in couples where HIV is an issue from a relational perspective. For those women who are HIV positive, venues to educate discordant partners and provide acceptable strategies for sexual safety, as well as interventions that focus on the quality of the couple's relationship generally and sexual relationship specifically may be beneficial.⁶⁴

Other emotional constructs may also be relevant to women with abuse histories negotiating disclosure and condom use that were not explored here. A recent study exploring abuse, attachment in relationships, and sexual risk concluded that attachment anxiety had direct effects on sexual risk behaviors,⁶⁵ thus relational factors such as attachment could be an important link between the effects of abuse and sexual risk. Additionally, for those young women with abuse histories, understanding cognitions related to intimacy, safety, and esteem of self and others may be an important focus for changing behavior and increasing sexual safety.

This study has several limitations. First, all women had abuse histories, so comparing the experiences of those HIV-positive women with abuse histories and without abuse histories on disclosure and links to condom use would help clarify those factors that are unique to the experience of abuse. It is possible that women with childhood abuse histories are not different than their non-abused counterparts in the way that they approach disclosure with partners. Future studies should use quantitative and qualitative methods to pursue this question further. Nonetheless, given the high prevalence of abuse in HIV-positive women and the theoretical and empirical support for vulnerability to low assertiveness and poorer sexual communication in women with child abuse histories, it is important to understand their lived experiences and begin to target interventions to their needs. An additional limitation is the focus on a clinical population. All women were engaged in HIV related clinical services, and this may reflect a higher functioning group that is not representative of the larger population of HIV-positive women with abuse histories. Most of the women were African-American and represent a narrow age range. Disclosure strategies may vary as a function of ethnicity and developmental stage. Time since trauma, and the presence of cumulative trauma may also be relevant variables that impact adjustment and disclosure. Further research should include exploration of these issues in a range of women using both quantitative and qualitative methods. Finally, the impact of abuse on sexual communication and behavior is relevant to men with HIV as well. Further studies should include men and women and examine gender as a potential modifier in these relationships. Women with abuse histories continue to engage in unprotected sex, and may be particularly vulnerable due to sequelae of their abuse experiences. In addition to addressing their mental health

symptoms, there is great need to address communication and disclosure strategies, and assist women with relational factors influencing sexual behavior.

Acknowledgments

We acknowledge the ATN sites that participated in this study: Montefiore Medical Center, Bronx, NY; University of Miami School of Medicine, Division of Adolescent Medicine, Miami, FL; and Children's Hospital of Philadelphia, Philadelphia, PA. We thank ATN's Behavioral Leadership Group, ATN Coordinating Center at University of Alabama at Birmingham, and Westat, Inc. We are grateful to the members of the ATN Community Advisory Board and to the youth who participated in this study. This study was funded by grant No. 5-K01MH070278 to the first author from the National Institutes of Health through the National Institute of Mental Health. Additional funding and support was provided by The Adolescent Trials Network for HIV/AIDS Interventions (ATN) which is funded by Grant No. U01 HD40533 from the National Institutes of Health through the National Institute of Child Health and Human Development (A. Rogers, R. Nugent, L. Serchuck), with supplemental funding from the National Institutes on Drug Abuse (N. Borek), Mental Health (A. Forsyth, P. Brouwers), and Alcohol Abuse and Alcoholism (K. Bryant).

Author Disclosure Statement

The authors declare no conflicts of interest with respect to the authorship and/or publication of this article.

