

CANADIAN RÉSEAU HIV•AIDS JURIDIQUE LEGAL CANADIEN NETWORK VIH•SIDA

The Provision of HIV-Related Services to People Who Inject Drugs:

A Discussion of Ethical Issues

prepared by Jennifer Gold



Canadian Strategy on HIV/AIDS The state

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Table of Contents

Introduction	1
Background	1
A Public Health Crisis	1
The Legal Status of Drugs	2
Effects of the Legal Status of Drugs	2
Objective of the Paper	4
Methods	4
The Provision of HIV-Related Services to People Who Inject Drugs:	
Four Scenarios	5
Hospices, Hospitals, and Drugs: Tolerating Use on Site	
and Assisting Patients to Inject?	5
No Needle Exchange Programs in Prisons: A Sentence to HIV?	7
Providing Injection Equipment to Minors: What Has Age Got to Do with It?	8
HAART and Injection Drug Users: To Prescribe or Not to Prescribe?	9
Results	11
Hospices, Hospitals, and Drugs: Tolerating Use on Site	
and Assisting Patients to Inject?	11
Interview Responses	12
Prison Health-Care Staff: Providing Prisoners with Sterile Injection Equipment?	13
Interview Responses	13
Providing Injection Equipment to Minors: What Has Age Got to Do with It?	15
Interview Responses	15
HAART and Injection Drug Users: To Prescribe or Not to Prescribe?	17
Interview Responses	17
Recommendations	20
Tolerating Use on Site and Assisting Patients to Inject	20
Providing Prisoners with Sterile Injection Equipment	21
Providing Injection Equipment to Minors	21
Prescribing HAART to People Who Use Injection Drugs	22
Conclusion	23
Notes	24



Introduction

Background

A Public Health Crisis

Canada is in the midst of a public health crisis concerning HIV/AIDS, hepatitis C (HCV), and injection drug use.¹ The number of HIV infections attributable to injection drug use has been unacceptably high. In 1999, 1430 of the estimated 4200 new HIV infections were among people who inject drugs.² Over 60 percent of new HCV infections are related to injection drug use.³

There have been several studies documenting a rise in the prevalence and incidence of HIV among people who inject drugs in the larger cities of Canada.⁴ For example, in Montréal, HIV prevalence among people who inject drugs was 19.5 percent in 1997, compared to approximately five percent in 1988.⁵ In Toronto, HIV prevalence among injection drug users in 1997-98 was 8.6 percent, up from 4.8 percent in 1992-93.⁶ In Vancouver, HIV prevalence among injection drug users increased from four the second second

HIV prevalence among injection drug users increased from four percent in 1992-93 to 23 percent in 1996-97.⁷ Similar trends have been observed in Québec City, Winnipeg, Ottawa, and other cities.⁸

HCV infection rates are even higher. In some cities over 90 percent of people who inject drugs have HCV.⁹ In addition, a rise in the number of injection drug users with HIV infection (and/or HCV) has also been observed outside major urban areas.¹⁰ Given the geographic mobility of people who inject drugs and their social and sexual interaction with non-users, the dual problem of injection drug use and HIV/AIDS and HCV is one that ultimately affects all Canadians.

The number of HIV infections attributable to injection drug use has been unacceptably high.

The dual problem of injection drug use and HIV/AIDS and HCV is one that ultimately affects all Canadians. Further Reading

- For additional and regularly updated information on prevalence and incidence of HIV among injection drug users in Canada, consult HIV/AIDS Epi Update: HIV/AIDS Among Injecting Drug Users in Canada. Ottawa: Health Canada, April 2002. Available via www.hc-sc.gc.ca/pphb-dgspsp/hast-vsmt/index.html.
- For additional information on HCV, consult Hepatitis C: Information for Health Professionals. Ottawa: Health Canada, 2002. Available at www.hc-sc.gc.ca/hppb/hepatitis_c/pdf/ hepcInformation.pdf.

The Legal Status of Drugs

Since the early 1900s, criminal statutes aimed at the control of particular drugs have existed in Canada. The *Opium and Drug Act*, promulgated in 1911, and the *Narcotic Control Act* and the *Food and Drugs Act*, governed drug use for 85 years. In 1997, the *Controlled Drugs and Substances Act* (CDSA) was proclaimed.¹¹

In general, under the CDSA, the *unauthorized* possession, manufacture, cultivation, trafficking, export, and import of substances listed in several schedules appended to the CDSA constitute criminal offences. Currently, these schedules list cannabis, heroin, methadone,

Treatment approaches, admission protocols, and staff and public attitudes are more reflective of the legal status of drugs than of the treatment needs of injection drug users. cocaine, barbiturates, amphetamine, and a large array of other substances as "controlled." In addition, under certain circumstances, it is an offence to seek or obtain a "controlled" substance from a practitioner, such as a physician. Finally, the CDSA makes it a criminal offence to possess, import, export, traffic, etc, not only the drugs themselves but also "any thing that contains or has on it a controlled substance and that is used ... in introducing the substance into a human body." This means that if a syringe or other equipment used for injecting drugs contains residue of a drug, that equipment is a "controlled substance" and the person with the syringe could be found guilty of possession.¹²

Effects of the Legal Status of Drugs

Several major reports released since 1997 have concluded that the legal status of drugs in Canada hinders efforts to prevent the spread of HIV among injection drug users, and efforts to provide care, treatment, and support to HIV-positive injection drug users.

The illegal status of drugs marginalizes and stigmatizes drug users. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS: A Consultation Report*¹³ stated that the pharmacological effects of the illegal drugs used by injection drug users are not in themselves necessarily harmful. The report pointed out that much of the harm is secondary, caused either by the legal status of the drugs themselves, or by things such as dangerous injecting practices, criminal behaviour, and uncertain drug strength or purity that result from the legal status of drugs. The report further

pointed out that the legal status of drugs is a barrier to utilization by injection drug users of much of the addiction and medical services system; and that treatment approaches, admis-

sion protocols, and staff and public attitudes are more reflective of the legal status of drugs than of the treatment needs of injection drug users.

