Research Update

In the United States, the number of new HIV infections annually has remained steady for the past decade, demonstrating a need for more and better prevention tools. At the same time, research indicates that up to one-third of HIV-positive people continue to have unprotected sex, sometimes without informing their HIV-negative or unknown-status sex partners.1

Research also shows that more people are “serosorting,” that is, choosing to have unprotected sex with partners of the same HIV status, possibly without increasing the overall rates of new infections.2 All of these factors suggest that disclosure can both increase awareness of HIV risk and support conscious sexual decision in order to reduce HIV risk.

What is Disclosure?

“Disclosure” is the process of revealing one’s HIV status—HIV-negative, HIV-positive, or unknown—to another person. It may refer to a conversation between current, past, or potential sex or injection partners. For HIV-positive people, disclosure also refers to the notification of past partners about their potential HIV risk. This may be done through a partner notification service such as Partner Counseling and Referral Services (PCRS).

Research suggests that disclosure helps people who are already HIV-positive build their support networks, and notification brings people who may have been exposed to HIV into testing and, if necessary, care. Disclosure also increases awareness of HIV risk and can lead to risk reduction. However, studies suggest that disclosure alone does not guarantee safer sex.3 Likewise, non-disclosure does not necessarily lead to riskier sex.4 In 2004, researchers reviewing the HIV literature found 23 studies on disclosure, including 15 that provided some information about the relationship between disclosure and risk reduction. The authors concluded that “disclosure alone does not automatically lead to safer sex in the way one might presume.” For example, some people disclosed a positive HIV status, but then did not use condoms because they wanted to demonstrate a commitment to the relationship, because they were under the effects of substances, or because their partners chose not to use protection. Instead, the authors found that it was sexual negotiation skills, not disclosure itself, that reduced risk.1

Barriers to Disclosure

The combination of disclosure and a conversation about risk reduction is
more likely to lead to risk reduction than disclosure alone. Yet clients who consider having such conversations face several barriers. Sex and illness are difficult for many people to discuss for a variety of personal or cultural reasons. Further, disclosure can be complicated by the risks of judgment, loss of confidentiality and discrimination, and partner violence. Power imbalances between sex partners based on age, race, gender, class, and self-esteem influence both a person’s willingness to disclose HIV status and to implement risk reduction after disclosure. The setting of sexual contact can also inhibit disclosure; for example, conversation may be less common in some places, such as public sex environments.¹

In the review article cited above, the authors noted that studies have found that people disclosed status more frequently to steady partners than to casual or anonymous partners.² They also described how the norms and values of a culture influence whether or not a person even sees a need for disclosure. For example, early prevention messages encouraged gay men to assume every person even sees a need for disclosure. For example, early prevention messages encouraged gay men to assume every partner to be HIV-positive, and these messages may have contributed to a cultural belief that discussing HIV status is not necessary.³

In 2000, researchers interviewed 150 men who have sex with men in San Francisco about their disclosure attitudes and practices. The descriptions of these participants reveal the complexity of this issue for HIV-negative as well as HIV-positive people. Some HIV-negative men were afraid to reveal their status because they are afraid of being rejected by HIV-positive sexual partners or of interrupting the spontaneity of the sexual encounter. In contrast, some HIV-positive men were “eager to disclose their positive status” so that they could engage in unprotected sex without being concerned about transmission.⁴

**Risk Reduction without Disclosure**

It is possible to reduce risk without disclosing. Some people may see disclosure as unnecessary because they take actions that reduce HIV risk. Some authors refer to this as “uninformed protection.”⁴ For example, a person might have oral sex instead of anal or vaginal sex or use condoms not just to lower HIV risk but also to lessen the need to discuss HIV. On the other hand, disclosure itself may enable people to reduce risk while having unprotected sex. One San Francisco study found that disclosure facilitated unprotected anal intercourse among men who have sex with men, without appearing to increase the rates of new infections.⁵ The authors suggested that many of these men were serosorting—choosing to have sex with partners with the same HIV-status. If partners who are using serosorting know their true HIV status and accurately communicate it, unprotected sex does not increase the risk of seroconversion.