References

- Marks G, Crepez N. HIV-positive men's sexual practices in the context of self-disclosure of HIV status. *J Acquir Immune Defic Syndr* 2001;27:79–85.
- Simoni JM, Walters KL, Nero DK. Safer sex among HIV+ women: The role of relationships. *Sex Roles* 2000;42:691–708.
- Wilson TE, Feldman J, Vega MY, et al. Acquisition of new sexual partners among women with HIV infection: Patterns of disclosure and sexual behavior within new partnerships. *AIDS Educ Prev* 2007;19:151–159.
- Clum GA, Chung SE, Ellen JM, et al. Victimization and sexual risk behavior in young, HIV positive women: Exploration of mediators. *AIDS Behav* 2012;16:999–1010.
- Hamburger ME, Moore J, Koenig LJ, et al. Persistence of inconsistent condom use: Relation to abuse history and HIV serostatus. *AIDS Behav* 2004;8:333–344.
- Brown LK, Lourie KJ, Zlotnick C, Cohn J. Impact of sexual abuse on the HIV-risk-related behavior of adolescents in intensive psychiatric treatment. *Am J Psychiatry* 2000;157:1413–1415.
- Molitor F, Ruiz JD, Klausner JD, McFarland W. History of forced sex in association with drug use and sexual HIV risk behaviors, infection with STDs, and diagnostic medical care: Results from the young women survey. *J Interpers Violence* 2000;15:261–278.
- Wingood GM, Diclemente RJ. Child sexual abuse, HIV sexual risk, and gender relations of African-American women. *Am J Prev Med* 1997;13:380–384.
- Schafer KR, Brant J, Gupta S, et al. Intimate partner violence: A predictor of worse HIV outcomes and engagement in care. *AIDS Patient Care STDS* 2012;26:356–365.
- Clum GA, Andrinopoulos K, Muessig K, Ellen JM. Child abuse in young, HIV-positive women: Linkages to risk. *Qual Health Res* 2009;19:1755–1768.
- Cloitre M, Scarvalone P, Difede J. Posttraumatic stress disorder, self- and interpersonal dysfunction among sexually retraumatized women. *J Traum Stress* 1997;10:437–452.
- Nimh Multisite Hiv Prevention TG. A test of factors mediating the relationship between unwanted sexual activity during childhood and risky sexual practices among women enrolled in the NIMH Multisite HIV Prevention Trial. *Women Health* 2001;33:163–180.
- Wilson HW, Widom CS. An examination of risky sexual behavior and HIV in victims of child abuse and neglect: A 30-year follow-up. *Health Psychol* 2008;27:149–158.
- El-Bassel N, Gilbert L, Rajah V, Foleno A, Frye V. Fear and violence: Raising the HIV stakes. *AIDS Educ Prev* 2000;12:154–170.
- Stirratt MJ, Remien RH, Smith A, Copeland OQ, Dolezal C, Krieger D. The role of HIV serostatus disclosure in antiretroviral medication adherence. *AIDS Behav* 2006;10:483–493.
- Kalichman SC, Nachimson D. Self-efficacy and disclosure of HIV-positive serostatus to sex partners. *Health Psychol* 1999;18:281–287.
- Parsons JK, Schrimshaw EW, Bimbi DS, Wolitski RJ, Gomez CA, Halkitis PN. Consistent, inconsistent, and non-disclosure to casual sexual partners among HIV-seropositive gay and bisexual men. *AIDS* 2005;19:S87–s97.
- Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care* 2008;20:1266–1275.
- Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV Stigma Scale. *Res Nurs Health* 2001;24:518–529.
- Buseh AG, Kelber ST, Hewitt JB, Stevens PE, Park CG. Perceived stigma and life satisfaction: experiences of urban African American men living with HIV/AIDS. *Intl J Men's Health* 2006;5:35–51.
- Bunn JY, Solomon SE, Miller C, Forehand R. Measurement of stigma in people with HIV: A reexamination of the HIV Stigma Scale. *AIDS Educ Prev* 2007;19:198–208.
- Batterham P, Rice E, Rotheram-Borus M. Predictors of serostatus disclosure to partners among young people living with HIV in the pre- and post-HAART eras. *AIDS Behav* 2005;9:281–287.
- Obermeyer CM, Bajjal P, Pegurri E. Facilitating HIV disclosure across diverse settings: A review. *Am J Public Health* 2011;101:1011–1023.
- D'Angelo LJ, Abdalian SE, Sarr M, Hoffman N, Belzer M. Disclosure of serostatus by HIV infected youth: The experience of the REACH study. *J Adolesc Health* 2001;29:72–79.
- Duru OK, Collins RL, Ciccarone DH, et al. Correlates of sex without serostatus disclosure among a national probability sample of HIV patients. *AIDS Behav* 2006;10:495–507.
- Serovich JM, Craft SM, Reed SJ. Women's HIV disclosure to family and friends. *AIDS Patient Care STDS* 2012;26:241–249.
- Green G, Sobo EJ. *The Endangered Self: Managing the Social Risk of HIV*. London: Taylor and Francis; 2000.
- Vu L, Andrinopoulos K, Mathews C, Chopra M, Kendall C, Eisele TP. Disclosure of HIV status to sex partners among

