

how does disclosure affect HIV prevention?

why is disclosure important in HIV?

Disclosure of HIV+ status is a complex, difficult and very personal matter. Disclosing one's HIV+ status entails communication about a potentially life threatening, stigmatized and transmissible illness. Choices people make about this are not only personal but vary across different age groups, in different situations and contexts, and with different partners, and may change with time, depending on one's experiences. Disclosure may have lifelong implications since more people are living longer, and often asymptotically, with HIV.

Public health messages have traditionally urged disclosure to all sexual and drug using partners. In reality, some HIV+ persons may choose not to disclose due to fears of rejection or harm, feelings of shame, desires to maintain secrecy, feelings that with safer sex there is no need for disclosure, fatalism, perceived community norms against disclosure, and beliefs that individuals are responsible for protecting themselves.¹ This Fact Sheet primarily focuses on disclosure in the context of sex.

Discussing and disclosing HIV status is a two-way street. Be it right or wrong, most people feel that when a person knows that he/she is HIV+ then he/she has an obligation to tell the other person, and counselors are encouraged to help people with this process. Also, laws in some areas require disclosure of HIV+ status prior to sex.² However, both partners should be responsible for knowing their own status, disclosing their own status when it seems important, and asking their partner about their status if they want to know.

Most HIV+ persons disclose their status to some, but not all, of their partners, friends and family. Disclosure generally becomes easier the longer someone has been living with HIV, as he/she becomes more comfortable with an HIV+ status. Disclosure to sex partners is more likely in longer-term, romantic relationships than in casual relationships (one-night stands, anonymous partners, group scenes, etc.).³ Disclosure also varies depending on perceived HIV status of partners, level of HIV risk of sex activities, sense of responsibility to protect partners (personal vs. shared responsibility) and alcohol or drug use.

does disclosure affect sexual relationships?

The relationship between disclosure, sexual risk behaviors and potential transmission of HIV varies. Research findings have presented a mixed picture.⁴ Some studies have found that increased disclosure is associated with reduced sexual risk behavior.⁵ Other studies show that disclosure doesn't always alter risk taking behaviors.⁶ Even with disclosure, unsafe sex sometimes occurs. Some people engage in safer sex behaviors without any discussion of HIV status.⁷

Disclosure can provide psychological benefits. In one study, HIV+ injection drug users who disclosed their status experienced increased intimacy with partners and reaffirmation of their sense of self.⁸ Many HIV+ persons who disclose their status find that it reduces anxiety about transmission, so sex can be much more comfortable and relaxed.

A challenging issue for many people is the timing of disclosure. If it's not done relatively early, it can become more difficult as time goes on, and can cause significant disruption to an ongoing relationship if the disclosed-to partner feels betrayed due to the lack of an earlier disclosure. HIV+ persons who have thought through a disclosure plan and have a consistent strategy for managing disclosure are less likely to engage in risky sexual behaviors than those who do not disclose or have inconsistent disclosure strategies.⁵

does disclosure affect social relationships?

Yes. Disclosure to significant others can help increase support for HIV+ persons. A study of Latino gay men found that disclosure was related to greater quality of social support, greater self-esteem, and lower levels of depression.⁹ Disclosure also can lead to support that facilitates initiation of, and adherence to, HIV treatment and medications.^{10,11}

Disclosing HIV+ status can and sometimes does result in rejection, discrimination or violence. Disclosing to certain persons also can be more of a burden than a benefit. One study found that friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members.¹²

Says who?

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what are the controversies?

There is debate around whether partners have a right to know if their partner is HIV+, in order to be able to make a fully informed decision about what sexual behavior to engage in. Some HIV+ persons believe that if they only have protected sex, there is no need for disclosure, especially with casual partners, and that encouraging disclosure only serves to further stigmatize HIV+ persons. These issues can be complicated by complex gender role norms and local laws—23 states have laws that make it a crime for a person to engage in certain risk behaviors without disclosing their HIV status.²

People may use disclosure as a way to limit their partners to only persons of the same status, be it HIV+ or HIV- (sometimes known as serosorting). The success of serosorting as a prevention strategy depends upon honest and accurate disclosure on the part of any two sexual partners.¹³

Even when persons do choose to disclose, their awareness of their own HIV status may not be accurate.¹⁴ For example, some people who think that they are HIV- may be, in fact, in the acute stage of HIV infection. If an individual is in the acute stage of HIV infection, which are the initial weeks to months after acquiring HIV when the body has not yet produced a detectable antibody response, then he or she will have a negative result on a standard HIV test. This is especially concerning because when people are in this stage of infection, they more readily transmit the virus during unprotected sex than at other times.¹⁵

what's being done?

Because many experts believe that HIV+ status disclosure helps prevent HIV transmission and increases social support for HIV+ individuals, there are efforts to develop programs to encourage disclosure and make it a constructive experience. Most programs to support HIV status disclosure have been part of overall prevention and well-being programs for HIV+ persons. Programs may include discussions of the benefits of disclosure, when to disclose and to whom. Programs should include practicing skills to discuss HIV status in the context of sexual negotiation and dating.

The Healthy Living Project is a 15-session, individually delivered, cognitive behavioral intervention to help HIV+ persons cope with the challenges of living with HIV. The project addressed issues of stress, coping and adjustment, safer behavior, including disclosure to partners, and health-related behaviors. Participants reported fewer unprotected sexual risk acts with persons of HIV- or unknown status.¹⁶

Healthy Relationships is a 5-session, small-group skills-building program for HIV+ persons, and is one of the CDC's Diffusion of Effective Interventions (DEBI). It is designed to reduce participants' stress related to safer sexual behaviors and disclosure of their HIV status to family, friends and sex partners. Participants reported significantly less unprotected intercourse and greater condom use at follow-up.¹⁷

Other disclosure approaches have aimed at encouraging both HIV+ and HIV- persons to not make assumptions about their partner's HIV status, to get tested, to disclose their own status and practice safer sex with all partners. The Department of Public Health in San Francisco, CA, created the Disclosure Initiative social marketing campaign which aims to normalize the disclosure of HIV status for both HIV+ and HIV- men.¹⁸

what needs to be done?

We need to normalize and facilitate comfortable discussions about HIV, so that disclosure of HIV+ status isn't such a difficult thing to do. The more HIV is talked about, and the more people come out about being HIV+, the less stigma there will be.

Disclosure is a two-way street. That means it is up to both people who are having sex with each other to address the issue. People living with HIV often are much happier in their relationships (long and short-term) when their HIV status is known by their partner.

There's no simple answer or policy for disclosure of HIV. Clinicians, counselors and programs need to be sensitive to the complexity of disclosure, and understand that disclosure is not for all people in all contexts. However, disclosing one's HIV status can facilitate support for HIV+ persons and may lead to better communication, including discussion of risk reduction practices between sexual partners.

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