**Disclosure Assistance**

Despite the real barriers to disclosure and the capacity to reduce risk without it, there are many benefits to disclosure. A 2004 study of 158 HIV-positive, sexually active, injection drug users reveals some of these benefits. Of the 99 participants with a primary partner who responded to disclosure questions, 39 did not disclose their HIV status to partners prior to sex. Among these non-disclosers, 89 percent said that the negative consequences they imagined if they did disclose would not have been as bad as the actual consequences they experienced as a result of not disclosing. For example, one participant described her “closeness” with her husband as having diminished. Another said that having waited so long to disclose still “tears [him/her] apart.” Participants who did disclose cited three rewards of disclosure: social support and intimacy, reaffirmation of a sense of self, and the opportunity to share personal experiences and feelings with sexual partners.⁶ Discussing HIV status also helps HIV-negative people choose what kind of sex to have, with whom to have it, and whether or not to use condoms and other risk reduction methods. Two types of programs—disclosure assistance and partner counseling and referral—can help people address the barriers between their intentions to prevent HIV through disclosure and their ability to discuss their own HIV status. Disclosure assistance is any service that helps people decide whether, when, how, and where to talk about HIV status with sex and needle-sharing partners. One program in San Francisco—called the Disclosure Initiative—is designed to help both HIV-positive and HIV-negative people discuss HIV status, to help providers discuss disclosure, to lessen stigma around the topic, and to more explicitly connect the concept of disclosure with the process of sexual negotiation.

The Disclosure Initiative embodies a few concepts that are not always the focus of disclosure programs. First, it emphasizes the fact that disclosure can take place at any point in time (see chart on page 6). Disclosure to sexual partners,
for example, may occur upon meeting in person or chatting on the internet, after beginning to date, when preparing to have sex for the first time, in the midst of a sexual relationship, or after a sexual relationship or encounter has concluded. The Disclosure Initiative emphasizes that at any point, disclosure assistance services can help prepare people to “ask and tell” about HIV status.\(^6\)

Second, the initiative reaches out directly to community members. It does this using several routes: billboards and pamphlets, a web site, and through trainings of test site counselors and other HIV providers throughout the city. In addition, initiative staff serve as an ongoing resource, helping providers and clients think through and role-play their concerns about disclosure. Staff also assist with referrals to programs including Partner Counseling and Referral Services. Third, it targets not only the HIV-positive people who are the typical focus of partner notification services, but also HIV-negative people, seeking to make HIV status disclosure a community norm for people of either status.\(^6,7\)

**PCRS: Three Ways to Help**

Partner Counseling and Referral Services (PCRS) is the name used both by the Centers for Disease Control and Prevention (CDC) and the state of California for partner notification. PCRS seeks to help HIV-positive people consider whether and how to disclose to past sexual and needle-sharing partners that these partners may have been exposed to HIV. PCRS takes three forms: self-notification, assisted or “dual” disclosure, and third-party notification.

Self-notification is the process by which the HIV-positive individual discloses to past contacts his or her HIV-positive status. PCRS provides coaching about whether or not to undertake self-notification and how to undertake it if an individual chooses this approach. It may also include role playing.

Dual-notification is the process by which a client discloses his or her HIV status to a past partner in the presence of a trained counselor. During dual notification, the counselor does not disclose the client’s status. Instead, he or she seeks to support the client and partner once disclosure has occurred.

Third-party notification involves a counselor or other provider asking for (or “eliciting”) the names and contact information of the client’s sexual and needle-sharing partners. The counselor then forwards this information to a PCRS provider who contacts the partners, notifies them that they may have been exposed to HIV, and then offers them HIV counseling and testing. The name of the original (or “index”) client is never revealed to the partners who are being contacted.