- HIV-infected men and women in Cape Town, South Africa. *AIDS Behav* 2012;16:132–138.
29. Resick PA, Schnicke MK. Cognitive processing therapy for sexual assault victims. *J Consult Clin Psychol* 1992;60:748–756.
 30. Resick PA, Schnicke MK. *Cognitive Processing Therapy for Rape Victims: A Treatment Manual*. Thousand Oaks, CA US: Sage Publications, Inc, 1993.
 31. Tarakeshwar N, Fox A, Ferro C, Khawaja S, Kochman A, Sikkema KJ. The connections between childhood sexual abuse and human immunodeficiency virus infection: Implications for interventions. *J Commun Psychol* 2005;33:655–672.
 32. Cohen M, Deamant C, Barkan S, et al. Domestic violence and childhood sexual abuse in HIV-infected women and women at risk for HIV. *Am J Public Health* 2000;90:560–565.
 33. Perrino T, Fernández MI, Bowen GS, Arheart K. Low-income African American women's attempts to convince their main partner to use condoms. *Cult Divers Ethnic Minority Psychol* 2006;12:70–83.
 34. Sales JM, Lang DL, DiClemente RJ, et al. The mediating role of partner communication frequency on condom use among African American adolescent females participating in an HIV prevention intervention. *Health Psychol* 2012;31:63–69.
 35. Noar SM, Carlyle K, Cole C. Why communication is crucial: Meta-analysis of the relationship between safer sexual communication and condom use. *J Health Commun* 2006;11:365–390.
 36. Allen CF, Simon Y, Edwards J, Simeon DT. Factors associated with condom use: Economic security and positive prevention among people living with HIV/AIDS in the Caribbean. *AIDS Care* 2010;22:1386–1394.
 37. Niccolai LM, Dorst D, Myers L, Kissinger PJ. Disclosure of HIV status to sexual partners: Predictors and temporal patterns. *Sexually transmitted diseases* 1999;26:281–285.
 38. Sturdevant MS, Belzer M, Weissman G, Friedman LB, Sarr M, Muenz LR. The relationship of unsafe sexual behavior and the characteristics of sexual partners of HIV infected and HIV uninfected adolescent females. *J Adolesc Health* 2001;29:64–71.
 39. Stevens PE, Hildebrandt E. Life changing words: Women's responses to being diagnosed with HIV infection. *Adv Nurs Sci* 2006;29:207–221.
 40. Sullivan K, Voss J, Dongmei LI. Female disclosure of HIV-positive serostatus to sex partners: A two-city study. *Women Health* 2010;50:506–526.
 41. Lieblich A, Tuval-Mashiach R, Zilber T. *Narrative Research: Reading, Analysis, and Interpretation*. Thousand Oaks, CA US: Sage Publications, Inc, 1998.
 42. Dansky BS, Saladin ME, Brady KT, Kilpatrick DG. Prevalence of victimization and posttraumatic stress disorder among women with substance use disorders: Comparison of telephone and in-person assessment samples. *Intl J Addictions* 1995;30:1079–1099.
 43. Kilpatrick DG, Acierno R, Saunders B, Resnick HS, Best CL, Schnurr PP. Risk factors for adolescent substance abuse and dependence: Data from a national sample. *J Consult Clin Psychol* 2000;68:19–30.
 44. Foa EB, Cashman L, Jaycox L, Perry K. The validation of a self-report measure of posttraumatic stress disorder: The Posttraumatic Diagnostic Scale. *Psychol Assess* 1997;9:445–451.
 45. Cloitre M, Miranda R, Stovall-McClough KC, Han H. Beyond PTSD: Emotion regulation and interpersonal problems as predictors of functional impairment in survivors of childhood abuse. *Behav Ther* 2005;36:119–124.
 46. Finkelhor D, Browne A. The traumatic impact of child sexual abuse: A conceptualization. In: Chess S, Thomas A, eds. *Annual Progress in Child Psychiatry and Child Development*, 1986. Philadelphia, PA US: Brunner/Mazel; 1987:632–648.
