HIV disclosure to sexual partners

An overview

HIV disclosure, health and human rights

Disclosing one's HIV status is not easy. HIV status is intensely personal information and the act of disclosure can lead to both positive and negative results. This is why people living with HIV (PHAs) are **entitled to control over this crucial decision** and should be provided with all **the necessary support and information —** including information about their obligations under the criminal law — **to decide if, when and how they will tell other people about their HIV status.**

The topic of disclosure of HIV status has been the subject of discussion, debate and deliberation since the beginning of the AIDS epidemic. Most of it has been about a few people who do not disclose their HIV status before they engage in behaviours at higher risk of transmitting HIV. The focus on a few HIV-positive people who put others at risk of HIV transmission and the increasing use of the criminal law to deal with HIV non-disclosure has distorted the discussion and made life more difficult for PHAs. It has reinforced the climate of fear, stigma, and discrimination that surrounds HIV infection and has even resulted in violence against some PHAs.

Whether or not we like or agree with the criminalization of HIV non-disclosure, it is the law until the Supreme Court of Canada or the Canadian Parliament decides otherwise. So, we must respond to it. Our responses must be guided above all by a concern for the health and human rights of people living with and vulnerable to HIV.

What does health have to do with HIV disclosure? According to the World Health Organization (WHO), health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The goal of client counselling in the context of HIV disclosure is to promote client health. The closer PHAs are to this state of complete physical, mental and social well-being, the more likely they are to feel comfortable disclosing their HIV status in situations where they can enjoy the positive benefits of disclosure. As a result, counselling about HIV disclosure issues can contribute to the promotion of public health.

What do human rights have to do with HIV disclosure? From a human rights perspective, people are entitled to enjoy the conditions that would enable them to realize their health and well-being. This means that under international law, governments are obliged to respect, protect, and fulfill the rights of people. The guiding principle of human rights is that every human being deserves to be **treated with dignity**. And while

community-based organizations are not part of government, they should strive to fulfill the guiding principle of human rights by treating all clients with dignity. AIDS service organizations (ASOs) and other service-provider programs (including counselling), based on human rights (rights to privacy and to the highest attainable standard of health) and legal and ethical principles (confidentiality and informed consent), serve to lessen the adverse impact of HIV on individuals and communities. In this way, health and human rights complement and mutually reinforce each other.

UNAIDS and the WHO encourage **beneficial disclosure**. This is disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for those individuals *and* for their families and sexual and drug-injecting partners; leads to greater openness in the community about HIV; and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV. (Source: WHO and UNAIDS, *Opening up the HIV/AIDS epidemic*, 2000.)

Disclosure to sexual partners is complex

Most people living with HIV do not want to transmit HIV and believe that either safe sex practices or disclosing their HIV-positive status to their sexual partners, or both, is the right thing to do.[1] But disclosure is an intensely personal and difficult undertaking. **Whenever a person discloses intimate details about his or her personal life, emotions are engaged**. Disclosing intimate personal information may involve thoughts, memories, feelings and sensations. People faced with a stressful situation may remember other stressful situations, feel scared or feel like "running away," their heart may beat faster, or they may feel sick to their stomach. Disclosing one's HIV status to a sexual partner means talking honestly about sex, sexual orientation, sexual acts, possible drug use, disease and death. All of these are often taboo subjects that are at very least difficult to talk about openly and honestly in most if not all societies and communities.

Even for the most self-affirming, self-confident person, these are difficult subjects to talk about. Vulnerabilities surface: self-image, self-perception and self-esteem are all involved. Counsellors need to be aware of all the powerful psychosocial factors that influence a person's decision to disclose or not disclose his or her HIV-positive status, including the fear of rejection, stigma, discrimination, potential criminalization, violence and death.

Social barriers to disclosure

In our society, **stigma** is often associated with having any disease, particularly a serious disease that can be passed from person to person. HIV is now a chronic and manageable condition when people have proper access to treatment and enjoy the personal circumstances that enable them to adhere to this or that prescribed treatment.[2] Some progress has been made in terms of shifting the public's perception of HIV since the beginning of the epidemic. But, despite that progress, PHAs continue to be particularly stigmatized worldwide.[3]

Factors which contribute to HIV stigma include:

- The mistaken belief that HIV always lead to AIDS and/or death;
- Ignorance and misconceptions about how HIV can be transmitted;
- An exaggerated sense of HIV risks of transmission, especially through sex;
- Religious or moral beliefs around sexuality and drug use;
- The fact that already stigmatized and/or marginalized groups — such as men who have sex with men, people who inject drugs, sex workers, prisoners, Aboriginal peoples or migrants — are disproportionally affected by HIV.