In all three forms of notification, counselors conduct thorough screenings for domestic violence and other psychosocial issues that could threaten the index client’s safety during disclosure. It is important to note that PCRS programs do not force disclosure but, rather, help clients consider the benefits and risks, as well as the various methods of notification.\(^8\)

**PCRS and Prevention**

Partner notification has been very effective at reaching out to people at risk for HIV who would not ordinarily come into testing services. Based on the most conservative estimates, one literature review between 1975 and 2004 found a seropositivity rate of 8 percent among people contacted through third-party notification. This rate is far higher than is found in most testing programs. The true percentage may be higher still because it does not include people who declined to test during initial contact, but who tested on their own afterwards. It also does not include those who tested after being notified through the self- or dual-notification methods.\(^9\)

Another study, this one a meta-analysis of 25 studies conducted between 1985 and 2002, found support for partner notification among HIV-positive people. In the studies reviewed, the authors reported that 78 percent to 92 percent of clients believed that the health department should offer partner notification services, that “most potential PCRS clients would be willing to participate in partner referral,” and that few clients who had used the services had experienced negative consequences.

Despite the benefits of PCRS and the interest on the part of clients, providers have had a difficult time referring HIV-positive clients to the services. Among the reasons for this are lack of training, coordination, and knowledge about how PCRS works.\(^10,11\)

**Changes to PCRS**

Between 1999 and 2002, a pilot project in California explored changes to traditional partner notification, in order
to make the services even more client-centered and to educate providers on its availability. After the project, some localities changed the name of their PCRS programs, as in San Francisco’s Disclosure Assistance Program, Los Angeles’ Disclosure Assistance Services, and Alameda’s Disclosure Assistance and Partner Services. Counselors and clients can check with their local health department for the name of their local PCRS program.

The California Department of Health Services conducted the pilot project in several California counties, training HIV service providers and pairing them with sexually transmitted disease investigators to learn disclosure support and partner elicitation. Out of 1,784 clients offered disclosure assistance services, 25 percent accepted the service. Of those, 30 percent chose provider-only notification, which led to 90 notified partners who elected to test for HIV. Half of these individuals had never tested before, and 18 percent of them tested HIV-positive. This compares with a general counseling, testing, and referral program seropositivity rate of 1.38 percent. These numbers do not include the people who were notified by partners directly. Additionally, of the 161 people located, 13 percent already knew they were living with HIV, which then gave providers an opportunity to offer “prevention with positives” outreach.

While disclosure assistance and partner notification have been available for many years in California, the changes to PCRS help providers and agencies strengthen their disclosure assistance and notification services. The goal is more than preventing new infections and bringing people into HIV care. PCRS also aims to enhance quality of life, offering quality support and partner notification services throughout the continuum of care. PCRS is offered at all points at which a person might access HIV care because disclosure is an ongoing, dynamic process that changes as relationships to partners change and as a person’s experience of living with HIV changes.

The Office of AIDS and the STD Control Branch of California’s Department of Health Services have worked together to enhance the PCRS program. Throughout the state, providers are being trained to talk with clients about client disclosure options before as well as after a sexual or needle sharing encounter; to discuss when disclosure is appropriate; to assess for domestic violence and other factors that might stand in the way of disclosure; and to help determine which form of notification (self-, dual-, or third-party), if any, is most appropriate. As with traditional PCRS, notification is confidential and voluntary.

Conclusion

The research on disclosure suggests that both clients and their partners often benefit from the process, but the relationship between disclosure and risk reduction is complex. Further, both clients and counselors may find conversations about disclosure challenging. Disclosure assistance programs, including PCRS, can help both counselors and clients have these conversations, so clients can explore their needs and desires around disclosure, and take steps to share their HIV status with partners.

References


For more information about PCRS, providers can call:
J. Phoenix Smith, MSW
PCRS Unit Supervisor
California STD Control Branch
510-620-3182
Implications for Counseling

HIV counselors are in a unique position to begin the conversation about disclosure with clients. There are many opportunities within the limits of the counseling session to assess a client’s readiness to disclose, to offer options, and to support the client’s choices about next steps.