The National Action Plan prepared by the Task Force on HIV, AIDS and Injection Drug Use¹⁴ also observed that the legal status of drugs in Canada contributes to the difficulties encountered in addressing HIV among injection drug users.

Many others have pointed out that the criminal approach to drug use may increase harms from drug use. First, drugs are available only through illegal means; generally, they are obtained on the street through dealers. The drugs may therefore be impure, contaminated, or of variable strength, resulting in overdose or harm to the user.¹⁵ The illegal nature of drugs also makes sterile equipment hard to come by, and this scarcity prompts users to share or reuse their syringes. Third, fear of arrest and prosecution prompts users to consume drugs in the most efficient and dangerous way possible: injection.¹⁶ When fearing arrest, users often become anxious, make mistakes injecting, and do not follow risk-reduction measures before, during, and after injection.¹⁷ When users are rushed, they often inject quickly and do not test the strength of their drugs, which increases the risk of overdose.¹⁸ An increase in injecting practices combined with a lack of sterile injection equipment, sterile water, filters, and cookers puts the user at a substantially increased risk for HIV and HCV infection, soft tissue infections, and fatal and non-fatal overdose. Fourth, and possibly most important, the illegal status of drugs marginalizes and stigmatizes drug users. This frequently results in judgmental and dismissive treatment. The effect of this is a reluctance on the part of people who inject drugs to utilize health and social services, including drug rehabilitation programs or facilities that provide HIV testing and treatment. Reluctance to the use of such social programs may translate into increased spread of HIV and HCV, furthering the epidemic among injection drug users and ultimately the general public. The illegal nature of drugs, and the stigmatization that follows from this status make providing adequate care to injection drug users a challenge.

Further Reading

For additional information on the legal status of drugs, its effects, and potential alternatives, consult Injection Drug Use and HIV/AIDS: Legal and Ethical Issues. Montréal: Canadian HIV/AIDS Legal Network, 1999, at 22-32; and E Oscapella, R Elliott. Injection Drug Use and HIV/AIDS: A Legal Analysis of Priority Issues. In Injection Drug Use and HIV/AIDS: Legal and Ethical Issues: Background Papers. Montréal: Canadian HIV/AIDS Legal Network, 1999, at A4-A16. Both documents are available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

Objective of the Paper

Practical ethical issues facing health-care and service providers who work with injection drug users living with or at risk for HIV are the focus of this paper.

The paper attempts to determine how health-care and service providers confront ethical dilemmas on a practical level; and to provide, based on their responses, a general set of ethical decision-making guidelines. From 1997 to 1999, the Legal Network undertook a comprehensive analysis of various legal and ethical issues related to injection drug use and HIV/AIDS infection, which resulted in the publication of a report containing 66 recommendations,¹⁹ a volume of background materials,²⁰ and a series of 12 info sheets.²¹ Recommendation 10 in the report called for Health Canada to "fund an ethical and legal analysis of four or five situations or scenarios frequently encountered in the provision of HIV-related services to drug users." In the summer of 2001, the Network obtained funding from Health Canada to conduct such an analysis. This paper is the result of that analysis, and is intended to build on the report, as well as on *HIV*, *AIDS*, and *Injection Drug Use: A National Action Plan*,²² and McAmmond's consultation report on

Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS.²³ The paper attempts, by means of interviews with health-care and service providers, to determine how they confront ethical dilemmas on a practical level; and to provide, based on their responses, a general set of ethical decision-making guidelines. People who are either currently using or formerly have used drugs were also interviewed, in order to obtain a broad perspective on the issues.

Methods

In order to create four ethical vignettes relevant to health-care and service providers working with HIV-positive or at-risk injection drug users, a thorough literature review was conducted. Major sources included the Legal Network report on *Injection Drug Use and AIDS: Legal and Ethical Issues*,²⁴ the volume of background materials used in the preparation of the report,²⁵ and the *National Action Plan on HIV, AIDS, and Injection Drug Use*.²⁶

In consultation with health-care and service providers, the four vignettes were drafted in line with their perceived importance and practical nature. Upon the selection of these four ethical issues, health-care and service providers in relevant areas, and people who either formerly or currently use drugs, participated in interviews with the author. These people were recruited though the Legal Network, its contacts and associates, and represent institutions, networks, and organizations across the country. The interviews were done in person or over the telephone, as circumstances required. Interviewees were asked a set of questions concerning the particular scenario in order to determine their professional ethical concerns and decision-making processes. All responses were recorded and are presented here for discussion and analysis.



The Provision of HIV-Related Services to People Who Inject Drugs: Four Scenarios

Many health-care and service providers work with people who use injection drugs. These include staff of needle exchange programs (NEPs) and AIDS service organizations; health-care professionals at hospitals, clinics, prisons, and drug treatment centres; homeless-shelter workers; residential hospice staff; and employees of occupancy hotels and supportive housing. The ethical quandaries faced by these providers are unique and complex, and are confounded by legal and clinical variables.

Hospices, Hospitals, and Drugs: Tolerating Use on Site and Assisting Patients to Inject?

From a purely legal perspective, in situations where illegal drug use is *permitted* or *tolerat-ed* in health-care and social-service facilities, both drug users and service providers may be subject to criminal prosecution. They may be criminally liable for possession of illegal drugs, in contravention of s 4 of the CDSA. A facility employee who stores a patient/resident's illegal drugs and provides them at specific intervals could likely be convicted of trafficking. Questions of criminal or civil negligence also arise: Has the facility caused or contributed to injury or harm by tolerating drug use? Has this tolerance lead to harm – for example, an overdose?²⁷

Actively assisting a patient or resident with injection would open the door to civil or criminal liability if the user were injured through overdose or toxicity, vein damage, or infection. But some service providers feel they cannot provide proper care, treatment, and support if they must insist on their clients being and staying abstinent. For example, some hospices for people with HIV/AIDS feel they should not close their doors to a client or potential client who is not or is not yet ready to stop using. Some hospitals might prefer to allow patients to continue using while receiving HIV/AIDS-related medical care, rather than let them suffer withdrawal symptoms that could interfere with their HIV/AIDS treatment. And some

Some service providers feel they cannot provide proper care, treatment, and support if they must insist on their clients being and staying abstinent. providers feel that they should at least be able to supervise (if not actively assist in) their clients injecting, so that they can provide medical assistance should problems arise – for example, an overdose.

