

UNLOCKING OUR FUTURES

A National Study on Women, Prisons, HIV, and Hepatitis C



Co-Principle Investigators:

Anne Marie DiCenso, MSW - Giselle Dias - Jacqueline Gahagan, PhD

Report by the Prisoners' HIV/AIDS Support Action Network

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Preface

This project would not have been possible without the support, advice, and contribution of many people across the country.

We would first and foremost like to thank the members of the National Steering Committee who have generously donated their time and experience over the past two years to help ensure the success of this project – Victoria Arshad, Jacquie Gahagan, Tim McClemon, Maggie McGinn, Viviane Namaste, Kim Pate, Marcie Summers, Sherri Quinn, Pat Tait, and Art Zoccole.

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We would like to thank those Correctional Service of Canada staff that supported the study and assisted us during the research.

We would like to thank Health Canada's HIV/AIDS Policy, Coordination and Program Division for funding this project as part of the Canadian Strategy on HIV/AIDS, and particularly Jeff Dodds, Paul Lapierre, Sheila Braidek and Patti Murphy for their assistance and support.

And most of all we would like to thank all the women across the country who participated in this study, and who shared their experiences with us. This report is dedicated to them.

Anne Marie DiCenso
Giselle Dias

PASAN

1. Executive Summary

Unlocking Our Futures is a qualitative evaluative study investigating the perceptions and lived experiences of federally incarcerated women regarding HIV/AIDS and hepatitis C (HCV). This community-based research project was initiated by the Prisoners' HIV/AIDS Support Action Network (PASAN) and was designed and conducted with the assistance of a National Steering Committee.

The study documents the specific needs of federal women prisoners regarding HIV/HCV prevention, care, treatment, and support. Drawing upon the women's experiences, the report explores the current response of both correctional and community services, addressing issues such as need, accessibility, quality, satisfaction level, and trust. Research was conducted during 2001/02, and involved interviews with 156 federal women prisoners housed in 9 different facilities across Canada.

The research found that high-risk behaviours for the transmission of HIV and HCV are common among incarcerated women. It also found that the current response from both the Correctional Service of Canada and from community-based health organizations in terms of prevention education/harm reduction programs and care, treatment, and support/counselling services for women living with HIV and/or HCV is failing to meet the needs of this population in many significant areas.

In many cases, the research found that current programs and services were marked by inconsistent implementation and accessibility, both within individual institutions and across the system as a whole. Concerns about confidentiality were pervasive, and affected program participation and access throughout the various topic areas examined. The data also identified areas where new or innovative initiatives were required in order to effectively meet the needs identified among study participants. The report documents these gaps in the current response among correctional and community stakeholders.

In addition to identifying gaps in service, the report identifies elements of good practice in the provision of HIV and HCV services. These guidelines are drawn from the information provided by the women themselves, as well as from national and international recommendations and experience.

Based upon these findings, the report provides a series of recommendations for the Correctional Service of Canada, Health Canada, public health departments, community health centers, and community-based organizations. These recommendations are intended to assist in the development and implementation of a "best practice" framework in this sector, and ensure that the diverse needs of incarcerated women living with HIV and/or HCV are met in a comprehensive and compassionate manner.

2. Background to the Study and Final Report

The purpose of this study is to examine the experiences and perceptions of women living in Canadian federal correctional facilities on HIV and hepatitis C (HCV) prevention, care, treatment, and support. Based upon the data collected, this final report provides a series of recommendations to Correctional Service of Canada, Health Canada, public health departments, community health centres, and community-based organizations.

The project was conducted by the Prisoners' HIV/AIDS Support Action Network (PASAN) and was developed and coordinated with the assistance of a National Steering Committee.

The purpose of the study was four-fold.

1. To determine the HIV and HCV programming needs of women in federal prisons in Canada, including knowledge and perceptions of existing programs, and access to and utilization of such programs.
2. To determine if current programs are meeting the needs of women in federal prisons in Canada, both in terms of accessibility as well as content.
3. To develop "best practice" recommendations to address any identified gaps in current HIV and HCV prevention programs for women in federal prisons in Canada.
4. To develop "best practice" recommendations to address any identified gaps in programs for HIV or HCV care, treatment, and support for women prisoners living with HIV and/or HCV.

The research was conducted using qualitative data collection and analysis techniques. These were designed to explore the lived experiences and perceptions of women in federal prisons regarding knowledge of and/or utilization of HIV and HCV programming. The techniques included in-depth, one-on-one interviews with incarcerated women, and the thematic analysis of the transcribed interviews. The study protocol was ethically reviewed and approved by Dalhousie University.

