A Guide to AIDS Research and Counseling

Encouraging individuals, particularly those with HIV, to disclose their HIV status to potential sexual partners has been part of HIV prevention efforts since early in the epidemic. Recent efforts by the U.S. Centers for Disease Control and Prevention to develop and evaluate prevention interventions specifically targeting people with HIV, however, have resulted in renewed attention to the issue of disclosure.

Underlying this attention is the belief that disclosure will decrease the likelihood that an individual will engage in behaviors that transmit HIV. This belief assumes that disclosure will highlight the potentially negative consequences of unprotected sex for the partner, including a new infection if the partner is HIV-negative or HIV superinfection or infection with another sexually transmitted disease if the partner is HIV-positive. This awareness, in turn, is expected to lead to risk reduction.

Both the research literature and clinical practice, however, suggest that the association between disclosure and risk reduction is much more complex. This article summarizes key findings from a recent review of the literature and suggests strategies for promoting disclosure in the context of HIV prevention efforts.

Does Disclosure Lead to Safer Sex?

A review of the scientific literature through February 2004 located 15 studies with data that addressed the relation between disclosure of HIV-positive status and safer sex (using more than one definition). The findings were decidedly mixed. Seven studies reported no consistent association between the two variables. In seven of the remaining eight studies that did note a significant association disclosure was positively related to safer sex.

Specifically, two studies found that, compared to those who had not disclosed, HIV-positive individuals who disclosed their status were more likely to engage in protected anal, vaginal, or oral activity, but only with HIV-negative partners. Other studies found that: disclosers reported a smaller proportion of partners with whom they had unprotected insertive anal sex than did non-disclosers; disclosers were more likely than non-disclosers to report consistent condom use for insertive anal sex (but only with non-primary partners); consistent condom users were more likely to disclose their status than inconsistent condom users; and male disclosers had higher rates of condom use, especially during anal intercourse, than non-disclosers.

Few studies, however, employed a partner-by-partner analysis. Partner-by-partner analysis, which leads to more accurate conclusions, asks participants about the combination of disclosure and sexual risk taking with each particular partner. Also, many of the literature’s statistically significant results were limited to only one subgroup of participants, making these findings less generalizable.

In summary, while some data suggest that disclosure is positively associated with safer sex, the literature demonstrates clearly that disclosure does not guarantee safer sex and, conversely, that non-disclosure does not necessarily lead to riskier sex. One interpretation of these findings is that, because disclosure is a relatively general communication and does not focus specifically on the target behavior of risk reduction, disclosure alone may be insufficient to ensure the use of protection. This is consistent with the finding that the combination of HIV status disclosure and a discussion of risk reduction is more likely to lead to risk reduction behaviors than either action alone. An alternate explanation is that individuals frequently utilize “uninformed protection” (non-disclosure with...
Editorial: The Evolution of Knowledge
Robert Marks, Editor

The foundation of the scientific method is observation. Over time and repeated experimentation, observations cohere into theories, and theories evolve into strategies and policies. Sometimes, in the absence of research, a combination of theory and common sense precede observation and determine policy. Especially during a crisis.

Early in the epidemic, with little HIV-related data, prevention planners embraced serostatus disclosure as a fundamental step in the risk reduction process. This was not foolish; for many years, disclosure of other sexually transmitted diseases had been an accepted disease control tactic, and this approach met the common-sense test. It seemed reasonable to assume that disclosure would contribute to safer sexual activity. Two decades later, however, a review of the published literature on the topic suggests a more complex story.

In general, most scholarly articles include a brief review of the research as an introduction to a discussion of the authors’ study and findings. These mini-reviews accomplish the goal of putting the study in context. But the articles, themselves, rarely offer a comprehensive analysis of the research on a topic, including a synthesis of the study’s findings into this analysis. Instead, it is up to the reader to do the hard work of evaluating and comparing every study on a topic and deciding what it all means.

There is an alternative: the genre of research literature review. The authors of these reviews survey an entire topic, seeking to understand the value of each study and each finding, how all of these findings cohere and, once cohered, what they suggest about the topic.