Previous interviews with staff at facilities that provide services for people who inject drugs and are at risk of or living with HIV indicate that it may be feasible to have a policy stipulating no onsite drug use or dealing in non-residential facilities (eg, clinics, treatment centres). However, it is generally not possible – nor reasonable – to prevent people from using drugs in a residential facility.²⁸ And on at least two occasions, in Vancouver and in

Winnipeg, facilities have admitted to having supervised clients inject. As more facilities that provide services to people who use drugs begin to adopt a harm-reduction approach to drug use among clients, drug use will likely be increasingly tolerated by staff and service providers at these sites. Harm reduction, according to McAmmond,

is a philosophy and an approach to care that minimizes harm from substance abuse, and increases the health and quality of life of the person. It recognizes that the person is the expert on their life, respects their decisions about substance abuse, and endeavours to minimize the harm to the person, caregivers and the community. For injection drug users, this could mean safer drug use practices, safer forms of use, reduced amount of use, or cessation of use.²⁹

Adopting a harm-reduction approach to dealing with injection drug users has many implications at the organizational level. In accepting a harm-reduction approach, many organizations will adopt principles and practices that are increasingly tolerant of onsite drug use. This tolerance has ethical implications for health-care and service providers. Ethical dilemmas facing such workers may include, for example, ambivalence concerning the tolerance of practices they believe to be harmful to clients. Health-care providers have a specific duty of beneficence or "doing good" that may conflict with client autonomy or the principles of harm reduction. Another potential ethical dilemma is how to supply drugs to a client who is incapacitated or seriously ill with HIV/AIDS: the legal prohibition on providing drugs to another (a trafficking offence) conflicts with the ethical duty to provide the best possible care.

- Further Reading ——

6

For a more in-depth legal and ethical analysis of the issues relating to tolerating or permitting drug use in the course of providing health-care and social services, consult *Injection Drug* Use and HIV/AIDS: Legal and Ethical Issues. Montréal: Canadian HIV/AIDS Legal Network, 1999, at 33-41. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

No Needle Exchange Programs in Prisons: A Sentence to HIV?

Needle exchange programs (NEPs) enable people who use injection drugs to obtain new, sterile syringes by exchanging their old, used ones. The objective of NEPs is that free access to sterile equipment will decrease needles sharing among users, reducing the risk of HIV transmission.³⁰ NEPs are a form of vector control, because they reduce the time that unclean needles are in circulation.³¹ Studies conducted over the past decade have indicated that NEPs are indeed effective at decreasing the spread of HIV, and it is currently estimated that there are hundreds of needle exchange sites in Canada.³²

However, needle exchange programs in prisons do not exist in Canada, despite the fact that injection drug use is prevalent in correctional facilities.³³ Studies show that many people who inject drugs continue to do so while incarcerated, and there is evidence that some start injecting in prison.³⁴ The lack of sterile injection equipment available to prisoners inevitably leads to increased sharing. The final report of the Expert Committee on AIDS and Prisons (ECAP) indicated that many drug users share needles while in prison because there are no other options available, that they had not shared needles before, and would not have shared if they had had a choice.³⁵ ECAP urged the Correctional Service of Canada (CSC) to implement needle exchange pilot studies in Canadian prisons.³⁶ The recommendation, however, was rejected. Meanwhile, an increasing number of prisons in

Switzerland, Germany, and Spain have successfully established and evaluated syringe exchange programs in prisons, with positive results.³⁷ More recently, needle exchange or distribution programs in prisons have also been established in some countries of the former Soviet Union, such as Moldova.³⁸

The fact that prison systems in Canada have failed to establish NEPs has several ethical implications for prison health-care workers. Nurses and other health-care professionals who provide services in correctional facilities are faced with difficult ethical ques-

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tions. For example, what is the ethical responsibility of nurses and other health-care professionals who know that HIV- or HCV-positive and negative drug users are sharing needles? Do nurses and other health-care professionals have a responsibility to provide users with sterile syringes? Is there a fiduciary duty to disclose an inmate's seropositive status to a needle-sharing partner? Bleach is often available to prisoners as a means for cleaning injection equipment. However, evidence concerning the efficacy of bleach to properly disinfect syringes contaminated with HCV is inconclusive. What are the ethical implications of a physician providing and advocating what is possibly substandard therapy – especially when the alternative (provision of sterile needles) is available outside the facility?

Further Reading -

- For additional information on (1) the prevalence of injection drug use in prisons; (2) evidence of HIV transmission in prisons; and (3) needle exchange in prisons, consult R Jürgens. HIV/AIDS in Prisons: Final Report. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996. Shorter, more up-to-date information can be found in the Legal Network's series of info sheets on HIV/AIDS in Prisons, and in many articles in the Canadian HIV/AIDS Policy & Law Review accessible via www.aidslaw.ca/Maincontent/issues/prisons.htm.
- For an account of how a prison doctor in Switzerland began distributing sterile injection equipment without informing the prison director, because he felt he could no longer compromise his ethical and public health principles, see J Nelles, T Harding. Preventing HIV transmission in prison: a tale of medical disobedience and Swiss pragmatism. Lancet 1995; 346: 1507 (also cited in Jürgens, supra, at 58-59).

Providing Injection Equipment to Minors: What Has Age Got to Do with It?

Health-care and service providers who work at needle exchange facilities may be faced with

People who work at needle exchange facilities may be faced with requests for needles by youth under 18 years old, and in some cases even under 14 years old. requests for needles by youth under 18 years old, and in some cases even under 14 years old. The issues surrounding the provision of sterile injection drug equipment to minors are complicated. The laws governing such a practice are unclear or conflicting. For example, in Québec, the *Youth Protection Act* seems to indicate that either obtaining parental consent or reporting the minor to the youth protection directorate would be necessary under such circumstances.³⁹ However, the *Public Health Protection Act* permits this action, providing that professionals can justify their actions. Professionals who provide needles to young people could be charged under the *Youth Protection Act*, whereas those who do

not provide needles could be charged under the *Public Health Protection Act*.⁴⁰ Caught in a legal grey zone, this conflict makes it difficult for professionals to know what is the proper

Should young users be treated differently at needle exchange facilities?