Broaching Disclosure in the Session

Many counselors begin by letting clients know how the session will unfold. They may ask, “Is anyone here with you today?” or “Who knows that you are here today?” During single-session counseling, the counselor might say, “In about 45 minutes, you will either receive an HIV-negative test result or a preliminary positive HIV test result. Is there someone you can talk with about either of those results?” This is a client-centered way to assess the availability of social support for the client. At the same time, it allows the counselor to explore to whom the client feels about disclosing, and how the client feels about disclosure.

As counselors begin the interviewing process, asking questions about partners and filling out the Client Information Form (CIF), there are opportunities to gather information that will be useful for a discussion of disclosure later in the session.

For example, counselors can gain a sense of how many sexual and needle-sharing partners a client has, whether partners are anonymous or known to the client, how the client meets partners, and whether or not the client discusses HIV status with partners prior to sex or needle use. Each of these pieces of information helps the counselor appreciate what disclosure means for this client.

During HIV test result disclosure, asking open-ended questions can help counselors discover how the client may use this information and how disclosure might serve the client. For example, after giving an HIV-negative result, a counselor might say, “What does this mean for you?” and “Does this change anything about the way that you talk to your partners about sex (or sharing needles)?” In confidential testing settings, a client’s request for results in writing can open up a discussion of how the client plans to use the results, particularly in discussions with sexual or needle-sharing partners.

Because studies have shown that disclosure of HIV status to partners is not enough, by itself, to reduce the risk of HIV transmission, counselors can explore with clients how to take the next step. What can help clients use disclosure as part of a negotiation that helps them reach their risk reduction goals? For clients who feel comfortable sharing their HIV status, this exploration can be a natural part of helping the client plan an achievable risk reduction step. Counselors can also talk with clients about how clients respond to their partners’ disclosures about HIV status. How does the client decide whether or not this information is reliable? What activities is the client willing to engage in with a partner who says he or she is of the same HIV status? Which are off-limits with a partner of a different HIV status? Are any of these topics especially difficult for the client to negotiate? As the session continues, counselors can provide referrals to offer further support around disclosure. Many sites permit additional sessions with a counselor—sometimes a specified “linkage counselor”—who can help HIV-positive clients access further disclosure assistance, including their county’s Partner Counseling and Referral Services.

Disclosure Challenges for Clients

The fact that the counseling session offers opportunities to explore the topic of disclosure does not mean that disclosure is easy for clients to do—or for test counselors to discuss. Many people with HIV fear that they may suffer discrimination, rejection in relationships, loss of sexual opportunities, and the loss of their privacy. Some people are involved in relationships in which it would be unsafe for them to disclose their status because of a partner’s anger or violence. Counselors can help clients begin the process of deciding who they want to tell, whether it is safe to tell that person, and how to disclose.

Some HIV-negative people also feel reluctant to raise the issue of their HIV status. For example, some HIV-negative gay men fear that HIV-positive men will reject them as sexual or relationship partners.

Clients, whatever their status, may also be reluctant to discuss HIV status prior to sex because the discussion can interrupt an exciting sexual encounter by introducing the possibility of illness and death. They may also fear that initiating a discussion of HIV status implies that they do not trust their partner. They may fear that disclosure requires them to take risk reduction steps that they are not willing to undertake. Finally, they may believe that disclosure is unnecessary because they have planned to reduce their risk in other ways such as using condoms or engaging in lower-risk activities.
Counselors can begin to help clients imagine ways to make disclosure conversations work. For example, counselors can help clients think about the timing of the disclosure conversation—before meeting (for instance, for partners who meet on the internet), upon meeting, when it becomes clear that sex will happen, or after sex. Counselors can also help clients think about the language they want to use to talk about their own and their partners’ HIV status.

**Challenges for Counselors**

Many counselors feel awkward about bringing up the topic of disclosure in the context of HIV prevention. In some cases, counselors fear they won’t know what to say, are unfamiliar with disclosure assistance resources, or are afraid of shaming the client or of being perceived as judgmental. When counselors remember that many clients are interested in talking about disclosure, and work through their own discomfort, they model an openness and ease with the topic for their clients.