David Pantalone, Mary Plummer, and Jane Simoni present in this issue of FOCUS a wonderful example of the value of a literature review. They report that while there may be many reasons to encourage serostatus disclosure, the literature reveals inconsistencies in study methodology and findings that suggest that disclosure, in and of itself, may not lead to risk reduction. Instead, they suggest that risk reduction may require specific discussions about, well . . . risk reduction.

Of course, the lack of a consistent association between disclosure and safer sex in all populations and contexts does not mean that disclosure is irrelevant to the practice of risk reduction. Instead, this conclusion suggests that disclosure is not easily defined and that the relation between disclosure and safer sex is more complex than the few initial studies have been able to decipher.

Encouraging Disclosure: Who, When, and How
How can service providers best intervene to help their HIV-positive clients disclose their serostatus and facilitate discussions of sexual risk reduction? No published work has provided empirical support for a “best practices” approach. However, some guidelines can be deduced from the literature.

Research suggests that certain subgroups of individuals living with HIV are both less likely to disclose and more likely to engage in sex that can lead to HIV transmission. These subgroups include young people, people who have recently tested HIV-positive, people who are of lower socioeconomic status, or people who have had past experiences with partners who were HIV-positive, who injected drugs, or with whom they had unprotected anal sex.

Since disclosure is often a continuous, dynamic process rather than a one-time event, prevention providers should consider raising the topic of disclosure with HIV-positive clients early and often. Some research indicates that the more often providers talk to a client about disclosure, the more likely the client is to disclose.

Discussions should focus on deciding when and how to disclose, to whom to disclose, and the importance of coupling disclosure with discussions of risk reduction. Over

References
4. Nicolas Sheon employs another less common method of examination: the analysis of narratives drawn from ethnographic research. Sheon’s article—which documents narratives about a specific incident of unprotected anal sex—uncovers another aspect of the disclosure puzzle: ambivalence among HIV-negative men about both seroconversion and serostatus disclosure. His findings suggest that the reticence to engage in discussions about disclosure among HIV-negative men may undermine attempts by HIV-positive men to address both serostatus and risk reduction.

Both articles suggest issues for future research and specific counseling approaches to respond to these concerns today. No one would suggest that 20 years of prevention emphasizing disclosure has been a waste. But now that research has uncovered the complexity of the disclosure dynamic, we are obliged to reflect these findings in our prevention messages: disclosure may be important but insufficient by itself to ensure risk reduction, and risk reduction may be achieved without disclosure.
time, discussions may focus on potential changes in the client’s attitudes toward and experiences with disclosure and the communication of sexual risk limits, that is, his or her preferences regarding specific transmission-related behaviors.

An early step in the intervention process should be an assessment of the client’s unique barriers to disclosure. There are significant disincentives to revealing one’s HIV-positive diagnosis, potentially including rejection, abandonment, discrimination, and physical or sexual violence. Also, divulging HIV-positive status may expose other stigmatized behaviors such as injection drug use or same-sex sexual behavior. Individuals who are already disempowered because of their race or class may be particularly reluctant to risk these adverse consequences. Following assessment, providers and clients can work to address these barriers and move towards the goals of routine disclosure and consistent risk reduction.

Practitioners should encourage clients to make explicit statements about their HIV-positive status and about their sexual risk limits. Explicit communication minimizes misunderstandings that arise when people use indirect means such as assuming that any partner who does not ask about serostatus must also be HIV-negative; leaving HIV-related medications within a partner’s view; or inferring that a partner’s preference for a sexual position such as a “top” or “bottom” indicates tacit disclosure of serostatus.6 Further, providers should emphasize the need for clients to initiate discussions of HIV status with their partners rather than relying on partners to bring up the topic.6

As stated previously, it may be useful for clinicians to explain that disclosure alone often is not enough to ensure risk reduction goals are met. Counselors may suggest that clients pair an explicit HIV status disclosure with a forthright discussion of sexual risk limits. Likewise, while explicit disclosure and discussion of risk limits are always preferable, it may be helpful for providers to discuss ways that clients can achieve risk reduction goals without disclosure in some situations, for example, by avoiding, altogether, activities with an unacceptably high likelihood of transmitting HIV.

