

## **HIV Disclosure and Confidentiality**

When addressing the complex issues raised by disclosure and confidentiality of HIV status, it is hard to ignore the need to focus on human rights and privacy, including many issues related to law and respect for the rights of individuals. Confidentiality is crucial to persons living with HIV or AIDS. Since HIV infection is associated with sexual and drug related activities, disclosure can expose HIV-positive individuals to stigmatization, discrimination, and rejection by family, friends, and community. In addition, HIV/AIDS disproportionately affects already marginalized individuals who would be even further ostracized if their status were to be disclosed. Federal, provincial, and community-based agencies view disclosure differently in various situations.

## **Constitutional Right to Privacy**

The Canadian Charter of Rights and Freedoms recognizes the individual's right to privacy in relation to information about themselves and the individual's right to be protected against unreasonable search or seizure and "unreasonable invasions of privacy" (Holmes, 2006). When deciding whether or not confidential information should be disclosed to prosecutors, the court must balance the need for individual privacy with the need for effective law enforcement.

The Supreme Court of Canada has indicated that in balancing privacy and law enforcement interests, specific factors should be considered (Elliot, 1999):

- The nature of the information;
- The nature of the relationship between the party releasing the information and the party claiming its confidentiality;
- The place where the information was obtained;
- The manner in which it was obtained;
- The seriousness of the crime being investigated;
- The issue of medical confidentiality is so important in the HIV testing and reporting context because it has been widely recognized as a central element in the effective response to AIDS. (Jurgens, 1998)

The safeguarding of personal information is something that is focused on when it comes to the protection of privacy in Canada. Due to the changing nature of personal information and the accessibility of this information, privacy acts and legislation have required updating numerous times to remain abreast of new means to obtain, store and access personal information.

In Alberta, the Freedom of Information Protection and Privacy (FOIP) Act was created for a number of purposes including:

- To allow a person the right to access their information that may be held or in the control of a public body\*;
- To control how personal information is collected from individuals by a public body, and to control how that information is used and/or disclosed;
- To all individuals, under the specific exceptions in this Act, a right to access personal information about themselves that may be held by a public body;
- To allow individuals the right to request their personal information that is held by a public body, be corrected;
- To provide for independent reviews of decisions made by public bodies under this Act, and for complaints to be resolved under this Act.

\* Public Body includes; "Government of Alberta ministries, boards, agencies and commissions, as well as school boards, post secondary educational institutions, municipalities, police services and commissions, health care bodies, Métis settlements, public libraries, drainage and irrigation districts, and housing management bodies."

It is important to know that the FOIP Act does not apply to private businesses or non-profit organizations in Alberta. For these, Alberta's *Personal Information Protection Act* (PIPA) will apply. This Act protects individual privacy by requiring private-sector organizations to obtain consent for the collection, use and disclosure of personal information in most cases, and provides individuals with a right of access to their own personal information. If any individual in Alberta wishes to make a complaint regarding the handling of their personal information, they should contact the office of the Information and Privacy Commissioner of Alberta online at [www.oipc.ab.ca](http://www.oipc.ab.ca) for more information.

## **Confidentiality and Testing**

Confidentiality is seen as crucial to encouraging those most at risk for HIV to come forward for testing and medical attention. On the other hand, the appropriate collection, use, and disclosure of HIV-related personal information can contribute to medical and social epidemiological knowledge which may aid in treatment, prevention, and education initiatives (Jurgens, 1998). HIV is a reportable disease in Alberta, meaning that each positive test must be reported to Alberta Health and Wellness. On an individual basis, however, disclosure of a positive HIV-antibody test may lead to social isolation, family estrangement, and loss of employment, housing, and insurance (Jurgens, 1998).

## **The Duty to Warn**

Canadian law recognizes the duty of healthcare professionals to maintain patient confidentiality. In most cases, it is considered professional misconduct for a healthcare professional to disclose patient information without consent. However, legal and professional bodies have recognized that confidentiality must give way in certain circumstances to protection of the public interest.