Some counselors may feel that they will not have adequate time in the session to introduce the topic and deal with the client’s emotions and concerns about it. It is also true that many clients who have just received an HIV-positive test result may not feel ready to have in-depth discussions about disclosure.

In these cases, however, it is helpful for counselors to remember that several key parts of the counseling session already relate to disclosure. The key is for counselors to use information already gathered to continue the discussion of disclosure. It is also useful to remember the limited role of test counseling. The counselor does not need to resolve all the client’s concerns but can help the client understand his or her disclosure goals and questions and offer referrals for additional support services.

Some of the most difficult situations may arise with clients who seem strongly opposed to partner disclosure. For example, a client who is angry about his or her own diagnosis might say, “No one told me. Why should I tell anyone else?” A counselor might encourage reflection and empathy by exploring that experience, asking, “How was that for you, that no one told you? How do you think things might have been different if the person who infected you had shared that he or she was HIV-positive?”

In such cases, the counselor can also explore the possibility that the person from whom the client acquired HIV did not know his or her own status. If this is the case, the counselor might affirm that the client has already taken an important step by testing and, now, has an opportunity to use that information to prevent further transmission. It is also important to remember that while a client’s anger at having been unknowingly exposed to HIV is genuine, it may also mask other feelings, such as shame, guilt, and fears about the client’s ability to share this information with others.

Counselors may also feel frustrated, anxious, and angry if HIV-positive clients

### A Counselor’s Perspective

“At times I catch myself getting caught up in whether or not a client is ready to disclose. I offer the client disclosure options, but I also explore other ways he or she may be ready to reduce risk.”
Case Study

Allen, a 36-year-old White gay man is in a long-term, non-monogamous relationship with an HIV-negative partner. After she discloses an HIV-positive result to Allen, Mary, his counselor, asks him: “How is it for you to hear this?”

Counseling Intervention

Allen shifts in his chair and sighs. “I knew it was a possibility. It’s just so weird to finally know.” Mary and Allen discuss what is going on for Allen emotionally, and then Mary broaches the topic of communication: “We talked about the fact that you came alone today, but you said your partner is at home. Does he know you are here?”

“No, but he knows I’ve tested before and been negative. We never really talked about . . . this.”

“Maybe that’s something we can think about now,” Mary replies. “What do you think his reaction will be? Do you have any concerns about telling him?” Allen says that Bill “needs to know,” but that he’s worried Bill will become anxious about his own status, since the couple often has unprotected anal sex. Allen says he “can’t deal with telling Bill tonight” and is afraid that Bill may become angry because “I should have been more careful with the guys I hook up with online.”

Mary nods. “Lots of people tell me that they have those kinds of concerns. Sometimes it works for people to wait a while until the dust settles before they make a decision about who it’s safe to tell and the best way to tell them.” Mary then assesses for the possibility of domestic violence, asking, “How does Bill behave when he gets angry?” Allen confirms that Bill usually gets tense and then stews, but says that Bill does not become physically abusive.

Mary says, “It sounds like you want to tell Bill soon, but not tonight. That’s something we can work on together. How do you think you might tell him?” Allen shrugs and looks down. “I guess I’ll just come out with it. It’s hard for me to think about right now.” Mary and Allen make a plan to meet again in two days, and talk more then about how Allen will tell Bill the news. Mary asks Allen what he thinks would be a good risk reduction plan over the next few days. Allen replies, “It’s hard for me to imagine having sex at all right now, but if that changes, I’ll definitely use a condom.”

Mary asks, “Until we meet again, is there anybody else who you would feel comfortable talking to about this, someone you feel can really be there for you?” Allen identifies a close friend and decides to have him pick him up from the appointment.

Mary returns to the topic of disclosure. “There may also be other partners besides Bill that you want to tell, since some of them may want to get tested, and there are a few different ways you can do that. Some people like the idea of talking with their partners here, with me or another counselor in the room for support. Some people are more comfortable telling their partners themselves, after talking about how to do it. And some people prefer to let some partners know by using a service that tells the partners for them; the service would keep your identity secret.”