Considering Contextual Factors

Providers should address contextual variables that may affect the likelihood of a disclosure conversation occurring. Among these variables are the venue in which sex occurs, the power dynamics of the dyad and, most importantly, the relationship status and HIV status of the client’s partner.

The setting in which sex occurs may affect disclosure. Some venues such as bathhouses or sex clubs have distinct cultural mores proscribing either disclosure, condom use, or both.6 Even outside of these venues, with some partners—especially those with whom a client has a history of unprotected sex—disclosure may not seem feasible.

Clients may wish to disclose but feel reluctant to transgress strong situational norms. In response, clinicians might focus on a client’s acceptance of the norms as immutable. Alternately, they can explore the client’s perceptions of the consequences of breaking norms and, when appropriate, highlight the consequences as less aversive than initially feared. Further, counselors might encourage harm reduction—for example, seeking sex in other venues or with other partners—and encourage experimentation with disclosure in “successive approximations,” that is, progressing over time from disclosing less threatening to more threatening situations.

Status-related power imbalances in a dyad—related to sex, race, class, age, or perceived level of attractiveness—may influence both the willingness to disclose and the ability to ensure condom use. Clinicians should normalize the feelings of unfairness and validate the added difficulty of disclosing when an individual already feels disadvantaged within a relationship. Providers may also encourage planning for disclosure to occur outside of the sexual arena. Counselors might offer to directly assist in the disclosure process by having the partner join the client’s session. For all clients, clinicians may assist clients in making contingency plans if the disclosure conversation does not go well.

Finally, it is essential to consider both the individual’s relationship to the partner and the partner’s HIV status. Clearly, disclosing to steady partners or spouses is different from disclosing to casual or anonymous partners, and disclosure strategies may differ based on a partner’s perceived or actual HIV status. In addition, strategies used and motivations for disclosure will vary based on these variables. For clients with HIV-positive partners, clinicians may focus on personal benefits to the client such as protecting themselves from HIV superinfection or other sexually transmitted diseases.7 For clients with HIV-negative partners, clinicians may focus on the needs of the partner, the client’s feelings of responsibility for the partner’s health, and the locality’s laws governing any legal obligations to disclose or to protect.6

Motivational Enhancement Therapy

In the absence of any empirically supported disclosure interventions, motiva-
HIV Status Disclosure

The first crucial aspect of motivational enhancement therapy is assessment, which, in the context of disclosure, includes a focus on the client's attitudes, behaviors, and goals regarding disclosure and sexual risk limits. The assessment process should result in identifying the unique barriers and contextual factors that are likely to impede the client's disclosure or increase HIV transmission-related behaviors. Addressing these barriers in the service of the client's goals should remain central in the intervention efforts that follow.

Conversation about the issues raised during assessment can gently examine any client ambivalence about disclosure. Essential to this process is considering the pros and cons of disclosure and highlighting the discrepancies between the client's actual behaviors and his or her goals or values. Throughout these conversations, the counselor should emphasize the client's demonstrated abilities and strengths. To avoid engendering defensiveness, this approach “rolls with resistance”: rather than challenging a client's argumentative comments, the counselor encourages his or her expression through questioning, and by clarifying, elaborating, or exaggerating the client's position. During this process, the counselor may offer new perspectives but avoids imposing them, and encourages the client to generate potential solutions to his or her disclosure challenges.8

For example, imagine a hypothetical client “Michael,” a 40-year-old gay White man diagnosed with HIV two years earlier. Michael reports inconsistent condom use for anal sex with casual partners. He states that he never discloses his HIV status to partners unless he is explicitly asked, asserting, “Everyone needs to take care of themselves. People know how HIV is spread. I’m no one’s caretaker.”