For example, the Canadian Medical Association advises physicians that disclosure of a patient's HIV status to a current sexual partner may not be unethical when specific criteria are met (Elliot, 1999):

- The partner is at risk of infection with HIV and has no other reasonable means of knowing;
- The patient has refused to inform their sexual partner;
- The patient will not allow a physician to inform the sexual partner on the patient's behalf;
- The physician has informed the patient of his or her intent to disclose the HIV status to the sexual partner.

According to the CMA and the Canadian Association of Social Workers, the healthcare professional should counsel the patient on possible barriers to risk reduction and should attempt to motivate the patient to disclose their HIV status or cease unsafe behaviours before reporting the situation to public health authorities (Elliot, 1999).

The Public Health department of the Calgary Health Region uses the following principles as a guide when addressing the non-disclosure of HIV/AIDS.

- Public health is mandated for the protection of people, not the punishment;
- To effectively prevent further spread of HIV, engage the population in voluntary testing, education and health promotion programs;
- A commitment to provide EVERY necessary support or intervention for anyone that may be Unwilling or Unable to protect themselves and others from HIV transmission;
- Public health must protect the needs of ALL groups, including those that may be marginalized;
- If an intervention is to take place, the individual's rights must be balanced with the protection of the public.

## **Disclosure of Counseling Records**

Maintaining confidentiality of discussions between patient and health or social work professional is important ethically, to maintain the dignity of the patient. This, however, is also pragmatic, as physicians and other professionals attempt to elicit information pledged to be confidential from patients and clients.

"In the absence of such a pledge, there can be no assurance of candor and in the absence of candor, the capacity to engage in effective clinical work would be impaired" (Elliot, 1999). This may be especially relevant in the case of HIV/AIDS, as disclosure can have massive repercussions. However, the Supreme Court of Canada has insisted on disclosure of relevant or admissible communications between a healthcare professional and a patient unless they can be determined to be 'privileged' by the following criteria (Elliot, 1999):

- The communication must originate in confidence that it will not be disclosed;
- This element of confidentiality must be essential to the full and satisfactory maintenance of the relation between the parties;
- The relation must be one that in the opinion of the community ought to be sedulously fostered;

- The injury that would inure to the relation by the disclosure of the communication must be greater than the benefit thereby gained for the correct disposal of litigation.

### **Partner Notification: Does it require disclosure?**

Partner notification (or 'contact tracing') has been defined as "the spectrum of public health activities in which sexual and injection equipment-sharing partners of individuals with HIV infection are notified, counselled about their exposure and offered services" (Jurgens, 1998). The Southern Alberta Clinic (SAC) works with Public Health to provide partner notification. Their philosophy is that HIV transmission can be reduced by early identification of asymptomatic individuals. All HIV-positive individuals are instructed to inform their sexual and needle-sharing partners of their status.

When an individual is unable or unwilling to disclose their HIV-positive status to partners, Public Health will provide partner notification services, while insuring the confidentiality of the index case. SAC nurses obtain information on sexual and needle-sharing partners at risk over the six months prior to time of seroconversion, or if time of seroconversion is unknown, from as far back as possible up to January 1978. If a patient refuses to inform their current sexual partner and high risk behavior is suspected, Public Health will inform the partner after informing the patient that this will occur. Partners notified will be given information on HIV, an HIV-antibody test, and a follow-up interview one month from testing. Partner notification does not involve disclosure, as at no time will the index case be identified to the partners contacted.

### **Confidentiality in Extended Healthcare Settings**

Under Canadian law, physicians and other health-care providers have a duty of confidentiality to their patients (de Bruyn, 1998). Unfortunately, preserving confidentiality and maintaining control over medical information in extended healthcare settings, such as hospitals or clinics, is difficult, if not impossible. In June of 2005, AIDS Calgary conducted a study looking at the difficulties accessing medical services for people living with HIV. The study indicated that 31% of survey respondents felt information about their HIV status was not kept confidential during a hospital stay. Another result of this study shows a large amount of trust placed in health care professionals, as 85% of the sample had disclosed their HIV status to doctors, nurses, dentists and EMS.

