

# Rapid Response Service

# Sexual abstinence among people living with HIV/AIDS



## Question

What is the impact of sexual abstinence (lack of sexual intimacy or loss of sex) on people living with HIV/AIDS?

# **Key Take-Home Messages**

- Diagnosis of HIV infection can have far-reaching implications: people's sexual interest, the pleasure they derive from sex, their sense of attractiveness or appeal as a sexual partner may change considerably irrespective of their age, sex, race, sexual orientation, housing status, drug use, or underlying diseases such as hemophilia.
- Risk perception evolves with time and experience, and the fear of infecting partners. This lack of libido may continue to affect sexual relationships well after the initial "settling down" period.(1;2) However, many people living with HIV later recover satisfactory sexual lives with their HIV-positive or negative partners.
- In many HIV-positive patients sexual desire decreases because of fatigue, generalized wasting, muscle aches, pains, paraesthesia, and depression. Medications such as protease inhibitors have been found to have an adverse effect on desire and arousal.(3)
- Among older adults (aged 50 and more) celibacy is more prevalent following diagnosis with HIV. Women report celibacy more than men. In general, older adults may have difficulty resuming healthy sexual relationships following diagnosis with HIV/AIDS.(4)
- Among HIV-positive adolescents with hemophilia, abstinence can be intentional and marked by a series of decisions and behaviors that are influenced by peer group norms and personal values.(5)
- Injection drug users (IDUs) are more likely to be abstinent when they have lower CD4 level (below 200), HIV-related medical symptoms,

## **EVIDENCE INTO ACTION**

The OHTN Rapid Response
Service offers HIV/AIDS programs
and services in Ontario quick
access to research evidence to
help inform decision making,
service delivery and advocacy.
In response to a question from
the field, the Rapid Response
Team reviews the scientific and
grey literature, consults with
experts, and prepares a brief fact
sheet summarizing the current
evidence and its implications for
policy and practice.

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- and lower neuropsychological memory test. In female IDUs, depressive mood is also associated with abstinence.(6)
- Although HAART use has been linked to sexual functioning of HIV-positive men, HIV-positive women describe highly similar experiences of diminished sexual activity, a loss of sexual interest, and decreased feelings of attractiveness both before and after the advent of HAART.
   (7)

# The Issue and Why It's Important

Research exploring sexuality in people living with HIV/AIDS shows that a diagnosis of HIV/AIDS may result in a subsequent loss of libido and cessation or reduction of sexual activity.(7) Learning about the diagnosis may affect people's sexuality in other more subjective ways, such as altering sense of personal attractiveness or sexual desirability. In addition, the pleasure derived from even protected sex may be diminished greatly by anxiety related to the possibility of infecting others or becoming re-infected, as most recognize that condoms can break. When such changes occur, the pleasure of sexual intimacy is greatly diminished and, as a result, there may also be a substantial decline in one's interest in sex.(7) This summary outlines research exploring sexual abstinence (lack of sexual intimacy or loss of sex) due to HIV-positive status.

## What We Found

Sexuality is an important part of being human and living a full life. Affectionate intimate relationships are an important part of the well-being of many individuals and contribute to health and quality of life. A chronic illness such as HIV/AIDS can have far reaching implications on people's lives.(3;7)

Many people newly diagnosed with HIV people go through an initial phase of desexualisation but, over the long term, many recover a satisfactory sexual life with either HIV-positive or HIV-negative partners. Sexual abstinence (lack of sexual intimacy or loss of sex) is one type of coping mechanism that people living with HIV/AIDS (especially those newly diagnosed) may use. This summary discusses currently available research evidence related to the prevalence and characteristics of sexual abstinence for different populations discussed in the literature (i.e., gay/bisexual men, heterosexual men and women, older people, adolescents, people who inject drugs, homeless and unstably housed people and hemophilia patients).

## Men (gay/bisexual, heterosexual) and women

Bogart et al (2006) examined patterns and correlates of deliberate abstinence among men and women with HIV and found a substantial proportion of the participants in their HIV Cost and Services Utilization Study (HCSUS) chose abstinence.(8) Women and heterosexual men were more likely to deliberately abstain than were gay/bisexual men. Gay/bisexual men who deliberately abstained were more likely than women and heterosexual men to be motivated by a perceived responsibility to protect others.