8

course of action.

Health-care professionals and service providers are faced with several ethical dilemmas. Can one be "too young" to benefit from needle provision? How young is too young? Should injection equipment be provided to a 17-year-old, but perhaps not to a 13year-old? When faced with a policy that allows the provision of needles to young people, what should a staff member do who feels it is simply "wrong" to provide a 13-year-old with drug injection equipment? Should young users be treated differently at needle exchange facilities? For example, do staff have a special professional duty to counsel these people and attempt to dissuade them from drug use?

- Further Reading _____
 - For a more in-depth discussion of issues related to providing access to sterile needles for people under the age of 14, consult R Cloutier, D Roy. Access to sterile needles for young people under the age of 14. Canadian HIV/AIDS Policy & Law Newsletter 1996; 2(3): 3-4. Available at www.aidslaw.ca/ Maincontent/otherdocs/Newsletter/April1996/04cloutiE.html.

HAART and Injection Drug Users: To Prescribe or Not to Prescribe?

The medical treatment of HIV has improved dramatically over the past years. Combination therapies consisting of a protease inhibitor or a non-nucleoside analogue reverse transcriptase inhibitor (NNRTI) and two nucleoside analogue reverse transcriptase inhibitors (NRTIs) have the potential to reduce morbidity and improve survival in seropositive individuals.⁴¹ However, antiretroviral treatment can be complicated and demanding. Whereas current regimens no longer require the patient to take 15 to 20 pills over the course of a day,⁴² five to six pills must still be taken two times a day.⁴³ The instructions with respect to these medications are complicated and vary between medications: for example, some need to be taken at specific times, with food, others on an empty stomach.⁴⁴ Side effects can also be severe, including vomiting, nausea, diarrhea, fat redistribution, diabetes, osteoporosis, and nervous-system side effects.⁴⁵

Health-care practitioners who treat HIV-positive injection drug users face a unique set of ethical problems. First, there is the question of adherence. Antiretroviral therapy requires strict compliance in order to be effective. As well, evidence is mounting that non-adherence can contribute to the development of treatment-resistant strains of HIV.⁴⁶ This has serious

consequences not only for noncompliant individuals, but could also result in a much larger public health crisis, because the transmission of drug-resistant viruses may confer significant treatment limitations on those infected. People who do not take their medications as prescribed stimulate the production of resistant strains. Such resistant viruses are then transmitted to others, and those people are also precluded from taking the medication. Physicians are therefore faced with the tough choice of what to do in the case of an HIV-positive person who

Is it ethical to impose abstinence or drug rehabilitation as a prerequisite for antiretroviral therapy?

uses injection drugs and is unstable. What decision-making process is employed by doctors in such situations, and how do they make these value-laden judgments? Should doctors prescribe therapy and hope for compliance or should they not provide therapy for fear that their patients may not comply? Can the duty of the physician to a patient be trumped by a larger responsibility to society? Some reports suggest prescribing only two reverse transcriptase inhibitors (rather than the two plus a protease inhibitor or a NNRTI) in an unstable patient.⁴⁷ Can prescribing suboptimal therapy ever be justified? How can physicians fulfill their professional obligation to provide the standard of care in difficult or impossible situations? Is it ethical to impose abstinence or drug rehabilitation as a prerequisite for anti-retroviral therapy?

Further Reading _____

For a discussion of whether it is legal and ethical to make cessation of drug use a condition for treatment of a drug user, consult *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues.* Montréal: Canadian HIV/AIDS Legal Network, 1999, at 42-52. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.



Results

Hospices, Hospitals, and Drugs: Tolerating Use on Site and Assisting Patients to Inject

Scenario I: Adam and Joe

Adam is a 24-year-old nurse working at Sue's Place, a hospice for people with AIDS. He enjoys his job and gets along well with his patients. Recently, Joe, a 45-year-old injection drug user with advanced AIDS, was assigned to Adam's care. Sue's Place tolerates onsite drug use, and has sharps disposals and needle-exchange services available for this purpose.

While at Sue's Place, Joe increases his drug intake considerably, and begins to deteriorate. Although Adam knows Joe is dying, he cannot help feeling as if he and the facility are contributing to his decline by permitting him to use

drugs. As well, Joe has begun to show signs of physical incapacitation. While he can still move around, it is increasingly difficult for him to execute fine-motor tasks, including injection. Joe has indicated he would like Adam to help him inject when he loses the ability to do so himself. He has also made it clear that, should Adam refuse, he will leave the hospice and end his days on the street.

Joe has indicated he would like Adam to help him inject when he loses the ability to do so himself.

Adam is very distressed. He has grown attached to Joe,

and does not want to see him die on the street. He also fears that on the street there is the possibility he will resort to sharing needles and may transmit the virus to others. Nevertheless, he is not comfortable with helping him to inject drugs. Moreover, he is aware that such an act would open the door to civil or criminal liability if the user were injured through overdose or toxicity, vein damage, or infection. He does not know what to do. Does he help Joe inject? Is that the ethical course of action? And what if he doesn't, and Joe takes to the street and dies? Will it be his fault? Adam feels torn.

Interview Responses

"If we don't let them inject

at all."

Because of legal concerns, a majority of the health-care and service providers interviewed indicated they would not help Joe inject drugs. Most were reluctant to engage in an act that could open the door to civil or criminal liability. As one nurse said, "my organization wouldn't cover it ... it would be too risky." However, from an ethical perspective, most respondents believed that helping Joe was "the right thing to do."

Because of the legal and professional barriers to directly provide assistance – that is, help him inject – most had creative suggestions on how to proceed in what they believe is an ethically responsible manner. One respondent said she would try every legal drug possible for Joe – for example, provide methadone, if her patient was a heroin addict. She added that proper pain management was essential in this case, indicating that perhaps this would "reduce his cravings." Another respondent suggested enlisting the help of a friend of Joe to assist him with injecting – that way, she explained, the health-care provider is not directly

involved and does not risk professional discipline. Or, as another person suggested, see if there is anyone on staff who does not mind helping Joe. Several people also said they would go so far as to give Joe money to buy the drugs, but would stop short at assistinside, they won't come in here ing with injection.

