Legal and Ethical Issues in HIV Disease

INTRODUCTION

Psychiatrists working with people living with HIV may struggle with a number of ethical dilemmas. Often they will be faced with situations that bring various social values, including civil liberties, public health concerns, confidentiality, autonomy, and discrimination, into conflict. In dealing with these situations, the psychiatrist must find a delicate balance among diverse interests and use a thoughtful approach that weighs the benefits and disadvantages of various solutions.

While established ethical principles continue to apply, certain features of the HIV epidemic require special consideration. The political and social contexts of the illness can influence ethical decision making in ways that are sometimes not apparent. In addition, the tendency of the virus to affect the central nervous system can make situations more complex.

Individual and Social Rights and Responsibilities

Much of the legal and ethical debate around HIV infection focuses on the conflict between society’s right to protect itself against the spread of disease and the rights of infected people to confidentiality and civil liberty. In fact, this perceived antagonism is misleading. Measures intended to protect the individual also protect society. The public health response to the epidemic is compromised by discrimination and the stigma attached to those victimized by the disease.
HIV is a disease of behaviour. In the overwhelming majority of cases, it is transmitted accidentally. An effective response to the epidemic depends on prevention and on the willingness of individuals to be tested and to cooperate in contact tracing and measures aimed at limiting the spread of the disease. Because so many people are not aware that they are HIV-seropositive, the responsibility for protection ultimately has to rest with everyone, and not just with the person who is infected.

A few well-publicized cases of people living with HIV who have deliberately and maliciously infected others have created a strong emotional reaction and demands for coercive measures and specific criminal laws to prevent the spread of infection. These measures would apply to a very small number of people and provide only an illusion of protection. If HIV-seropositivity can result in criminal liability, people will be discouraged from being tested. Testing is a key component of an effective HIV-prevention strategy. In contrast, measures aimed at protecting those who are infected encourage testing and, therefore, the possibility for intervention.

According to the July 1996 issue of the Canadian HIV/AIDS Policy and Law Newsletter, there is little evidence that criminal prosecution and penalty serve any significant rehabilitative function. Counselling and support are widely believed to be more effective means of rehabilitating a person who has engaged in high-risk activities.

The small number of people who cannot or will not change their behaviour to prevent the spread of HIV continue to pose a challenge to public health authorities. Many reasons may underlie this behaviour and include denial, anger, ignorance, substance abuse, violence and threat, economic imperatives, disorganization, an experienced inability to change, or a lack of concern for others. Only a concerted approach involving mental health resources, social services, and cultural and community groups can address these complex situations.

Public health legislation usually includes provisions authorizing the use of the state’s coercive power to prevent the spread of disease, including:

- orders restraining a person with a communicable disease from conduct that may infect others
- powers to detain a person who contravenes such an order

Given the way HIV is transmitted, however, those powers have to be used judiciously.

**CASE STUDY**

**SOMEONE WITH HIV POSES A RISK FOR OTHERS**

Susan is a 22-year-old HIV-seropositive woman who has a bipolar disorder. Her management is complicated by her poor adherence to treatment and by her use of crack. She trades sex for money, drugs, or shelter.

Susan was brought to the emergency room in a manic phase characterized by hyperactivity, decreased sleep, elation, hypersexuality, disinhibition, and disorganized behaviour. She was hospitalized involuntarily under provincial mental health legislation. On the ward, her sexual disinhibition was of concern to the staff.

Although cases such as this one are rare, they create great distress when the related ethical issues are discussed. In this clinical situation, the psychiatrist faces many dilemmas that have been addressed in Canadian Psychiatric Association (CPA) and American Psychiatric Association (APA) guidelines on AIDS and HIV disease. (See Appendix III.)

**Can Susan be denied a psychiatric admission based on her HIV-seropositive status and the potential risk she represents to other patients?**

No. Most professional organizations, including the CPA and the APA, have adopted resolutions against discrimination based on HIV-seropositivity status.

**Can Susan’s HIV seropositivity be disclosed to other patients?**

No. Patients have a right to confidentiality. The limits of that right are discussed below.
Given that sexual activities and/or needle sharing can occur on inpatient units, can all patients be screened for HIV infection to allow better protection of the uninfected?

No, for the following reasons:

- A negative test does not completely exclude the possibility of a patient’s being HIV-seropositive because the patient may be in the window period (see Chapter 1 for a medical overview of HIV disease).
- Testing for HIV can only be done with informed consent, when the person has received appropriate pre- and posttest counselling (see Appendix I), and when medically indicated. An acutely psychotic patient might not have the capacity to give informed consent.
- Disclosure of a patient’s HIV status is not a substitute for adequate supervision.

What protective measures are indicated on an inpatient unit?

Given the risk of HIV transmission on an inpatient unit, the following measures are indicated at all times, whether or not a patient on the ward is known to be HIV seropositive.

