what is the role of disclosure assistance services in HIV prevention?

why assistance for disclosure?

Disclosure assistance services (also known as partner counseling and referral services or PCRS) are an array of voluntary and confidential services available to persons living with HIV and their exposed sex and/or needle-sharing partner(s). Disclosure assistance can play a critical role in both identifying those individuals most at risk for HIV infection, and linking those who are infected to early medical care and treatment. It is cost-effective, is based on a proven public health approach to reducing the spread of disease and is an integral part of any comprehensive HIV prevention program.

In the past few years, HIV counseling and testing programs across the US have shifted their emphasis from testing anyone, to finding and testing persons at greatest risk for HIV infection. At general HIV testing sites, around 1% of clients tested are found to be HIV+, whereas 8-39% of clients tested through disclosure assistance are found to be HIV+.

After more than 20 years of the HIV epidemic, with advances in treatment and increases in understanding and acceptance of HIV, getting an HIV+ diagnosis still can be a traumatic experience. HIV+ persons must come to terms with their own infection and be concerned with possible infection in past and future partners. Talking to partners about HIV is especially hard because even though it is a manageable disease, HIV still is not curable. HIV+ persons often need support for telling their partners about HIV, whether by encouragement for self-disclosure, or by having someone who is well-trained carefully and confidentially notify a partner for them. In one study, persons who received disclosure assistance were over three times more likely to have informed a partner of their risk.

what is disclosure assistance?

Disclosure assistance is first offered when a person receives a positive HIV test result. It is not a one-time only service, but should be offered as clients’ risk circumstances and needs change. The main element is helping HIV+ persons tell their sexual and/or needle-sharing partners about possible HIV exposure. This can happen three ways:

Self disclosure—The client chooses to notify a partner him/herself. The disclosure assistance provider guides and prepares the client before disclosure. Currently, most HIV+ persons choose this method. However, evaluating partner outcomes is difficult.

Dual disclosure—The client chooses to notify a partner in the presence of a provider. The provider supports the client during disclosure and acts as a resource for the partner. This method is rarely chosen and requires highly skilled providers.

Provider disclosure (anonymous third party)—The client prefers a professional to notify a partner, and gives his/her provider identifying and locating information for partner(s). Most often, providers give this info to Disease Intervention Specialists who then locate and notify the named partners, keeping client identity strictly confidential. This method is chosen less often, yet it is the only way for the client to remain anonymous.

Disclosure assistance mistakenly has been thought of as only provider disclosure. Each option has advantages, and there are valid reasons to choose or not choose any of them.

For the partners of an HIV+ client, disclosure assistance services can include: being notified of exposure to HIV, HIV prevention counseling, HIV testing options, referrals for HIV medical evaluation if positive and referrals for other social or medical services.

how does it work?

Disclosure assistance services can be provided by HIV service agencies, health departments (HDs) and most clinics and hospitals. Most service agencies can provide coaching and support for self or dual disclosure and gather partner identifying and locating information which is forwarded to HD staff who do the actual notification in the field. Most notification of partners has been done by local HDs because they have the capacity, expertise, trained staff and protection from liability necessary for this task. Physicians at private clinics and hospitals often are unaware of disclosure assistance services.

Disclosure assistance services are always voluntary and the ultimate decision of when and how to utilize them is always made by the HIV+ client. They can be integrated from any point in which a client receives services including HIV counseling and testing, early intervention services, STD screening or treatment or HIV medical treatment.
While HDs have been using disclosure assistance and partner notification strategies for some time, some service providers and HIV+ persons have been reluctant to use it based on concerns around relationship dissolution, potential discrimination, partner violence or even fear of criminal or civil prosecution. However, in one study, the top reasons clients chose not to inform their partners were "inability to locate" and "thought partner already knew status" and not fear of abandonment or confidentiality.5

Some HIV service providers may feel that discussing disclosure with HIV+ clients is not appropriate, assuming that clients are "too overwhelmed" to deal with it upon hearing their HIV status, or that clients do not want to discuss it. However, a study of HIV+ persons in Seattle, WA, 80% of whom were gay men, found 84% believed the HD should routinely offer everyone diagnosed with HIV help in notifying their partners, and 20% indicated they wanted help in notifying a recent sex partner.4

Counselors should assess clients for partner/domestic violence issues. However, a study of HIV+ persons and their partners who received disclosure assistance found that emotional abuse and physical violence decreased significantly after notification.9

Another concern is that disclosure assistance will lead to the breakup of partnerships and increase new partnerships, resulting in greater risk of HIV transmission. Although partnership dissolution is often high after disclosure, it is high in general, and dissolution after disclosure happens most with casual, not main, partners. Disclosure assistance services do not increase partnership breakup or new partnerships.10

Disclosing HIV status to partners can be scary, but also can be empowering. In one study, HIV+ injection drug users who disclosed their status found increased social support and intimacy with partners, reaffirmation of their sense of self and the chance to share experiences and feelings with sexual partners.11

North Carolina utilizes trained disease intervention specialists to deliver disclosure assistance for all reported new HIV infections. In 2001, 87% of all newly infected HIV+ persons used it, identifying 1,523 sex or needle-sharing partners. Over a third (39%) of named partners had been previously tested for HIV. Half (50%) of named partners had never had an HIV test, and of those, 68% got tested and 22% were HIV+.12

A program developed by ISIS-Inc offers gay men in California a way to self-disclose STD infections to partners via the internet, where many men meet their partners. inSPOT (Internet Notification Service for Partners or Tricks) lets men e-mail a card to up to six partners using fun, lighthearted slogans. While e-mail notification has been used by HDs in the past, this is the first method for clients to self disclose anonymously (or give their e-mail address). The cards do not include notification of HIV, but provide an option for a personal message and a link for e-mail assistance with HIV disclosure.13

California instituted a voluntary disclosure assistance program that includes counseling and preparing HIV+ persons for self disclosure; anonymous third party provider notification; counseling, testing and referrals for notified partners; and training and technical assistance to providers in public and private medical sites. About one-third of patients opted for provider disclosure and 85% referred partners. Of the partners located, 56% tested for HIV and half had never tested before. Overall, 18% of partners tested HIV+.14

Disclosure assistance services can be an effective way to identify persons most at risk for HIV infection and to slow HIV transmission. Effective programs require 1) extensive work with the community and healthcare workers to gain support, 2) intensive training, supervision and quality assurance for providers and 3) full integration into comprehensive HIV care and prevention services.12 Streamlined rapid HIV testing is also a potential invaluable tool for field testing of notified partners.

It is important to offer disclosure assistance services to HIV+ persons at several stages of their HIV diagnosis and care. It is not the role of providers to decide whether or not a client will need or want disclosure assistance, but to offer clients support and choices, whether or not a client chooses to disclose. Disclosure assistance services should be made available not only at initial HIV diagnosis, but on an ongoing basis as HIV+ persons’ circumstances and needs change.

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