156 women were interviewed, approximately 40% of the total population of federally incarcerated women.

Interviews were conducted during 2001/02 in 9 of the 11 Canadian facilities housing federal women prisoners. Participation in the study was strictly voluntary, and women were notified of the project by posters placed within each facility. In order to protect the confidentiality of the study participants, a unique identification number was assigned to each participant and location to assist in the data analysis process. This information is available only to the research team. All personal identifiers and institutional references have been removed.

In total, 156 women were interviewed as part of the study. This represents approximately 40% of the total population of federally incarcerated women. Interviews took place at Nova Institution for Women (Truro, Nova Scotia), Springhill Institution

(Springhill, Nova Scotia), Établissement Joliette (Joliette, Québec), Grand Valley Institution for Women (Kitchener, Ontario), Regional Psychiatric Centre (Saskatoon, Saskatchewan), Okimaw Ohci Healing Lodge (Maple Creek, Saskatchewan), Saskatchewan Penitentiary (Prince Albert, Saskatchewan), Edmonton Institution for Women (Edmonton, Alberta), and the Burnaby Centre for Women (Burnaby, British Columbia). The age distribution of study participants was generally representative of that of the population of federal women prisoners as a whole. The participation of Aboriginal women in the study was very high, much higher proportionally than the general population of Aboriginal women prisoners.

No compensation was permitted by CSC from the investigators to be distributed to the women participating in the study. The exception to this was the Burnaby Centre for Women, a provincially administered institution in British Columbia that houses a population of federally sentenced women. In this instance only, a \$10 honoraria was paid directly to the women themselves. This was in keeping with the policy of this facility.

Following the preparation of the final draft recommendations, meetings were held within several of the institutions where the original interviews took place. These “member checks” were organized to brief the women on the findings of the research, and solicit their opinions and feedback prior to finalizing the document for public release.

The project was evaluated by an external investigator.

3. Summary of Main Findings

HIGH-RISK BEHAVIOURS: High-risk behaviours for the sexual and intravenous transmission of HIV and hepatitis C were common in federal women's prisons. 1 in 4 women was found to be engaging in tattooing, 1 in 4 having unprotected sex, and 1 in 5 engaging in injection drug use.

PREVENTION EDUCATION: Correctional Service of Canada (CSC) prevention education programs were not meeting the needs of women. Community-based AIDS service organizations were not providing adequate prevention education programs for incarcerated women.

HARM REDUCTION MEASURES: CSC's provision of harm reduction measures such as condoms, dental dams, lubricants, and bleach were inconsistent, and are particularly inaccessible to women engaging in risk behaviour. Harm reduction measures such as syringe exchange, safer tattooing options, and information on safer slashing/cutting were not provided, despite significant evidence of high-risk behaviours related to these practices, and the desire of women to access such measures.

HIV/HCV TESTING: There was a high uptake of both HIV and hepatitis C testing among incarcerated women. However, the provision of pre- and post-test counselling was poor, with 64% of women reporting receiving no counselling.

CONFIDENTIALITY: Confidentiality and privacy was integrally linked to satisfaction with all programs and services, as well as their accessibility. Women living with HIV and/or HCV were not satisfied with the current level of institutional confidentiality, and identified particular concerns about how various institutional routines inadvertently disclosed serostatus.

MEDICAL SERVICES: There was overall dissatisfaction with the quality and accessibility of CSC medical services. Fewer than 1 in 10 women described their interactions with health services as positive. Women living with HIV and/or HCV identified numerous barriers to accessing adequate medical services. These included difficulty obtaining blood tests, accessing physicians/specialists, obtaining adequate pain management, and accessing medications to relieve the side-effects of HIV/HCV therapies.

DIET AND NUTRITION: Women living with HIV and/or HCV were unsatisfied with the standard of diet and nutrition provided, and identified barriers in accessing vitamins and nutritional supplements.

SUPPORT AND COUNSELLING: While support and counselling services were available from a variety of sources in the prison and the community, women generally felt that the programming did not meet their needs. Women living with HIV and/or HCV strongly identified the lack of support and counselling services specific to their needs.

4. Summary of Main Recommendations

PREVENTION EDUCATION

Recommendations to CSC, Health Canada, Community-based Organizations

- Access to women-specific HIV and HCV prevention education programs must be expanded and made consistent throughout the system. Both correctional and community-based programs must be offered on an ongoing basis.
- HIV and HCV information materials must be made widely available in various forms. Information should be up-to-date, presented in plain language, and discreetly packaged.