The same study found that health factors were more strongly associated with deliberate abstinence among women and heterosexual men than gay/bisexual men.(8) Compared with gay/bisexual men, heterosexual men not taking HAART and with poorer emotional functioning were more likely to be deliberately

abstinent. Health factors, including worse physical functioning and lower CD4 count, also predicted deliberate abstinence for women, although these effects were not significantly different from those for gay/bisexual men. Bogart et al. (2006) also found that gay/bisexual men who drink were less likely to deliberately abstain, although the effect for drug use was not significant. In addition black gay/bisexual men were more likely than white gay/bisexual men to abstain, which was highlighted as potentially being the result of stigma within their own social networks and isolation from gay communities. Other potential explanations were that black gay/bisexual men may be more cautious about initiating sexual relations or have less information on lower-risk sexual practices.(8)

## Men

Many HIV-positive men experience some form of dissonance associated with sexual intimacy and their HIV status (such as guilt, shame, isolation, or avoidance when making decisions about selecting a partner, disclosing serostatus, and coping with the resulting sexual behaviors). In managing these issues, HIV-positive men make choices and select different types of intimate relationships.(9) A study by Relf et al (2009) identified three types of intimate sexual relationships after HIV diagnosis: "avoiding sex," "just sex," and sex in a "going somewhere" relationship.(9) For those study participants who chose to avoid sexual relationships entirely, the intense discomfort of disclosing HIV serostatus, and the subsequent fear of potential rejection was so great that they completely avoided sexual intimacy with another person. Study participants from the "just sex" group managed their dissonance by making decisions about what types of sexual behavior they would engage in to avoid infecting others (i.e., practising what they defined as "safer sex"). Unlike "just sex participants", the "going somewhere" men disclosed their serostatus and did not see avoiding disclosure as an option but, if given the choice, they would have chosen to be in a relationship with a seroconcordant partner.

A pilot study by Palmer and Bor (2) exploring challenges to intimacy and sexual relationships for gay men in HIV serodiscordant relationships found that some seropositive study participants had little, if any, desire for sex after diagnosis. They found that this lack of libido continued to affect the sexual relationship with their partners well after an initial "settling down" period. Even if they were concerned about this, participants did not access services for help with these sexual difficulties. The seronegative participant in these relationships typically negotiated permission with his HIV-infected partner to have a casual sexual relationship with other men and his partner's lowered sexual interest (possibly because of antiretroviral treatment or advancing illness) made this more possible. The seropositive partner also perceived their reduced sexual interest as unalterable, as if it were an expected consequence of having become infected.

Physical experience of sexual activity may become a constant reminder of HIV. Rather than being an enjoyable, intimate experience, sex may reinforce the infectivity of the seropositive partner, the vulnerability of the seronegative partner to infection, and provide an opportunity for amplification of difference between the couple.(2) All this may lead to further decrease of sexual intimacy or loss of sex.

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#### Women

A loss of enjoyment of sex also affects seropositive women and appears to be related to women's knowledge of their HIV status.(1) From interviews with 21 seropositive heterosexual women, Keegan et al. (2005) found that any relationship between HIV and sex is likely complicated by other factors such as current health, length of time since diagnosis, mental health, and social circumstances. Fears around disclosure, in particular rejection upon revealing a positive HIV status, were highly important for many study participants when considering or starting new relationships and a significant barrier for some. Relationship avoidance and discouraging sexual contact appeared to be linked with the earlier stages of HIV adjustment. However, Keegan et al. note that despite these challenges, the sexual and relational aspirations of HIV-positive women appeared to mirror those of women generally with many women living with HIV continuing to pursue sexual relationships.(1)

The picture that emerges from another study (Siegel et al, 2006) is one of women who, due to the possibility of sexual transmission of their disease and/or reinfection by a partner, felt that sex had become too plagued with anxiety, worry, danger, and stress to still be pleasurable.(7) Most who were sexually inactive insisted that they had little or no desire for sex and did not miss it. Nevertheless, a few did express being open to seeking the friendship and companionship of a man who they could talk to, but insisted that they wanted the relationship to stop there. Most women who had previously suffered rejection still felt so hurt by those experiences that they were unwilling to risk putting themselves in a situation again where disclosure would be necessary. As a result, Siegel et al. note that some made a choice to become celibate, while others drifted in to a "de facto" celibacy by avoiding any relationships that might eventually become sexual ones.

Siegel et al. (2005) note that because sexual relationships can produce such feared outcomes (such as disease, death, emotional pain, pregnancy and infected children), many women felt it was best to suppress their sexual desires and remain sexually inactive.(7) This study also found that HIV-positive women described highly similar experiences of diminished sexual activity, a loss of sexual interest, and decreased feelings of attractiveness both before and after the advent of HAART.(7)

Lambert et al. (2005) also studied sexual activity among HIV-positive women and found that the majority of women in the study (72%) resumed sexual activity after becoming HIV positive.(10) However, more than half indicated that their HIV status had impaired their enjoyment of sex or made it impossible. The study also suggests that HIV status alone may be insufficient to explain why some women do not resume sexual activity after HIV diagnosis because high rates of past sexual abuse were found and abstinence since diagnosis was significantly associated with a past history of sexual abuse.(10)

## Older age

Siegel et al (2003) suggest that sexual abstinence correlates strongly with age and gender. Many older adults may have difficulty resuming healthy sexual relationships following diagnosis with HIV/AIDS.(4) Almost half of study population of older adults (aged more than 50) were currently celibate or had been celibate following diagnosis with HIV. Women reported celibacy (78%) more than men (36%). Both men and women reported that fear of infecting

others and fear of becoming re-infected with another strain of HIV or with another STD were primary deterrents to any sexual involvement. A small number of men and women attributed at least some of the decline in their interest in sex to their age.