Although there are laws in Canada that can protect PHAs from discrimination, discrimination remains common and disclosure can expose PHAs — directly and indirectly — to discrimination in housing, employment or access to health and social services. Disclosure can also lead to rejection by family, friends and community, and can even result in the discloser being subjected to violence.

HIV also disproportionately affects individuals who are already marginalized. These people risk being further marginalized if they disclose their HIV-positive status.

Several studies have shown that **fear of violence** and rejection can have a strong impact on the decision to disclose or not, particularly among some HIV-positive women who fear potential reactions of their male sexual or drug-injecting partners.[4] People may also fear that their partners may **reveal their status to others.** Concerns around confidentiality are particularly real in tight-knit communities in which many immigrant PHAs live in Canada, as well as for positive women with children.[5] **Social exclusion and isolation** can also play a role. Several studies of gay and bisexual men have demonstrated that internalized homophobia, isolation from the gay community, lack of familiarity with the majority culture, and being "in the closet" can have a negative impact on some men's decision to disclose to sexual partners.[6, 7, 8]

The criminalization of HIV non-disclosure can also make disclosure to sexual partners more challenging for PHAs who may fear being subjected to false accusations and/or prosecution if they tell their partners they have HIV. This is of particular concern for PHAs in abusive relationships or after a bad breakup.[9] Counsellors should be aware that fear of criminal prosecutions can also hinder a PHA's capacity to talk openly about their disclosure or sexual practices with their counsellors since information provided to a counsellor can be compellable as evidence in a criminal investigation.[10]

The timing of disclosure

Many complex factors influence a person's ability to disclose and the timing of disclosure. **Disclosure of one's HIV-positive status is generally a complex undertaking and not a one-step process**. Studies among HIV-positive men have shown, for instance, that for many of them "disclosure [wa]s a process of testing the waters or dropping hints."[11] And only a few may be able to disclose in a clear and explicit manner.[12]

The ability to disclose one's HIV-positive status can be related to the degree to which an individual has accepted his or her HIV diagnosis. It is often most difficult to

disclose soon after diagnosis, when a person is grappling with the initial impact of his or her HIV-positive status.[13]

A person's ability to disclose his or her HIV status can also be affected by the physiological and psychological changes brought on by sexual arousal, drug use or drug addiction. The release of chemicals in the body during erotic arousal can change perception, cognition and boundary-setting. An intense pre-orgasmic state may strongly impact a person's ability to disclose. Both the psyche and the body are in harmony and focused on building sensuality and not necessarily on rational or ethical thinking. People who use drugs may also experience the same type of blurring of their rational and ethical vision. Disclosure may be easier before intense erotic arousal or when the physiological and psychological need for drugs is not so great.

The criminalization of HIV non-disclosure may also have an impact on the ability of a PHA to disclose his or her status to a partner with whom he or she has already had sex, especially if no condom was used, as disclosure may result in potential accusation and prosecution for not disclosing HIV-positive status before the first sexual encounter.

The context of disclosure

Disclosure may be easier or more difficult depending on the context in which it takes place. In many cases, due to fears of rejection and breach of confidentiality, disclosure to potential sexual partners may be more difficult than disclosure to trusted friends or family. **Disclosure may be less common with casual partners or in a commercial sex setting**, especially if condoms are used. In the environments where **anonymous sex** takes place, serious conversations about HIV status usually do not occur. People may also engage in sexual acts on the basis of non-verbal disclosure signals, assumptions, or underlying physiological and psychological factors.

Tariq, who is HIV-negative, may assume that a partner who wants to have unprotected sexual intercourse is also HIV-negative. The partner, who is actually HIV-positive, is assuming that Tariq would only have unprotected sex if he were already HIV-positive.

Disclosure in the context of a **long-term or committed relationship** may also be extremely difficult. Relationships may not always be based on trust, honesty, openness, safety, or good communication. PHAs may fear their partners' reactions. A PHA may fear losing his or her partner, children, financial security and sometimes immigration status, or be subjected to physical and emotional violence. **PHAs, especially HIV-positive women in longer-term heterosexual relationships, may also face specific challenges** affecting disclosure and safe sex practices due to norms of discontinuing condom use once a relationship becomes "serious," expectations related to childbearing, or assumptions about women's sexuality that may vary from one community to another.