In response, the therapist might first empathize with how difficult it is to disclose one’s HIV-positive status and affirm the tenet that people are, indeed, responsible for their own actions. The therapist might reflect that Michael uses condoms in some situations and discloses when asked, yet, in some contexts, both of these actions seem less important: when Michael has partners who do not ask about his serostatus, he does not disclose. The therapist might ask Michael to talk about how these situations differ and how any differences relate to his decision to use or not to use condoms. Through this process, the therapist makes explicit Michael's previously unstated decision rules and creates a framework through which Michael can examine these rules in the context of his risk reduction goals.

The therapist highlights any areas of ambivalence Michael expresses, no matter how small. The process examines behaviors that are not in line with Michael’s current goals by exploring their pros and cons. Further, Michael and the therapist may establish a hierarchy of homework assignments that move towards his disclosure and risk reduction goals and may role-play both a variety of disclosure tactics and the confrontation of potential disclosure roadblocks.

Conclusions

Although the literature on serostatus disclosure and risk reduction is mixed, providers may consider four tactics. They should couple disclosure with a discussion of sexual risk limits, broach the topic of disclosure early and often, emphasize the need for explicit disclosure, and tailor interventions to the contextual factors and characteristics of each client and the client’s partners.

References


In San Francisco, before the HIV antibody test became available in 1985, HIV prevention messages focused on the injunction to assume that all partners are potentially HIV-positive and, in response, to use a condom every time. After 1985 came the additional injunction to test regularly and disclose one’s sero-status to one’s partners.

The high prevalence of HIV among gay men and the uneasy coexistence of these two contradictory prevention messages have contributed to a growing ambivalence about seroconversion and disclosure. To better understand how HIV risk and disclosure practices have evolved in light of these conflicting prevention messages and advances in treatment, researchers in San Francisco interviewed 150 gay men in 2000.

Gay Men’s Views on Disclosure

The in-depth interviews pivoted around a detailed narrative of a specific incident of unprotected anal sex. The narratives revealed important differences between HIV-positive and HIV-negative men’s views on disclosure practices.

HIV-positive men described disclosure as a duty. Disclosing up front to their partners, whom they assumed were also HIV-positive, gave these men permission to engage in barebacking. The apparent willingness to disclose was somewhat counterintuitive given the research literature’s emphasis on the stigma encountered by HIV-positive people in disclosing their status.

By contrast, HIV-negative men saw little advantage in disclosing to casual partners. Like the HIV-positive men, HIV-negative men assumed their partners were seropositive. In justifying their reticence to disclose, HIV-negative men alluded to strong community norms against HIV disclosure to both casual partners and boyfriends.

For example, one HIV-negative respondent described disclosure as “just something I don’t think about anymore. It’s just so common here for people to not really talk about. Even in the context of a serious relationship, it just never really comes up. I mean I had hoped he [my boyfriend] would have shared it with me, but I just never found the right time to bring it up as a subject without it laying some kind of uncomfortable pall on the whole scene. I just learned to believe that anybody that says they’re negative might be lying anyway so to me it doesn’t really make a lot of difference.” This quotation illustrates the ambivalence created by the two conflicting prevention messages described earlier: while the respondent wishes his partners to disclose, he asserts they cannot be trusted to reveal their true status.

These ambivalent statements reflect the conflict between the desire to practice safer sex and the desire to belong, to see oneself as an authentic member of the gay community.
Ambivalence surrounding HIV-negative status was reflected in respondents’ fatalistic statements about seroconversion. As one HIV-positive man stated: “I think some people feel like it would be just easier to get the virus now and get it out of the way than to always have it in the back of your mind.” This points to a crucial difference between HIV-negative and HIV-positive status. HIV-negative status is inherently unstable because it can become positive, while HIV-positive status provides a stable identity. HIV-negative status is always subject to doubt due to both the antibody window period and partners’ dishonesty or denial about their status.