When asked to respond to Adam's feeling that by tolerating drug use he was inadvertently contributing to his patient's decline, most pointed out that, considering the alternatives, such feelings

tended to disappear. "If we don't let them inject inside, they won't come in here at all ... we wouldn't be able to give them any help," one nurse commented. Another called it the "lesser of two evils." There was also consensus that it was necessary to respect Joe's autonomy and his right to choose to inject drugs. "It's his choice," said one respondent, "this is what he wants to do. People have the right to make choices...[and we must] give them as much support as possible." One care-worker emphasized the importance of harm-reduction education for hospice staff. She felt that feelings of guilt associated with drug tolerance would probably lessen with an adequate understanding of the harm-reduction concept, as well as a shift away from the medical model. "According to the medical model, sure it seems like a failure," she said. "But if you take another perspective, it doesn't seem so bad ... he's going to die. Everyone dies eventually. It's a hospice, and the goal is to make people comfortable." Similar responses were given when asked if, in Adam's shoes, they would feel responsible if Joe takes to the street and is found dead after Adam refuses to provide injection help. "You can't stop people," said one respondent. "You do as much as you can. If you do everything and they still go, you've done your ethical duty."

The response of individuals who either are injecting or have injected drugs was similar. One respondent suggested that the possible legal consequences for Adam and the facility, should it become known that staff are assisting (not just supervising) people injecting drugs, were too grave to risk helping Joe: "it would cause harm to a great many other people if the centre is closed down as a result," he explained. However, it was also pointed out that since the centre is "already tolerating drug use on site," extending such tolerance to helping patients inject was perhaps the reasonable, ethical, thing to do. One person said: "The only treatment Joe is getting is palliative, anyway. There is no additional harm being done to the client by Adam helping him ... [I]f Joe moves out, he will be increasing his own personal harm and may well harm others."

12 Providing HIV-Related Services to People Who Inject Drugs Further Reading _

For a discussion of legal and ethical issues related to the establishment of safe injection facilities in Canada, see R Elliott, I Malkin, J Gold. Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues. Montréal: Canadian HIV/AIDS Legal Network, 2002. Available via www.aidslaw.ca/Maincontent/ issues/druglaws.htm.

Prison Health-Care Staff: Providing Prisoners with Sterile Injection Equipment

Scenario 2: Mary Chan

Mary Chan is a nurse at the Claiborne Correctional Institution. Injection drug use is frequent in the prison. Approximately one of every 60 inmates is known by the institution to be HIV-positive, and approximately one of three inmates is known to be HCV-positive. Mary knows that the prisoners share needles because there are very few needles in the prison, and is very concerned about HIV and HCV transmission. However, the prison does not have a needle exchange or distribution program. This frustrates Mary, since she feels that this policy is directly contributing to the spread of HIV. However, bleach distribution is permitted, and the doctor encourages prisoners to use it to sterilize their

needles. She knows, however, that the evidence that bleach is an adequate sterilizing agent is inconclusive. This adds to her guilt and frustration, since she feels she is providing her patients with suboptimal advice and care.

One morning, Mary is conducting a physical on an inmate. The patient is HIV-negative, but confesses to sharing needles. Mary knows that at least one of the people he shares with is HIV-positive. On the table between them are clean syringes that she normally uses for vaccination. She knows Is there an ethical duty for health-care providers in prisons to provide prisoners with sterile needles?

that if she turns away, the syringes may "disappear." This is against prison policy, but could help prevent needle sharing. What should she do? What is the ethical course of action when legal and ethical duties clash? Is there an ethical duty for health-care providers in prisons to provide prisoners with sterile needles?

Interview Responses

Responses to this case varied. A prison nurse said that perhaps three years ago she would never have supplied prisoners with injection equipment, things have changed. "We lost a ... man to hepatitis C," she said bitterly. "How long can you wait for prison policy to catch up to what is the moral thing to do? So I turn my back, and they take the needles." Another nurse was adamant that he would not provide the needles under any circumstances. While not opposed to needle exchange in prisons per se, he indicated that "until the policies are

"How long can you wait for prison policy to catch up to what is the moral thing to do? So I turn my back, and [the prisoners] take the needles."

- Interview response by a prison nurse

changed to adopt a holistic philosophy of harm reduction, which would include needle exchange" it was necessary to follow prison policies and codes of conduct. He also felt that one person covertly distributing needles to an inmate "wouldn't make a difference, ethically – it would just be for one person. It doesn't change things." Other workers had the same opinion. "Policies are in place for a good reason," said one. "You may not always agree, but it doesn't help putting your own practice at risk. You can do other things – lobby, or advocate." Another agreed. "Having one inmate take one or two needles doesn't solve the problem," she

said. Another respondent said:

There are two choices for how to bring about change – you can work from within the system or work from outside. If you choose to work within the system, you can advocate but you have a moral responsibility to follow the rules. If it's morally repugnant to you, you can choose to leave the system and lobby from the outside.

Most respondents believed that a sanctioned form of needle exchange is long overdue in correctional facilities. One nurse suggested establishing inmate committees to distribute needles in order to remove distribution from the hands of prison workers. Another proposed providing inmates with their own needles. Said one worker, "I've heard that there have been comparisons between the failure to provide needles in prisons and the tainted blood scandal – maybe in 2010 there will be an inquiry similar to Krever."

A majority of respondents also believed that merely providing sterile needles is not enough. "We need to support these people, to address their addiction," said one worker. "We need to ask, more holistically, how can we work with this individual? We should be working with inmates to help them overcome this challenge and give them the tools for reintegration in society." Another respondent emphasized the importance of proper diagnoses, pointing out that some people who use drugs are also mentally ill. "Many don't just have addiction," he explained. "[They] may additionally have depression or bipolar disorder... [I]f we don't

screen people they won't get the proper treatment, they will just self-medicate with drugs."