“And the great thing is, you can use the way that works for you with each kind of partner. For example, you could tell Bill yourself, or with me here, and you could use anonymous partner notification for the guys you met online.”

“Wow, that’s a lot of information,” Allen says. “Do I have to decide today?”

“No, you absolutely don’t,” Mary replies. “This is something we can talk about in a few days at your linkage meeting, and after that. The important thing is that you are not alone now—or later. We’re going to talk about resources to help keep you healthy, deal with this news, talk to Bill and other partners, and also have a great sex life. But first things first. Let’s just get you through the next few days. Here’s a number you can call 24 hours if you need to talk, and I’m looking forward to seeing you again on Tuesday at noon.”

do not agree to disclose to past and current partners right away. The counselor may feel that this means that he or she has somehow failed to counsel effectively. Counselors may be especially affected when they are aware that there is a particular individual, such as a current partner, who is at risk for contracting HIV. As with all aspects of client-centered counseling, clients will move at their own pace according to their levels of readiness.

Counselors can help clients who do not want to use disclosure as part of a risk reduction plan to consider other steps—for example, using condoms or having oral sex instead of anal or vaginal sex—that do not require disclosure to be effective. At the same time, counselors can offer referrals for further support if clients wish to consider future disclosure. Once again, it is critical that counselors remember their limited role, and that they are “planting a seed” about the options for disclosure that may bear fruit later.
Test Yourself

Review Questions

1. True or False: Safer sex is impossible if both partners do not know and disclose their HIV status to each other.

2. The term “disclosure” refers to which of the following? a) Sharing a client’s HIV test result with him or her; b) The moment when an HIV-negative person shares his or her HIV status with a sexual partner; c) The process by which a PCRS staff member informs past sexual contacts of an HIV-positive person that they may have been exposed to HIV; d) All of the above.

3. True or False: Although providers offer PCRS throughout the country, research suggests that clients are not interested in the service.

4. Counselors can begin to assess to whom a client might want to disclose by: a) role-playing disclosure scenarios with the client early in the session; b) asking who the client’s partners are and whether anyone knows the client is testing; c) asking for contact information on past sexual and needle-sharing partners; d) all of the above.

5. True or False: PCRS offers two options to assist clients in notifying former partners that they have been exposed to HIV: dual-notification with the support of a provider, and anonymous, third-party notification.

6. Name three benefits of PCRS.

Answers to Review Questions

1. False. Many people who do not disclose their HIV status reduce risk in other ways, such as by using condoms or substituting lower-risk activities for higher-risk activities.

2. d.

3. False. Research suggests that clients are interested in PCRS, and want to be offered these services.

4. b.

5. False. PCRS offers three options: self-notification, dual notification, and anonymous, third-party notification.

6. There are many correct answers, including any of the following: allows people who have been exposed to HIV to find out their status; helps HIV-positive people get into care; helps HIV-positive people inform partners while keeping their identities confidential if they wish; supports providers in talking with clients about disclosure.

Discussion Questions

1. How important do you think disclosure is as a prevention tool? How do your beliefs about the importance of disclosure influence your counseling?

2. What are some of the ways you use the counseling session to further the conversation about disclosure? How are your discussions different with HIV-positive versus HIV-negative clients?

3. Have you ever made a referral to PCRS? What was your experience?

4. What concerns do you have about bringing up the issue of disclosure to partners with HIV-positive clients?

5. How do your feelings about the importance of disclosure change depending on the client you are counseling? For example, for a client in a long-term relationship versus one with only anonymous partners?

6. How do you work with a client who states that he or she is not interested in disclosing to partners?
DID YOU KNOW?

You can access a FREE searchable archive of back issues of this publication online! Visit http://www.ucsf-ahp.org/HTML2/archivesearch.html.

You can also receive this and other AHP journals FREE, at the moment of publication, by becoming an e-subscriber. Visit http://ucsf-ahp.org/epubs_registration.php for more information and to register!

ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.