The difference between "disclosure" and "partner notification"

In the context of HIV infection, **partner notification** — sometimes referred to as **contact tracing or partner counselling** — is a **public health measure** designed to prevent HIV transmission and to encourage people who have been exposed to HIV to seek testing and,

if appropriate, medical care. Partner notification is not disclosure, but it may involve an act of disclosure. Disclosure is the act of telling or revealing (HIV status). Partner notification is a process that involves contacting the sexual or injection drug partners of a person who has a blood-borne or sexually transmitted infection (including HIV), advising them that they have been exposed to the infection, and advising them that they should seek testing and, if appropriate, medical care.

When a person first tests positive for HIV, a health care provider (usually a doctor or a public health nurse), will counsel that person to contact his or her sexual and injection drug partner(s). Health care providers or public health officials will also probably ask for information about the partners, including their names. The health care provider or public health official may contact those partners with or without the PHA's consent, depending on the circumstances and the public health unit. Generally accepted principles of good practice mean that the person doing the partner notification (e.g., a public health nurse) should not reveal the name or other identifying information of the person who is HIV-positive, although in practice and depending on the circumstance, a partner who is contacted may suspect or be able to determine the identity of the original client.

Legal and ethical obligation to prevent HIV transmission

Counsellors must remember that the concept of "ethical" obligations regarding disclosure and sexual practices, and responsibility to prevent HIV transmission remains highly **subjective**. Some may believe that all sexually active people, whether they know their HIV status or not, have an ethical obligation to protect themselves and their partners from HIV. Practising "safer sex" is one step people can take to reduce HIV transmission. But the intensification of prosecutions against PHAs who did not disclose their status shows that many, including some crown prosecutors, believe that the responsibility for preventing HIV transmission lies solely with PHAs.

Even among PHAs, ethics **may not be so clear-cut**. Some PHAs believe they have a moral obligation to disclose their HIV status to all potential partners. Others may take a more situational or conditional approach, believing that disclosure is unnecessary if safer sex is practised, assess how safe they feel before disclosing, or disclose only if a relationship has the potential to progress beyond a casual stage.[14] Some PHAs may decide they are behaving ethically when having unsafe sex and not disclosing their HIV status because everyone in their community knows about the reality of HIV and the risks of transmission.

See the section on "Criminal law and HIV non-disclosure" in this resource kit to learn about PHAs' **legal obligation** to disclose their status. The criminal law supposedly reflects the behaviour society considers unacceptable and deserving of punishment. We may not agree with it but it is the law, and PHAs need to know their legal obligations in order to make informed decisions around disclosure and sexual practices.

There are many reasons why people may not disclose their HIV-positive status and/or may engage in unprotected sex:[15]

- PHAs may not disclose their status but choose to engage in lower risk sexual activities (e.g., using condoms, oral sex) to protect their partner;
- PHAs who are informed about the effects of treatment on their own viral load and thus on their "infectiousness" and thus on the risk of transmitting HIV may use that information to inform their practices;
- Fear of rejection, violence, abandonment, and loss of privacy affect disclosure practices and condom use;
- Concerns that condom use signals a lack of trust or infidelity, and the desire to conform to social and cultural norms, affect people's sexual and disclosure practices, as does the desire to have children;
- Some PHAs who are open about their status may feel potential partners would already know about their HIV-positive status so there is no need to disclose.
- PHAs may engage in higher risk behaviours and/or not disclose their status as a result of denial, mental health issues or substance abuse issues.

Counsellors need to recognize they may be biased

Counsellors should strive to recognize their biases regarding sexual or drug-injecting behaviours in order to address them. A 1998 U.S. study of 309 marriage and family therapists, examining factors related to counsellors' breaking confidentiality when HIV-positive clients' disclosed high risk sexual behaviour, found that counsellors were more likely to breach a client's confidentiality if the counsellor was older, female, had less experience with lesbian or gay populations, was Catholic or was otherwise very religious.[16]

[1] See E. Bernard, *HIV and the Criminal Law* (London; NAM, 2010), p. 57 and studies cited therein, including C.L. Galletly & J.B. Dickson-Gomez, "HIV seropositive status disclosure to prospective sex partners and the criminal laws that require it: Perspectives of persons living with HIV," *International Journal of STD & AIDS*, 20(9) (2009): pp. 613–618; K. Siegel, H.M. Lekas, and Eric W. Schrimshaw, "Serostatus disclosure to sexual partners by HIV-infected women before and after the advent of HAART," *Women & Health* 41(4) (2005): pp. 63–85.