### **Disclosure and Insurance**

The insurance industry is a for-profit industry which has the power to decide who can or cannot be insured and who must pay a higher premium. Insurers, then, may exclude people with HIV/AIDS from coverage or benefits on the basis of low return on risk-sharing. Canadian human rights codes offer a defense to insurance companies such that they may exclude individuals with a pre-existing condition or disability (including HIV/AIDS) provided that they do so on 'reasonable grounds'. Disclosure for the purposes of health related insurance is not optional, since blood is tested and information must be sent to the insurance company (de Bruyn, 1998).

### **The Case of R vs. Cuerrier**

The most talked-about federal case regarding HIV/AIDS in recent years has been the case of R vs. Cuerrier. In 1992, Mr. Cuerrier learned that he was HIV-positive and was told that he should use condoms for sex and inform all of his sexual partners about his status. He said he could not disclose this in his small community. Following this, he became involved in sexual relationships with two different women (KM and BH), both cases involving unprotected vaginal sex. In neither case did he freely disclose his HIV status.

KM discovered his status after both she and Cuerrier had HIV-antibody tests and were told to use condoms during sex. Cuerrier told KM he did not want to use condoms and if she continued to test HIV-negative, he would seek out an HIV-positive partner. They continued to have unprotected sex for the next 15 months. KM later testified that she never would have had sex with him if she had known his HIV status at the outset. BH discovered Cuerrier's HIV status and confronted him, at which point he apologized and conceded that he should have told her. At the time of the trial, both KM and BH tested HIV-negative. This case questioned whether or not an HIV-positive person could be held criminally liable for not disclosing their status before engaging in behaviours involving risk of HIV transmission.

The Supreme Court's decision focuses solely on the question of whether an HIV-positive person's non-disclosure of their status can be considered 'fraud' for the purposes of the criminal law of assault. Seven (of nine) justices on the Supreme Court heard the case. All concluded that Cuerrier's non-disclosure of his HIV-positive status could constitute fraud (Elliot 1999).

More recently, a Supreme Court case called *R. v. Williams* established that even if a person has not tested positive for HIV, they may still be legally responsible for placing their partner(s) at risk of an HIV infection if they're aware that they have been exposed to a risk of HIV infection. This means that a person should disclose any KNOWN risks of HIV before engaging in risk activities with a partner.

### **Community-Based Organizations: A Need for Policy**

Staff, Interns, Contractors, Practicum Students and Volunteers working with AIDS Calgary Awareness Association are required to sign an Oath of Confidentiality stating that they are aware of "agency policy and procedures on confidentiality and understand its intent and limitations". Confidential information is to be protected unless disclosure is authorized or legally or professionally required. Without explicit policy such as this, community-based organizations may find themselves confronted by a legal obligation (by search warrant or subpoena, or through civil liability) to breach confidentiality. This obligation may arise if a client is charged with a criminal offense or if an organization employee failed to adhere to the common law 'duty to warn' someone at risk for HIV infection. Some organizations may refuse to breach confidentiality, thus risking the legal consequences. In any case, HIV/AIDS service organizations should consider developing policies or protocols regarding the parameters of the counseling relationship, professional and legal obligations, and how to respond to requests for confidential information by police or prosecution (Elliot, 1999).

"Some organizations may feel strongly that breaching confidentiality will undermine the trust relationship with the community they serve, ultimately damaging their efforts to prevent HIV transmission and to provide care, treatment, and support for people with HIV/AIDS" (Elliot, 1999).

### **Mandatory Testing and Disclosure Act**

This act came into effect, in Alberta, in October 2007. This act will allow anyone that is performing duties as a paramedic, firefighter or peace officer, or anyone providing emergency assistance, to apply for a Provincial Court order to obtain blood for testing from an individual that may have exposed them to HIV, Hepatitis B or Hepatitis C. The process involves the completion of two forms, including a physician's report highlighting the health risk to the applicant as a direct result of their contact with a body fluid belonging to the source individual and a process to determine whether the health risk warrants mandatory testing. However, it is anticipated that this process will be slow, and most people will need to make decisions regarding their treatment with post-exposure prophylaxis before testing is able to occur (within 72 hours of exposure).

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