Most respondents believed it was acceptable to recommend bleach to prisoners. One nurse indicated that while bleach is not ideal – that is, it cannot replace sterile needles – it is not unethical to advocate its use if that is all that is available. However, she also emphasized that inmates must be carefully and properly educated on how to use bleach, and that they must be informed that "bleach may not be effective for hepatitis C." "You have to be honest,"

another nurse agreed. "You can't misinform and say it will work absolutely. You have to tell them it works for HIV but not HCV. Provide them with the most current research." A third person added, "It's all part of the harm-reduction philosophy. It may not be the best solution, but you have to do what you can to minimize the harm." In the words of one correctional officer, "There's no black and white. Bleach isn't 'good' or 'bad.' You have to look at it from a harm-reduction perspective, and not a black and white medical perspective."

Current or former drug users responded that until needle exchange programs were available in prisons, they would choose to turn their back and allow inmates to take sterile

Most respondents believed that a sanctioned form of needle exchange is long overdue in correctional facilities. syringes. One respondent said: "I would indeed turn my back ... being Hep C-positive I am well aware that bleach is an ineffective process, [and] though better than nothing, simply encourages a false sense of security." There was a consensus that the risk taken by the prison nurse would be "worth it" in the long run – not only in terms of preventing immediate ill-

ness, but also by advancing the movement for needle exchange programs in correctional facilities. "The spread of HIV/AIDS and Hep C doesn't remain within the walls of correctional facilities," explained one interviewee. "Therefore there is, in my opinion, an ethical responsibility for Mary Chan and others like her to provide the means whenever possible to prevent the spread of these viruses through a harm-reduction approach."

"The spread of HIV/AIDS and Hep C doesn't remain within the walls of correctional facilities."

Providing Injection Equipment to Minors – What Has Age Got to Do with It?

Scenario 3: Ms Thompson and Jessie

Ms Thompson is a 34-year-old former intensive-care nurse who works at an urban needle exchange program. She began working at the facility after her younger brother, who used to inject drugs, contracted HIV from sharing needles. Ms Thompson finds her job fulfilling, and feels what she is doing is very important. She has no desire to see other users suffer as her brother has, as a result of a shortage of sterile injection equipment.

One afternoon, a very young girl enters the facility. She is disheveled and unkempt and has a bruise on her forehead. She approaches Ms Thompson and asks for sterile syringes. Ms Thompson is conflicted. The girl is so young. Can Ms Thompson, in good conscience, provide the girl with the means to inject drugs?

Ms Thompson asks the girl her name, and cautiously asks if she is okay and has a place to live. The girl replies that her name is Jessie. Ms Thompson learns that she is 15 and lives with her 21-year-old boyfriend, and had recently run away from a sexually abusive stepfather. Jessie refuses to answer whether her boyfriend is the one who gave her the bruise. One afternoon, a very young girl enters the facility. She is disheveled and unkempt and has a bruise on her forehead. She approaches Ms Thompson and asks for sterile syringes.

Ms Thompson tries to get Jessie to reconsider stop using drugs, but Jessie won't hear of it. "It's the only thing that helps the pain," she says sadly. She indicates that, if not provided with needles, she will certainly share because "my life doesn't matter anyway." She refuses Ms Thompson's offer for names of women's shelters, does agree to come back for some counselling, but persists in asking for needles in the meantime. Ms Thompson is uncertain what to do. Is the ethical course of action to provide Jessie with the needles? Or is there such a thing as "too young"? Her desire to prevent Jessie from contracting HIV is at odds with the desire to prevent her from using drugs at all.

Interview Responses

All respondents felt that Ms Thompson should indeed provide Jessie with sterile syringes – that this was "the ethical thing to do." One respondent argued that it was necessary to examine the opposite scenario: "How ethical would it be if you *didn't* give her the needles?" she

asked. "She says she *will* do something that puts her at great risk. So you have to provide." Everyone agreed that, in such a case, age should not be the only deciding factor. Most noted the fact that she had left home, and is therefore no longer in her parents' care. However, all

"How ethical would it be if you *didn't* give her the needles?" strongly believed that young users should receive extra care, and that (young) first-time users in particular should be encouraged to reconsider. As one respondent indicated, "you can't just hand over the needles. Just giving out needles is like a band-aid – it doesn't treat the problem. You need to provide counsel."

Everyone interviewed agreed that interactions with young users were an excellent opportunity to influence them in a positive manner and to provide help and counsel. There was consensus

that young users tend not to be as aware of available resources or the involved risks as older people, and that it is crucial to provide them with this information and assistance. Or, as one respondent suggested, "dissuade drug *injection* rather than drug use. Try to convince [him or her] to use another mode of ingestion. Follow a harm-reduction model." All agreed that if young people still insist on using drugs despite attempts to dissuade them from use, needles should always be provided. In the words of one respondent. "you can eventually get out of drugs, but you can never get out of HIV."

With respect to parents or guardians, one respondent believed that, where possible, it is good to get the parents involved. She indicated that many drug-involved young people may come from supportive families. She felt that the counsellor should establish a relationship with the teen and find out " what is really going on at home." "Parents," she says, "do have a legal responsibility for their children. We can't forget that. You get the young person to help

"A jaded 45-year-old addict will need different consideration than a 13-year-old. What will keep them coming back is unconditional acceptance and a sincere desire to help." you out, so you keep their trust." One of her proposals was to make a "contract" with the teen – for example, an agreement to work together for a month without informing her parents, and then talk again about telling the parents at the end of the month. The respondent compared the situation to oral contraceptive distribution in the 1960s and 1970s (prescribing the birth control pill to girls under 16 years of age without parental consent was prohibited until 1969). However, she went on, many doctors "gave the girls the Pill anyways. They chose to put patient health before the law."

People interviewed who currently use or formerly have used drugs were generally in agreement with the service providers. In response to whether it is ethical to provide a minor with syringes, one person said:

I believe this activity is entirely ethical, as I believe reducing harm in any way is the highest ethical goal we can have. To ostracize the girl by forcing one's mores upon her will simply drive her away from what help she might one day be ready for, and almost certainly doom her to HIV infection. How can that be "ethical" in anyone's book?

Another stated:

I've always contended that morality is a terrific concept for those who can afford it. Personal moral ethos [sic] have no place when others' health is at risk. If an NEP [worker] cannot put his or her moral hangups aside, she or he should get out of the business.

