Center for AIDS Prevention Studies
UCSF
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what is the role of disclosure assistance services in HIV prevention?

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why assistance for disclosure?

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.

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 is cost effective and can play a critical role in identifying those individuals most at risk for HIV infection, and linking those who are infected to early medical care and treatment.[1,2,3]

Most HIV+ persons make the decision to disclose or not disclose to their partners on their own. But HIV+ persons may want 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.[4]

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.[5] *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+.*[2]

what is disclosure assistance?

Often, disclosure assistance or PCRS mistakenly has been seen as only provider disclosure, but there are three forms of assistance:

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.

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 (DIS) who then locate and notify the named partners, keeping client identity strictly confidential. This method is chosen less often, yet it is the only one with client anonymity.

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.[6]

how does it work?

Disclosure assistance services are 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.

The quality and use of disclosure assistance services can vary widely. Services differ from state to state: some have legal mandates to provide it, some offer it through HIV, STD or combined HIV/STD programs, and states can receive referrals from clinicians, health departments or testing sites.[7]

Services can be provided by HIV service agencies, health departments 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 DIS staff. Most notification of partners has been done by DIS at local health departments because they have the capacity, expertise, trained staff and protection from liability.

Good provider disclosure depends on DIS staff who are properly trained and have enough experience and knowledge of the populations they serve. DIS staff should be evaluated regularly to assure quality and be provided with support and ongoing training.[6]

Says who?

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what are the concerns?

Public health messages have traditionally urged disclosure to all sexual and drug using partners. In reality, disclosure is complex and difficult. Some HIV+ persons may fear that disclosure will bring partner or familial rejection, limit sexual opportunities, reduce access to drugs of addiction or increase risk for physical and sexual violence. Because of this, some HIV+ persons choose not to disclose. Programs need to accept that not disclosing is a valid option.

Many HIV service agencies and testing and counseling sites routinely offer self disclosure and dual disclosure, working with HIV+ clients by preparing and supporting them to disclose to partners on their own.

Although provider disclosure services have been used for many years with other STDs, there is a wide variety in rates of acceptance of provider disclosure in HIV: in North Carolina, 87% of newly diagnosed HIV+ persons accepted provider disclosure,[8] in Florida 63.1%,[9] Los Angeles, CA 60%,[10] New York State 32.9%,[11] Seattle, WA 32%[12] and among anonymous testers in San Francisco, CA 3.1%.[13] In Los Angeles, the most common reasons for refusal were: already notified partner (23.4%), not being ready to disclose (15.3%), being abstinent (15%) and having an anonymous partner (11%).[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.[14] Another study of HIV+ persons and their partners who received disclosure assistance found that emotional abuse and physical violence decreased significantly after notification.[15]

what's being done?

Florida utilizes trained DISs to deliver disclosure assistance for all reported new HIV infections. In 2004, 63.1% of all newly infected HIV+ persons accepted provider disclosure, identifying 4,460 sex or needle-sharing partners. Among those, 21.8% had previously tested HIV+. Of the 2,518 persons notified, 84.2% agreed to counseling and testing and 11.5% were HIV+.[9]

The Massachusetts Department of Public Health piloted a client-centered model of disclosure assistance that is integrated into the client's routine prevention, care and support services. The program required significant changes to the standard model of DIS provider disclosure, building close relationships between service providers and DIS to better support clients' disclosure needs while protecting confidentiality.[16]

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+.[4]

what needs to be done?

New HIV testing technologies can be useful with disclosure assistance services. Improved rapid testing is a potential invaluable tool for offering HIV tests in the field to notified partners. Nucleic acid amplification testing (NAAT) can determine acute infections, that is, new HIV infections that do not show up during the window period of other HIV tests. Combining these testing strategies with disclosure assistance can help identify newly infected persons and provide immediate counseling, support and referrals to medical or social services as needed.[17]

Disclosure assistance services, and particularly provider disclosure, may need extensive changes from the traditional DIS model in order to work well and be accepted within HIV services. Health departments could forge closer ties between their STD and HIV programs and with outside service agencies. HIV staff also can be trained to be DIS providers to broaden access to and comfort with disclosure services.

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

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