 47. Strauss A, Corbin J. Grounded theory methodology: An overview. In: Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. Thousand Oaks, CA US: Sage Publications, Inc; 1994:273–85.
 48. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–1288.
 49. Bernard HR, Ryan GW. *Analyzing Qualitative Data: Systematic Approaches*. Thousand Oaks, CA US: Sage Publications, Inc, 2010.
 50. Muhr T, Friese S. *Users Manual for Atlas.ti 5.0*, 2nd edition. Berlin: Scientific Software Development, 2004
 51. Leonard AD, Markham CM, Bui T, Shegog R, Paul ME. Lowering the risk of secondary HIV transmission: Insights from HIV-positive youth and health care providers. *Persp Sex Reprod Health* 2010;42:110–116.
 52. Michaud P-A, Suris J-C, Thomas LR, Kahlert C, Rudin C, Cheseaux J-J. To say or not to say: A qualitative study on the disclosure of their condition by human immunodeficiency virus-positive adolescents. *J Adolesc Health* 2009;44:356–362.
 53. Hatfield E, Rapson RL, Aumer-Ryan K. Social justice in love relationships: Recent developments. *Social Justice Res* 2008;21:413–431.
 54. Sprecher S. Investment model, equity, and social support determinants of relationship commitment. *Social Psychol Quart* 1988;51:318–328.
 55. Rusbult CE. Commitment and satisfaction in romantic associations: A test of the investment model. *J Exp Social Psychol* 1980;16:172–186.
 56. Rusbult CE, Drigotas SM, Verette J. The investment model: An interdependence analysis of commitment processes and relationship maintenance phenomena. In: Canary DJ, Stafford L, eds. *Communication and Relational Maintenance*. San Diego, CA US: Academic Press; 1994:115–139.
 57. Sprecher S, Schwartz P. Equity and balance in the exchange of contributions in close relationships. In: Lerner MJ, Mikula G, eds. *Entitlement and the Affectional Bond: Justice in Close Relationships*. New York, NY US: Plenum Press, 1994, pp.11–41.
 58. Sprecher S. The effect of exchange orientation on close relationships. *Social Psychol Quart* 1998;61:220–231.
 59. Hult JR, Wrubel J, Branstrom R, Acree M, Moskowitz JT. Disclosure and nondisclosure among people newly diagnosed with HIV: An analysis from a stress and coping perspective. *AIDS Patient Care STDS* 2012;26:181–190.
 60. Noar S, Carlyle K, Cole C. Why communication is crucial: Meta-Analysis of the relationship between safer sexual communication and condom use. *J Health Commun* 2006;11:365–390.
 61. Crepez N, Marks G. Towards an understanding of sexual risk behavior in people living with HIV: A review of social, psychological, and medical findings. *AIDS* 2002;16:135–149.
 62. Fullilove MT, Fullilove RE, Haynes K, Gross S. Black women and AIDS prevention: A view toward understanding the gender rules. *J Sex Res* 1990;27:47–65.
 63. Stevens PE, Galvao L. "He won't use condoms": HIV-infected women's struggles in primary relationships with

- serodiscordant partners. *Am J Public Health* 2007;97:1015–1022.
64. El-Bassel N, Witte SS, Gilbert L, et al. Long-term effects of an HIV/STI sexual risk reduction intervention for heterosexual couples. *AIDS Behav* 2005;9:1–13.
65. Kershaw TS, Milan S, Westdahl C, et al. Avoidance, anxiety, and sex: The influence of romantic attachment on HIV-risk among pregnant women. *AIDS Behav* 2007;11:299–311.

Address correspondence to:

Gretchen Clum, PhD

Department of Community Health Services

Tulane University School of Public Health and Tropical Medicine

1440 Canal Street, TW-19

New Orleans, LA 70112

E-mail: gclum@tulane.edu