When asked if there is a special ethical duty to counsel young people when they ask for syringes, the group felt that you have a responsibility to help "*whoever* walks in the door." Said one individual:

Services appropriate to the person should be made available, and the worker must not treat all clients equally. A jaded 45-year-old addict will need different consideration than a 13-year-old. What will keep them coming back is unconditional acceptance and a sincere desire to help.

HAART and Injection Drug Users: To Prescribe or Not to Prescribe?

Scenario 4: Dr Champlain and Pierre

Dr Champlain is an infectious-disease specialist at a large urban health-care facility. Many of his patients are HIV-positive, and he has been treating them with combination therapy with a measurable degree of success. The highly active antiretroviral therapy (HAART) he prescribes consists of two reverse transcriptase inhibitors and one protease inhibitor. The drug regimen is demanding.

One Thursday afternoon, Dr Champlain sees a new patient, an HIV-positive man requesting antiretroviral therapy. Pierre is a 29-year-old who uses injection drugs and lives intermittently in a single-room occupancy hotel or on the street. His life, as he describes it to the doctor, is chaotic and unstable. Despite this, he is articulate and well informed, and wishes to be prescribed HAART.

Dr Champlain is conflicted. He has just read an article in the Lancet, which describes the consequences of non-adherence to HAART. He is afraid that Pierre will not comply with the complex drug regimen, and will contribute to the development of ART-resistant HIV strains. He feels a duty to public health and society but feels a strong obligation to

his patient. He is unsure about the proper course of action. One article he has read suggested prescribing two reverse transcriptase inhibitors but not the protease inhibitor for patients who are unstable. However, he feels this may be a substandard form of care. What should he do?

Interview Responses

There was a consensus among providers interviewed that Pierre should not be denied treatment simply because he chooses to inject drugs. However, all emphasized the importance of counselling and a complete medical assessment before handing over His life, as he describes it to the doctor, is chaotic and unstable. Despite this, he is articulate and well informed, and wishes to be prescribed HAART.

a prescription. As one respondent said, "Much 'joining' and relationship building needs to take place before the best and most appropriate treatment course can jointly be determined ... [M]edication may not be the first thing Pierre needs." Others agreed. "You can't just hand over the prescription and give no support. *That* is ethically wrong," commented one nurse.

Respondents also stressed the importance of discussing with Pierre the risks and benefits

of therapy, as well as the consequences of non-adherence, before prescribing the drugs. However, all felt it was ultimately his choice whether to begin HAART. Most also suggested many ways in which Pierre could be helped to adhere to his drug regimen. These included: directly observed therapy, where patients take their medications in front of someone else,

"You can't really know who will be compliant and who will not be. You can't assume anything. You need to give every person the best-supported chance." a pharmacist or home-care nurse; having patients wear a beeper, so they can remember to take their medications at pre-programmed times; providing flexible, accessible care that includes seeing patients on a walk-in basis; and developing support services through hospitals, public health, and community-based organizations. A majority of respondents also felt that Pierre should be put on the simplest HAART regimen, making it as easy as possible for him to comply with the treatment. Once-a-day regimes, though still experimental, were suggested as an alternative. One respondent said: "Patients know they are unstable. It's easy to negotiate with them to develop creative methods for adherence."

Said another, "you can't really know who will be compliant and who will not be. You can't assume anything. You need to give every person the best-supported chance."

With respect to the question whether the patient or public health should receive priority, everyone was adamant that the patient must always come first. Said one respondent: "It's unethical not to first and foremost consider your patient. You shouldn't consider the cost to society. We don't do this when a patient undergoes surgery or has a chronic illness. It's a slippery slope." Another respondent framed it this way: "You can't estimate the effect of one person on public health. It's impossible. And how much difference, really, is one individual going to make?"

Along similar lines, all health and care provider respondents felt it is ethically unacceptable to insist on abstinence or rehabilitation as a prerequisite for treatment. "You can advise abstinence, but you can't insist," said one physician. "But it would be unethical not to try and help at all. You have to provide whatever harm-reduction measures you can. Whatever makes it possible for them to adhere [to the treatment]." Another respondent used an analogy to explain his stance. "We don't make people stop smoking or drinking before we treat them,"

he said. "Besides, a patient can be compliant and still use drugs." Said one interviewee: "You cannot demand something from someone that they cannot or do not want to do. You must respect the choice of the patient."

Finally, no service provider felt it was appropriate to provide patients with substandard care merely because they use drugs – for example, prescribing two reverse transcriptase inhibitors, but not the protease inhibitor or an NNRTI. "Scientifically, it's just wrong," said one physician. "You can develop resistance to reverse transcriptase inhibitors too. And even if it wasn't scientifically wrong, it's still not acceptable. It's the patient's choice."

Another respondent explained as follows: "Every patient is deserving of the best standard of care. You should only not give the protease inhibitor if it will harm the patient, like if he has hepatitis C and is actively using. In that case I would use three reverse transcriptase inhibitors instead." One respondent put it this way: "It is never okay to withhold treatment from some-one who could benefit from it. If you know what you're doing is substandard, that is just eth-ically wrong."

"You can't deny someone lifesaving medicine just because you think they may not be totally reliable." Current or former drug users firmly believe Dr Champlain should provide Pierre with the regular medication regime. "You can't deny someone life-saving medicine just because you think they may not be totally reliable," said one individual. "Lots of people who aren't drug users ... might forget sometimes to take their pills ... [D]oes that mean we don't give them drugs?" It was emphasized that with counselling, Pierre would be more likely to adhere to his treatment. "You have to give him help, too," said one respondent. "You can't just give pills, and say 'Okay, go off now and take your meds.' You have to give lots of support."



Recommendations

The responses provided above give rise to a number of ethical decision-making guidelines that health-care and other service providers may find helpful in their own practice. The recommendations are outlined below.

Tolerating Drug Use on Site and Assisting Patients to Inject

Hospital or hospice staff members who work at facilities that tolerate drug use on site may sometimes feel they are inadvertently contributing to a patient's decline and eventual death. They may find it helpful to consider the following:

- 1. The alternative may be considerably worse. If patients who use drugs are not permitted do so within the facility, it is likely they will choose to remain on the street (which clearly increases the risk to the individual and the community).
- 2. The choice to inject drugs is the patient's, and not the staff's. Staff should try to respect the patient's autonomy.