HIV-positive and HIV-negative respondents attributed their own risk behavior to trends in the community such as barebacking, treatment optimism, and safer-sex fatigue. Many respondents described barebacking as a calculated risk. According to one HIV-negative respondent: “I know I’m playing Russian Roulette, but I feel the odds are in my favor [as] a top. I was just tested a month ago, but it was negative so I’m sure that’s—But again, I do really risky things sometimes and I’m still coming up negative, so again—I think people are being a lot more unsafe now than they were 10 years ago. People are living longer, so people are kind of going ‘Okay, if I do get it, I’ll kind of be alive until they figure something out.’ That’s not my philosophy, but I think that’s a lot of people’s philosophy. I mean, I remember there was a time when I was walking to get an HIV result and I just thought, ‘Oh, God, just let me have it. I’m so sick of this worry, and I’m so sick of being excluded.’ Because everyone I knew thought, ‘Oh, God, just let me have it. I’m so sick of this worry, and I’m so sick of being excluded.’ Because everyone I knew was positive.”

Ambivalence around seroconversion was also expressed in HIV-negative men’s envy of HIV-positive men for their membership in a more “authentic” gay culture. For example, one HIV-negative man who had “come out” in his thirties, expressed a need to make up for lost time in building his “gay résumé.” He said, “There aren’t a lot of prerequisites that you have to prove that you’ve done before you’ll be accepted, but on the other hand, I’ve often felt that I don’t quite belong here. I wasn’t in San Francisco in the ‘70s or ‘80s. I don’t have a lot of the experiences a gay man my age is supposed to have had and that has sometimes felt uncomfortable to me. Like I wasn’t quite a real gay man. I didn’t have a very good gay résumé. Sometimes I’ve even wondered if that wasn’t one of the reasons a lot of my friends were HIV positive. I wanted some of their experience to rub off on me or something.”

Ambivalent statements such as these reflect the conflict between the desire to practice safer sex on the one hand and the desire to belong, to perceive oneself as an authentic member of the gay community.

Using Ambivalence to Work with Clients

Clients often have conflicted feelings about their risk practices. The prevention counselor’s role is to help clients explore both positive and negative feelings about unprotected sex. Assessing all past risks since the last HIV test often places clients on the defensive and discourages a deeper, more candid discussion.2,3 Eliciting a detailed narrative or story about a particular risk incident with an anonymous or casual partner can help generate ambivalent statements that can offer an entry into a deeper discussion of the situational factors that lead to HIV-related risk behaviors.4

Ambivalent statements, however, can be double-edged. By definition, ambivalent people can argue both sides of an issue. Challenging clients from one side—by emphasizing the risks they are taking—often leads clients to argue from the other point of view and may actually produce resistance to change.5,6

Conclusion

The San Francisco study’s narratives invoked a macho, barebacking ethos that discourages disclosure in order to avoid “ruining the mood.” In the absence of a verbal disclosure, respondents ascribed serostatus based on faulty assumptions about their partners’ unprotected behavior. A partner willing to “bottom” was assumed to already be positive or willing to become infected, while a “top” was assumed to be negative because he would not knowingly infect others. Eliciting narratives about a specific risky encounter can enable providers and clients to explore the links among such assumptions, ambivalence about seroconversion, and disclosure.

Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
Recent Reports

**Patterns of Serostatus Disclosure**

HIV-positive men who identified as gay or bisexual were more likely to report sex without disclosure of HIV status than HIV-positive men who identified as heterosexual or HIV-positive women, according to a national study.

Researchers recruited a national probability sample of 1,421 HIV-positive patients from medical clinics in the United States. Participants had to be at least 18 years old and HIV-positive, and they had to have had at least one medical appointment during the first two months of 1996. Researchers conducted interviews in 1998 on sexual behavior in the prior six months, partners' HIV status, condom use, and HIV status disclosure to partners.

The sample was 51 percent White, 32 percent African American, and 13 percent Hispanic. Forty-seven percent of participants were under age 40, and 42 percent had an AIDS diagnosis. Researchers conducted analyses on three main groups: men who identified as gay or bisexual (43 percent); men who identified as heterosexual (21 percent); and women (36 percent).

Gay and bisexual men were significantly more likely than women or heterosexual men to report having any oral, vaginal, or anal sex without disclosure; 42 percent of gay and bisexual men reported such behaviors, compared with 19 percent of heterosexual men and 17 percent of women. Additionally, 16 percent of gay and bisexual men reported unprotected anal or vaginal sex without disclosure, compared to 5 percent of heterosexual men and 7 percent of women.

