Caring for HIV+ Substance Users

The number of HIV+ persons infected as a result of substance use, and now seeking Palliative Care, is increasing rapidly across Canada

"If I screw up royally, I don't want to be rejected or abandoned. Accept me for who and what I am."
– one voice –

Emergence of the HIV+, chemically dependent population presents support and service challenges to caregivers.

Those working in the Palliative Care setting must be aware that, to date, there has not been significant work published to provide guidelines toward development of appropriate interventions. However, this section presents the most current expertise on this subject (for medical intervention, see *Symptom Management*).

To work effectively with this population, caregivers need to:

- be able to assess competently the chemical dependency issues (see below)
- recognize that reasons for drug use vary, from fear, coping with a serious illness, anger, and pain, to such issues as dual-diagnosis (psychiatric complications and substance abuse issues) and low self-esteem
- understand that substance use may elicit different responses from each individual, even though they may be using the same drug
- continuously seek new information to expand their current knowledge base related to the care of the HIV+ chemically dependent person
- be aware of issues of safety and security

CHARACTERISTICS OF THE SUBSTANCE USER

- substance users may present with strong feelings of anxiety, insecurity and emotional instability
- among their behavioural problems may be manipulation, seduction and an unwillingness to tolerate frustration
- the relationship with the substance will be different depending on the type of drug used
- the substance user may have had severe problems as a result of substance use. Low self-esteem and self-destructive attitudes may be part of the individual's makeup
- the substance user may be tempted to self-medicate to anesthetize feelings associated with HIV/AIDS. Results may include:
  - in the community: missed appointments, frequent changes of address, coming to appointments intoxicated and a failure to follow treatment
  - in hospital: may not follow rules, may not tolerate pain well, may use pain to increase access to substance, and may, in face of any pain, demand rapid effective relief

CAREGIVERS' REACTIONS

Attitudes and behaviors associated with substance use can provoke a rift with caregivers who may feel invaded, overwhelmed and discouraged by the situation. Likewise, caregivers' fears, beliefs and attitudes can come into play, including the fear of encouraging dependency or of being manipulated by the user.

ASSESSMENT PROCEDURE

A thorough assessment, including a complete medical history, will provide a much clearer picture of the person's current health status, particularly as it relates to substance use, and will present a more focused view of the person's needs. Ideally, this assessment would be taken as part of a standard intake procedure prior to the

person becoming symptomatic. The importance of this assessment cannot be underestimated within the realm of HIV disease, as many medications prescribed have addictive potential or interact with non-prescription drugs and alcohol.

Elements of the assessment include:

SUBSTANCE USAGE	PSYCHIATRIC HISTORY	PERSON'S NEEDS/PERCEPTIONS REGARDING PAIN MANAGEMENT
• history of drug and alcohol use • date and time of last use • amount used • method of use • frequency of use • prescription medications (frequency and dosage) • cigarette smoking • history of drug and alcohol treatment and outcomes • reasons for using drugs and alcohol	• confirmation of diagnosis (if applicable) • treatments – therapies – past medications – current medications • hospitalizations • evaluation of the current situation	• evaluation of the person's perceptions and needs regarding pain relief (to establish clear treatment guidelines and a climate of trust) • evaluation of person's knowledge of analgesic medications (in terms of treatment of pain)

INTERVENTIONS

It is recommended that those working in the Palliative Care setting incorporate the assessment information in their intake package and, thus, begin the process of better understanding the drug using person with HIV disease

The purpose of interventions is not to "save" the person at all costs, but rather to support harm reduction.

HARM REDUCTION MODEL

Any Palliative Care setting should support a client-centred, harm-reduction model which assumes the client is the best person to make decisions about him/herself.

The philosophy of harm reduction is to reduce the amount of risk in drug-using behaviors and increase the health of the person living with HIV/AIDS, their caregivers and society as a whole. The hierarchy of harm reduction with the injection drug user begins with a focus on safer drug use techniques (i.e. safer injection techniques, safer location choice), cessation of injection, then cessation of drug use. Incorporated within this is attention to health problems and the prevention of health problems before they occur. The harm reduction model is not specific to injection drug use and can also be applied to all other drugs.