The same study highlighted that the choice to abstain from all sexual involvement was more emotionally driven for women than for men.(4) Women usually felt hurt and violated by the men who infected them and very fearful of additional harm (both physical and emotional) that could come from further sexual contact with men. The men's choice to be celibate was usually the outcome of a reasoned decision-making process.(4)

## **Adolescents**

HIV status is challenging for adolescents living with HIV since birth. Fernet et al. (2011) examined romantic relationships and sexual activities of the first generation of youth living in Montreal with perinatal acquired HIV.(11) For these adolescents, risk is not just related to sexual transmission but more so to the emotional risk of rejecteion. They initiate their romantic and sexual lives but are filled with anxiety about being rejected by their partner. The study indicates that HIV-positive youth reported their sexual debut as comparable or slightly earlier than that of the general Canadian population. Of those reporting protected sex at first intercourse, over half mentioned taking risks (e.g., multiple partners, sexual relations with alcohol, drugs or during menstruation) in subsequent relationships. This suggests that risk perception evolves with time and experience. The fear of infecting the partners, which was found to be particularly salient at sexual debut, gradually dissipates when viral load is undetectable or when past experience suggests that partners might not become infected.(11)

In a study with HIV-positive adolescents with hemophilia, improvement and maintenance of safer sexual behavior were significantly associated with perceived peer support for outercourse, perceived peer support for abstinence, and decreased general emotional distress.(5) The study suggests that maintaining abstinence can be intentional and marked by a series of decisions and behaviors that are influenced by group norms and personal values.(5)

## **Housing status**

Abstinence has been observed among homeless and unstably housed persons living with HIV/AIDS.(12) More than a quarter of participants in the Housing and Health Study in Baltimore MD, Washington DC and Los Angeles CA reported having no sex in the past 90 days and 20% reported that this was by choice.(12) Reasons for having abstained from sex in the past 90 days selected by the most participants were that they were not interested, did not want to infect someone, and did not have a partner.(12) A slightly lower percentage of heterosexual men were sexually abstinent compared to men who have sex with men (MSM) and women, but this trend was not found to be statistically significant. Those who had completed high school and who had no main partner or spouse were also found to be more likely to have abstained than others. Additional key findings from this study include:

- age and gender were not found to be significantly associated with sexual abstinence
- partner status (i.e., having a main partner or spouse) was associated with abstinence among all study participants
- abstinence among MSM was less likely among those with a detectable HIV

viral load

- among heterosexual men, abstinence was associated with higher education level and the experience of housing problems.
- among homeless women, abstinence was less likely among those with a history of sexual abuse and those whose social network members were more aware of their HIV status.

## **Injecting Drug Users**

Two longitudinal studies (Dolezal et al, 1999; Dolezal et al, 1998) concluded that intravenous drug users (IDUs) in New York City have modified their sexual behavior toward safer practices.(6;13) The studies found that for both HIV+ and HIV- IDUs, there were increases in abstinence and monogamy, decrease in frequency of unprotected sex and a decrease in sexual risk index scores. It was also found that men were more likely to abstain from sex, to limit their sexual behavior to one partner, and to reduce the number of times they had unprotected sex.(6) Among women who were abstinent there were higher levels of depression. As Dolizal et al. (1998) suggest, psychological status may be an important factor in sexual abstinence in this population as depressive mood is associated with less sexual activity in general. However, the strength of association is difficult to determine given that having unprotected sex is also associated with the loss or lack of a sexual partner and could therefore also result in psychological distress, loneliness, and depressive mood.(6;13)

# **Factors that May Impact Local Applicability**

All studies explored sexual abstinence (lack of sexual intimacy or loss of sex) due to HIV positive status in developed countries (primarily in the USA). Cultural and demographic characteristics of the study populations are similar to those in Canada. For this reason the results of this rapid review are likely applicable to the Canadian context.

## What We Did

We conducted a targeted search of PubMed in April 2011 using a combination of relevant search terms. Specifically, we conducted searches with two combinations of search terms: 1) HIV and (sexual abstinence OR sexualization OR intimacy) and 2) HIV and sexual intimacy.