It is notable, however, that only 3.4 percent of gay and bisexual men reported unprotected anal insertive sex to ejaculation without disclosure. Furthermore, across all three groups, most participants—63 percent—who reported any sex without disclosure also reported only having unprotected oral sex or protected anal or vaginal sex, activities that are less likely to transmit HIV than unprotected anal or vaginal sex. This suggests that people with HIV who do not disclose often use other forms of risk reduction in lieu of disclosure.

Among gay and bisexual men, 83 percent of the partnerships involving sex without disclosure were non-exclusive partnerships. The comparable figure was 48 percent for heterosexual men and 52 percent for women. This discrepancy may relate to the higher rates of HIV within the gay community and subsequent public health messages urging gay and bisexual men to assume that every partner is HIV-positive, potentially reducing the need and the perception of the need to disclose serostatus within casual partnerships.

**Safer Sex Negotiation and Disclosure**

A cross-sectional study of HIV-positive gay and bisexual men found that shorter length of time since diagnosis was correlated to more frequent use of sexual negotiation strategies.

Researchers recruited 256 HIV-positive gay and bisexual men who reported having had unprotected vaginal, oral, or anal sex with HIV-negative partners or partners with unknown status within the prior four months. The majority of participants were White, and the average age was 37 years. A questionnaire elicited negotiation frequency based on three items that rated “how often participants tried to talk their partners into practicing safer sex.”

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**There are five steps for negotiation:**

*Know what you want. Know what you will compromise.

Know as much as possible about your partner. Have a backup plan. Rehearse.*
“High-frequency negotiators” had been HIV-positive for an average of approximately two years less than low-frequency negotiators. High-frequency negotiators also scored significantly lower on alcohol use and on depressive symptoms, compared to low-frequency negotiators. Finally, high-frequency negotiators scored significantly higher than low-frequency negotiators on self-efficacy and outcome expectancies in relation to condom use, negotiation, and disclosure.

There are five recommended steps for sexual negotiation. Be prepared (that is, know what you want). Know what you are willing to compromise. Know as much as you can about your partner. Have a backup plan. Rehearse sexual negotiations.

**Consequences of HIV Status Disclosure**


More than half of HIV-positive injection drug users were influenced by fear of rejection when considering whether to disclose serostatus to sexual partners, according to a multi-site study on positive and negative consequences of HIV status disclosure.

Researchers recruited a total of 158 HIV-positive injection drug users in San Francisco and New York City. Participants had to be at least 18 years old and had to report having injected drugs and having had sex in the prior year. The sample was 51 percent male, 61 percent African American, 22 percent White, and 13 percent Latino. The average age among participants was 41.5 years.

Researchers also examined the role of responsibility associated with disclosure. Of the 24 participants who reported consistent disclosure to casual sex partners, 62 percent said they reveal their status as a result of a strong sense of personal responsibility. Five of these participants reported feeling a strong responsibility to disclose to their partners because of the experiences they had had with prior sexual partners who did not disclose to them. Although more women than men in this study consistently disclosed their status, all five of these participants were men.

Twenty-two percent of the participants who reported sex with casual partners explained that they disclose their HIV-positive status in order to relieve themselves of the responsibility of ensuring safer sexual activity. Another 12 percent, however, said they insist on safer sex in order to rid themselves of the responsibility of disclosure.

**Next Issue**

Methamphetamine use among men who have sex with men has exploded in urban centers and is implicated as a driver in new seroconversions. In the July issue of *FOCUS*, **Kristina Jones, MD**, Assistant Professor of Psychiatry at Weill Cornell Medical College in New York, reviews the literature on the psychological and physiological effects of methamphetamine, in particular, focusing on methamphetamine-related psychotic features and their effects on HIV treatment and HIV prevention.

Also in the July issue, **Steven Shoptaw, PhD**, a clinical psychologist with Friends Research Institute and the UCLA Integrated Substance Program, discusses treatment for methamphetamine addiction, including innovative approaches such as contingency management.
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