INTERVENTION SCENARIOS

CLIENT	ISSUES IN CARE	STRATEGIES FOR INTERVENTION
Person with current addiction	• steps toward abstinence may not improve quality of life • pain and health risks from detoxification, stress and emotional upheaval may cause damage • drug use (especially CNS stimulants) may lead to disruptive behaviour, which can put stress on housing and health care	**For all HIV+ persons with a current addiction** To implement an appropriate care plan, negotiation with the person around drug use and associated behaviour, with clear consequences defined, would be important. This person may be able to take part in a medically supervised detoxification program, conceivably providing health benefits and better quality of life. • tailor approach to the individual (i.e. novice or "veteran" user) and his/her current reality (i.e. hospital, street, at home) • create a climate of trust through consistent approach

CLIENT	ISSUES IN CARE	STRATEGIES FOR INTERVENTION
Person with current addiction *(cont.)*		• help him/her improve quality of life (better nutrition, community cooking, resources that offer meals) • provide support to help through the HIV/AIDS crisis • encourage him/her to seek support in the community • caregivers in the interdisciplinary team must work together to avoid manipulation, "splitting" and other behaviors characteristic of substance users **For HIV+ persons who stop using drugs** • provide psychological support • initiate external follow-up during detoxification • reinforce person's decision to stop • strengthen ties to his/her network • discuss potential relapse situations **For HIV+ persons who cut down on drug use** • reinforce person's choice to cut down drug use • foster self-awareness through repeated check-ups **For those who maintain or increase substance use** • provide psychological support if person so desires • foster self-awareness through repeated check-ups • encourage joining support groups • try a social approach, i.e. recreational activities, to create a sense of belonging to a group • use requests for physical care to strengthen bond of trust • propose short-term shelter (or permanent shelter in the final stages of life) to help break out of social isolation
Person with past addiction	• use of an analgesic medication (especially opioids) may be perceived as backsliding by some individuals. At the same time, a return to past drug use, particularly for the opiate addicted person, is a real possibility • many persons with a past history of drug addiction, having completed an abstinence oriented treatment program, are reticent to embrace what may have been their drug of choice for a second time. It is necessary that a knowledgeable physician offer appropriate options to the person, taking into consideration their fears of relapse	• informed decisions must be made around this issue with a strong understanding of the balance between appropriate medications, their health effects and non-medical use of medication • when a lifetime is often measured in months, addiction should not be an issue when considering the use of a medication. The focus should be on pain relief and the person's general sense of well-being
Abstinent person and pain medication	• many persons who have had experience with addiction may be resistant to pain medication, especially if these medications have addictive properties • use of these medications may be viewed as a failure or a relapse	• pain medication should be introduced to these individuals in the same context as insulin for a diabetic • pain medication should be presented to the person in a supervised manner and changes managed collaboratively. This latter action supports the person's confidence in him/herself

CONSIDERATIONS FOR CAREGIVERS

Caregivers are wise to consider that the crisis generated by HIV/AIDS diagnosis may well result in anger, denial and, possibly, violence. The following are some suggestions for caregivers to deal with some of the issues that may arise: (see also *Care for the Caregivers)*

SITUATION	CONSIDERATIONS
Fear of death and death anxiety	• ensure that all members of the staff can be psychologically supportive
Anxiety	• do not hesitate to discuss death. Defusing fears can ease pain • use of narcotics and anxiolytics can arouse concerns for both the person and the staff. When used judiciously and wisely, both can offer additional support that is indispensable to the person's sense of well-being
Psychiatric problems	• existing or new psychiatric problems can have a profound effect on the functioning of both the person and the Palliative Care team. Access to qualified, well-trained staff and appropriate medications are a necessary part of managing the HIV+ substance user
Violence	• accept anger as an outlet but do not accept violence in any form • set clear limits • be truthful • establish a firm contract to which both parties are committed • do not feel guilty if it is necessary to terminate an interview or course of action in order to impose limits • perform interventions with two people present if possible

Caregivers need to:

- access improved educational protocols to enhance their competence in dealing with the chemically dependent/HIV+ person
- insist upon an appropriate drug and alcohol assessment of the drug using person with HIV disease, thus enabling appropriate planning
- be aware of issues of safety and security (see *Issues in Occupational Exposure for HIV/AIDS Palliative Care*).

Inappropriate medications, lack of sufficient follow-up, or inappropriate referrals to substance abuse treatment may result in a rapid decline of a person who under other circumstances might have retained quality of life for a longer period of time.

SUGGESTED READING

McCrimmon M, Tschavkovsky, K "The HIV+ client: a guide for addiction treatment professionals. Toronto. ON: Addiction Research Foundation, 1992.

McCrimmon M, Kaine P, Cave D. "HIV clinic - an introduction". Toronto, ON: Addiction Research Foundation, 1994.

McCrimmon M, HIV clinic - "training courses". Toronto, ON: Addiction Research Foundation, 1994.

McCrimmon M, Sheyka, K P. "AIDS, Youth and Prevention: Focus on Street Youth". Toronto, ON: Addiction Research Foundation, 1990.

Kapur B M, Buchyns C, Poulos C. "Manual on AIDS and HIV infection". Toronto, ON: Addiction Research Foundation, 1989.