- All staff should use universal precautions.
- The behaviour of all patients should be monitored to avoid escalation. If a patient engages or threatens to engage in activities that put others at potential risk for HIV infection, staff should take appropriate measures to control the behaviour (for example, use of medication, isolation, or physical restraints).
- The unit should provide regular education for patients on the behaviours likely to transmit HIV and strategies they can use to deal with risk situations (see Chapter 10 on HIV and people with chronic mental illness). All patients engaging in high-risk behaviours should be encouraged to change their behaviour and assisted in doing so.
- Patients on psychiatric wards may engage in sex, but they are rarely prepared for it. In addition to providing adequate supervision, some units make condoms available to patients.

How should the psychiatrist deal with the dilemma of confidentiality in the context of the sex trade?

Susan has been sexually involved with several partners in the past few months. As some clients pay more money for sex without a condom, she has not always used them.

Several professional organizations, including the CPA and the APA, have developed recommendations to address these situations. These recommendations can be summarized as follows:

1. Psychiatrists are more likely to develop an ongoing, cooperative relationship with patients when patients understand the limits of medical confidentiality. Psychiatrists should clarify these limits before inquiring into patients’ HIV status.
2. Psychiatrists should encourage patients to stop risky behaviour or
inform identifiable partners. Partners can be informed directly by the patient, through a physician or health authority. People may require additional support throughout the process of informing partners.

3. All provinces require that AIDS cases (as opposed to HIV infection) be reported to public health authorities. Psychiatrists should be aware of the specific laws in their area. If patients refuse to change behaviour that is putting others at risk or to inform partners who are at ongoing risk, it is ethically permissible for psychiatrists to notify identifiable people at risk or to arrange for public health authorities to do so. For example, the unsuspecting partner of an HIV-seropositive person can be notified if the patient so refuses.

4. If patients’ behaviours pose a risk for unidentifiable persons, it is ethically permissible for psychiatrists to notify public health authorities. This would not replace the need for counselling, but rather would complement it. Health authorities do not have an easy solution for this problem either.

5. The importance of counselling in helping patients change their behaviour should not be underestimated. Factors such as lack of information, poor social skills, fear of rejection, low self-esteem, anger, and social and financial difficulties can be explored and resolved, possibly resulting in desirable behavioural change.

6. A trusting relationship is essential for counselling. The psychiatrist may consider focusing on the therapeutic alliance while working with another professional, such as the patient’s physician, who will do the “policing.”

7. Before breaching confidentiality, psychiatrists should reflect on their underlying personal values and assumptions. It has been shown that when clinicians decide to breach confidentiality to protect a third party, their decision may be affected by the patient’s race, sex, and sexual preference.

After three weeks on the inpatient unit, Susan was no longer manic and was well controlled on her medication. Based on previous experience, however, the psychiatrist was concerned that Susan would return to her usual lifestyle, putting others at risk through unprotected sex and needle sharing.

CASE STUDY

HIV DISEASE AFFECTS COGNITIVE ABILITY AND JUDGEMENT

John is a 42-year-old man, probably infected in the early 1980s, who has been attending an HIV clinic for seven years. His CD4 cell count is below 50 and he has been hospitalized twice for treatment of Pneumocystis carinii pneumonia. He lives alone but benefits from the support of friends, his sister, and parents. Affable, bright, funny, and grateful, his visits at the clinic are always a pleasure for those involved in his care. Over the past several months, staff and family have noted signs of HIV-1-associated cognitive/motor complex (HACM), including a slowing, in his movements, a decrease in his concentration and his capacity to retain new information, mental slowing, and irritability. When leaving the clinic after a visit, he nearly faints in front of the elevator, car keys in hand. He refuses to allow staff to call anyone, waits a few minutes, then leaves.

Given the presence of cognitive impairment, is it safe for John to drive?

This issue requires careful consideration. HIV infection can interfere with driving in many ways, including:
- generalized weakness
- poor vision (for example, retinitis)
- psychomotor slowing
- decreased judgement
Most people living with HIV who experience difficulty will, on their own initiative, restrict their driving to familiar areas and daylight hours and will avoid heavy traffic. Others do not, either because driving is so important to their sense of autonomy or because they lack insight into their limitations (common with HACM). Staff members may contribute to the problem by “forgetting” or hesitating to bring up the issue because of the discomfort they feel in limiting the autonomy of someone they care for.

After John had left the clinic, he was contacted by telephone and reluctantly agreed that his parents be called. They had reported a minor collision the preceding week. Much to their dismay (because John was their driver), they felt that his reaction time was slow and that it was no longer safe for him to drive.

How does the psychiatrist assess John’s capacity to drive?

To assess a patient’s capacity to drive, psychiatrists should follow the evolution of the person’s medical condition and mental status. When in doubt, psychiatrists should contact the occupational therapy department to arrange for a driving evaluation.

John agreed to stop driving, and arrangements were made to have his friend and his sister drive him to appointments. This remained a painful restriction for him.

Does the psychiatrist have an obligation to report patients who are unsafe drivers to the appropriate authorities?