[2] D. McLay et al., "Scientific research on the risk of the sexual transmission of HIV infection and on HIV as a chronic manageable infection" (updated December 2011). Originally published in E. Mykhalovskiy, G. Betteridge, and D. McLay, *HIV Non-Disclosure and the Criminal Law: Establishing Policy Options for Ontario* (Section 3). August 2010. Funded by the Ontario HIV Treatment Network.

[3] See E. Bernard, supra; "AIDS stigma is alive and well. And it is killing us," *Poz, Health, Life and HIV*, Dec. 2009, feature, available at www.poz.com; EKOS Research Associates Inc., *HIV/AIDS Attitudinal Tracking Survey 2006: Final Report* (Ottawa: Public Health Agency of Canada).
[4] A. Gielen, P. O'Campo, R. Faden, and A. Eke, "Women's disclosure of HIV status: experiences of mistreatment and violence in an urban setting," *Women Health*, 25(3) (1997): pp. 19–31; K. Siegel, H.M. Lekas, and Eric W. Schrimshaw, supra.
[5] E. Tharao, N. Massaquoi and S. Telcom, *Silent voices of the HIV/AIDS epidemic: African and Caribbean Women in Toronto 2002–2004*, Women's Health in Women's Hands Community Health Centre (publisher), 2005.
[6] J. Kennamer, J. Honnold, J. Bradford, and M. Hendricks, "Differences in disclosure of sexuality among African American and White gay/bisexual men: implications for HIV/AIDS prevention," AIDS Education Prevention, 12(6)2000: pp. 519–31.
[7] R. Ratti, R. Bakeman, and J. Peterson, "Correlates of high-risk sexual behaviour among Canadian men of South Asian and European origin who have sex with men," *AIDS Care*, 12(2) (2000): pp. 193–202.
[8] R. Wolitski et al., "HIV disclosure among gay /bisexual men in four American cities: general patterns and relation to sexual practices," *AIDS Care*, 10(5)(1998): pp.599–610.
[9] E. Mykhalovskiy, "The problem of 'significant risk': Exploring the public health impact of criminalizing HIV non-disclosure," *Soc Sci & Med* 2011; 73(5): 668–675
[10] Ibid.; P. O'Byrne et al., "Nondisclosure and HIV Prevention: Results From an Ottawa-Based Gay Men's Sex Survey," *Journal of the Association of Nurses in AIDS Care* (in press).
[11] B. Adams et al., "Effects of the Criminalization of HIV Transmission in Cuerrier on Men Reporting Unprotected Sex with Men," *Canadian Journal of Law and Society*, 2008, Volume 23, nos. 1–2, p.148, citing Robert Klitzman and Ronald Bayer, *Mortal Secrets: Truth and Lies in the Age of AIDS* (Baltimore: Johns Hopkins University Press, 2003), 51.
[12] Ibid., citing Michael Stirratt, "I Have Something to Tell You," in *HIV+ Sex: The Psychosocial and Interpersonal Dynamics of HIV-Seropositive Gay and Bisexual Men's Relationships*, eds. Perry N. Halkitis, Cynthia A. Gómez, and Richard J. Wolitski (Washington, DC: American Psychological Association, 2005); C. Dodds, A. Bourne, and M. Weit, "Responses to criminal prosecutions for HIV transmission among gay men with HIV in England and Wales," *Reproductive Health Matters*, 17(34) (2005): pp. 135–145.
[13] R. Holt et al, "The role of disclosure in coping with HIV infection," *AIDS Care*, 10(1)(1998): pp.49–60.
[14] B. Adams, "Drawing the line: Views of HIV-positive people on the criminalization of HIV transmission in Canada," presented at the Canadian HIV/AIDS Legal Network symposium, Toronto, June 2010.
[15] GNP+, *The Global Criminalisation Scan Report 2010*, July 2010. Available via www.gnpplus.net/criminalisation; E. Bernard, *HIV and the Criminal Law* (London; NAM, 2010)
[16] S. Pais, F. Piercy, and J. Miller, "Factors related to family therapists' breaking confidence when clients disclose high-risks-to-HIV/AIDS sexual behaviours," *Journal of Marital and Family Therapy*, 24(4) (1998): pp.457–72.