In the event that patients ask their health-care provider to assist with the injection of illegal drugs, practitioners may wish to consider a number of options, if they feel uncomfortable performing such actions. These include:

Health-care providers may consider providing saferinjection education as a means of fostering and maintaining a drug user's ability to inject.

- 3. Offering patients counselling that may serve to explore the reasons for escalating use (eg, inadequate pain management) and supporting patients in developing their own strategies, including possible alternative plans, for drug consumption or assisted injection.
- 4. Providing the patient with any legal drugs in an attempt to reduce cravings.

- 5. Enlisting the help of a friend of the patient or some other person who is comfortable helping the patient inject.
- 6. Providing safer-injection education as a means of fostering and maintaining the ability to inject, or promoting novel approaches to injection (eg, alternate injecting sites on the body). Many users are not very skilled in injection practices. Many give up on veins that appear collapsed. With training, many can become more skilled and can resume using veins (eg, in arms) they have given up on.
- 7. Exploring whether other methods of consumption are desirable or possible (eg, in the case of heroin, smoking or "chasing the dragon").
- 8. Contacting their professional regulatory body to explore alternative interventions that would fall within the profession's ethical guidelines (eg, inserting a subcutaneous butterfly valve that can be used for self-administration of illegal drugs).

Providing Prisoners with Sterile Injection Equipment

Health-care and service providers who work in prisons may find themselves distressed by prisoners who inject drugs and share needles. These practitioners could consider doing the following:

- 9. Lobby for change from within the system to implement needle exchange programs in prisons. Point to successful programs in other countries.
- 10. Work with and counsel persons to help them maintain control over their drug use in a less harmful way, or overcome medical or psychosocial addiction.
- 11. Provide prisoners with psychiatric assessment to check for any underlying mood or behavioural disorders that could be alleviated by medication and/or therapy.
- 12. Provide prisoners with bleach at all times, with a warning that bleach may not always be effective.
- 13. Provide education on how to properly bleach injection equipment.

Health-care and service providers who work in prisons should lobby for change from within the system to implement needle exchange programs in prisons.

Providing Injection Equipment to Minors

Practitioners involved in the care of minors who inject drugs and request new syringes may feel conflicted about what is the "right thing to do." Such persons may find the following to be of assistance:

- 14. Provide young persons with sterile injection equipment, but do not simply hand them over and let them walk away. Attempt to build a relationship based on mutual trust and respect, and provide counselling, information, and referrals.
- 15. Encourage first-time users to reconsider injection drug use, and offer them appropriate counselling services.
- 16. If someone insists on using drugs, try to encourage the person to use a means of ingestion other than injecting.

17. If possible and appropriate, try to get the families of youth involved in their care and rehabilitation. However, this must be assessed on a case-by-case basis. Many young people who inject drugs are running away from unbearable home situations, and do not have supportive families to turn to. Duty-to-warn guidelines indicate that private information should be disclosed only to those who are most likely to have a positive impact on outcomes. In many cases, this means that families should not be contacted.

Prescribing HAART to People Who Use Injection Drugs

People who inject drugs may live lives that their health-care providers consider "chaotic" or "unstable." Physicians involved in the care of such people may feel conflict about whether it is appropriate to prescribe complicated treatment regimens such as HAART. The following guidelines may prove helpful:

- 18. Discuss the benefits and risks of therapy with the patient. Emphasize the consequences of non-compliance.
- 19. Prescribe the simplest possible regimen. Even experimental once-a-day regimes should be considered.
- 20. Provide patients with counselling and support so that it may be easier for them to adhere to the treatment regimen, which may include directly observed therapy or the use of a beeper. Provide appropriate references regarding community care, supportive housing, and further contacts.
- 21. Maintain a flexible schedule with respect to these patients. Note that they may not be able to follow-up on appointments. Efforts should be made to provide them with care, even on a drop-in basis.
- 22. It is inappropriate to knowingly provide patients with substandard therapy. Prescribing two reverse transcriptase inhibitors but not the protease inhibitor or an NNRTI will not prevent the development of drug-resistant HIV strains.



Conclusion

In Canada, HIV and other bloodborne infectious diseases are prevalent in people who inject drugs. Care and service providers of these people face many tough ethical dilemmas in the course of their work or practice. This paper is intended to provide such practitioners with some general ethical decision-making guidelines based on the responses of colleagues regarding common, practice-related ethical problems.

Whereas the paper provides suggestions and potential solutions for dealing with these problems, it should be remembered that, in practice, each case is different, involves different persons, and must therefore be evaluated independently. For this reason, the responses given by those interviewed are not presented here as the absolute "right" solutions to the various problems. Often, there is no "right" or "wrong" answer to these problems, with possible resolutions residing in an ethical grey

"From this day onwards treat every drug user with the respect and dignity that you would like to be treated with yourself."

zone. The common themes of respect, dignity, humanity, autonomy, and health that shape the proposed solutions should underlie all moral deliberation in the context of injection drug use and disease prevention. In the words of Annie Madden, an Australian who formerly used injection drugs but is now an activist, and who spoke at the New South Wales Drug Summit in 1999:

If there is one thing I could leave you with today it would be a very simple request: from this day onwards treat every drug user with the respect and dignity that you would like to be treated with yourself.... Drug users are not the enemy. We are real people suffering a great deal of unnecessary pain, illness and death. Drug users are part of the community: we are your children, your sisters and brothers, parents and grandparents, taxpayers, employees; and, most importantly, we are your friends.⁴⁸



NOTES

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²² Supra, note 14.

²³ Supra, note 13.

²⁴ Supra, note 1.

²⁵ Supra, note 20.

²⁶ Supra, note 14.

²⁷ Supra, note 1, at 35-36.

²⁸ D McAmmond, Meeting the Challenge: Palliative Care for Injection Drug Users Living with HIV/AIDS. March 1998 at 10

²⁹ Ibid.

³⁰ Supra, note 1 at 81.

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