In some jurisdictions, the physician has an obligation to report unsafe drivers if they do not comply with a recommendation to stop driving. Laws can change over time, and the clinician should remain informed of current legislation.

What other legal issues should be addressed with this patient?

Ideally, psychiatrists should discuss the following issues with people living with HIV early on, in case they later become mentally incapacitated:

- power of attorney (POA) for personal care, in which people give someone of their choice the authority to make personal care decisions on their behalf if they become incapacitated. As patients’ views and preferences may change over time, the POA is not a one-time event, but an ongoing process that involves communication between the patient and the person with POA. The medical team should be aware of the POA for personal care.

- depending on the jurisdiction, a living will, in which patients identify the treatments or procedures they want in case of incapacity, may or may not be legally binding for physicians.

- power of attorney for financial decision making.

- a will.

- funeral arrangements, if the patient so desires.
People living with HIV who are faced with these issues may perceive that they are losing control or having control taken away from them. It is, therefore, essential that psychiatrists have a sense of timing and tact. Early attention to these concerns, however, will ensure that people living with HIV retain their dignity and control throughout their illness.

Is it safe for John to live independently?

John’s cognition continued to decline. When, on two occasions, forgotten cigarettes started small fires, caregivers became increasingly worried about his ability to live independently. John was not concerned and felt strongly that he was not a safety hazard.

This is one of the most difficult decisions that caregivers and clinicians have to make, and it is made more difficult by the person’s lack of concern. In trying to resolve the dilemma, psychiatrists should keep in mind that people living with HIV fear both losing their autonomy and being abandoned. Consider the following options:

- Can safety at home be improved? For example, can the person be encouraged to smoke only under supervision? Can caregivers keep candles and matches away, remove knobs on the stove, and arrange for food to be delivered or cooking to be done under supervision?
- Can the person use a pill organizer, arrange a schedule for regular phone calls or visits, and enlist the support of community services and volunteer organizations?
- Would the person agree to visit residential programs if available?
- If all options fail and if the psychiatrist feels the person is at risk and/or is putting others at risk (for example, fire hazard), the person may have to be declared legally incompetent and taken to hospital.

With the help of friends, family, community services, and volunteer organizations, round-the-clock supervision was arranged for John. Those involved needed support in dealing with his angry outbursts, largely explained by HACM.

Caregivers continued to struggle to maintain the balance between allowing him as much autonomy as possible and providing appropriate protection.

Two months later, John developed pneumonia. After discussing the issues with his physician, he decided to refuse treatment.

Does the fact that John suffers from HACM take away his right to refuse treatment?

The capacity to give informed consent is not global, but specific to a certain clinical situation. It involves the following on the part of the patient:

- the ability to communicate a fixed choice
- an understanding that he or she is ill and of the nature of the illness
- an awareness of treatment options, their nature, and their effect
- an understanding of the outcomes if treatment is refused

John understood that he had pneumonia. He was treated for a similar condition in the past, and he knew about treatment and its side effects. He was also aware that, if he refused treatment, he would die from this condition. He expressed the clear decision to forego treatment, which was consistent with previous discussions he had had with his physician.

EPILOGUE

John discussed his preferences with family members and they accepted his decisions. He died at home a few days later, surrounded by friends and family, as he had wished.

CONCLUSION

Caring for people living with HIV, such as Susan and John, can raise difficult ethical issues. To address these issues, the health care team must be willing to deal with ambiguity and uncertainty and to tolerate strong affects. Often there is no perfect solution. Team members can support each other through these difficult situations. Psychiatrists working in isolation may want to seek the support of colleagues in other areas. When available, a consultation with an ethicist might be helpful. In situations where litigation is possible, it may be wise for psychiatrists to consult risk management authorities in advance.

Impulsive decisions may end up being counterproductive in the long run. Except in some specific and limited situations, there is little ethical justification for infringing on individual civil rights, for permitting
discrimination against people living with HIV or those at risk, or for violating confidentiality.

RESOURCES


Canadian Psychiatric Association. 1996. CPA position statement on HIV disease. See Appendix III.


MULTIPLE-CHOICE QUESTIONS

1. Which one of the following statements is false?

   a) The best way to prevent intentional transmission of HIV is to criminalize it.
   b) Prevention is the cornerstone of an effective response to the HIV epidemic.
   c) The serostatus of a patient hospitalized in psychiatry cannot be disclosed to other patients.
   d) Behaviour that could transmit HIV should be controlled in all hospitalized patients.
   e) Admission of someone living with HIV to a psychiatry ward should not be solely for the purpose of preventive detention.

2. In a situation where someone living with HIV puts another person at risk on an ongoing basis, which of the following cannot notify the person at risk?

   a) Public health authorities
   b) The physician of the HIV patient
   c) The physician of the person at risk
   d) The patient
   e) The lab technician

3. If a male patient living with HIV becomes mentally incapacitated and has a power of attorney for personal care in the name of his gay partner, who has the power for decision making?

   a) The partner
   b) His ex-wife, if they are not legally divorced
   c) A sibling
   d) The physician
   e) His mother

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