Recommendation to CSC

- Access to peer health programs must be increased and made consistent across the system. CSC staff should work in cooperation with prisoners to ensure that each program is developed and implemented to meet the specific needs of women in each institution.

HARM REDUCTION MEASURES

Recommendations to CSC

- Condoms, dental dams, and water-based lubricants must be made equally and consistently accessible across the system. In particular, dental dams and lubricants must be provided and made easily accessible. Access to safer sex measures must meet the guidelines of *CSC Commissioner's Directive 821*, and not necessitate making a request to staff.
- Full-strength bleach, as well as information on its proper use for harm reduction, must be made generally and discreetly available to prisoners in various places in the institutions. Access to bleach should not necessitate making a request to staff.
- CSC should monitor the implementation of Phase II of its methadone policy to ensure equitable access to the program for women across the system. Efforts should be made to educate women on the selection criteria for the program, and the process for accessing the program.
- CSC should act upon the recommendations of the 1999 *Final Report of the Study Group on Needle Exchange Programs*, and pilot test needle exchange projects in all five regions of Canada, one of which must be in a women's institution.
- Harm reduction measures, as well as appropriate materials to practice tattooing and body piercing safely, should be made available.

- Information on safer slashing/cutting, as well as safer alternatives to slashing, should be developed and made available. Non-punitive responses to women who slash must be implemented in practice, not simply in policy.

HIV/HCV TESTING

Recommendations to CSC

- Pre- and post-test counselling must be provided as a mandatory part of all HIV and HCV testing. No one should be tested without receiving such counselling.
- Access to anonymous HIV testing must be made available.

Recommendations to CSC, Public Health Departments, Community Health Centres

- Collaboration between CSC health care and external public health nurses in providing testing services should be continued, and expanded wherever possible.

CONFIDENTIALITY

Recommendations to CSC, Health Canada, Community-based Organizations

- Confidentiality is an essential element of good practice in the provision of all HIV/HCV programs and services. Issues of confidentiality and privacy must be addressed as central elements in program design and implementation.

DELIVERY OF MEDICAL SERVICES

Recommendations to CSC

- Correctional health services must be reviewed and enhanced. CSC must provide adequate financial and human resources to enable medical staff to provide a standard of care comparable to that available in the community.
- Female physicians must be available in all women's institutions.

PAIN MANAGEMENT

Recommendation to CSC

- Accessibility of pain management medications – particularly prescription narcotic medications – must be increased and provided in a non-discriminatory fashion.

DIET AND NUTRITION

Recommendations to CSC

- Diet and nutrition must be improved for all prisoners. The standard of diet currently outlined in CSC guidelines must be adhered to in all regions.

- Special diets – particularly for women living with HIV and/or HCV – must be made more accessible, and made consistently available in all regions.

SUPPORT FOR WOMEN LIVING WITH HIV AND/OR HCV

Recommendations to CSC, Health Canada, Community-based Organizations

- Support and counselling services for women living with HIV and/or HCV must be expanded and made consistently accessible across the country. This is particularly true for services provided by community-based HIV and HCV organizations.

5. Background on Women Prisoners in Canada

The Canadian federal prison system is one of fourteen correctional jurisdictions in the country. The federal prison system, administered by the Correctional Service of Canada (CSC), falls within the responsibility of the Solicitor General of Canada. It houses people who have been convicted and sentenced to terms of two years or more. Each provincial and territorial government also administers its own separate prison system incarcerating people with sentences of less than two years.

Federally sentenced women are housed within 11 different facilities spread across five CSC administrative regions – British Columbia, Prairies, Ontario, Québec, and Atlantic. Ten of these are federally managed prisons of varying security classifications. The other – the Burnaby Centre for Women – is a provincial women’s institution in British Columbia that houses some federally sentenced women.

The CSC administered women’s institutions include five minimum or medium security facilities – Nova Institution for Women (Truro, Nova Scotia); Établissement Joliette (Joliette, Québec); Grand Valley Institution for Women (Kitchener, Ontario); Edmonton Institution for Women (Edmonton, Alberta); and Okimaw Ohci Healing Lodge (Maple Creek, Saskatchewan). Women classified maximum security are housed in women’s units within three male penitentiaries – Springhill Institution (Springhill, Nova Scotia); Regional Reception Centre (Ste-Anne-des-Plaines, Québec); and Saskatchewan Penitentiary (Prince Albert, Saskatchewan).

The CCRA mandates that health care services for prisoners “shall conform to professionally accepted standards.”

The federal correctional system is governed under legislation entitled the *Correctional and Conditional Release Act (CCRA)*. Internal CSC policy is guided by a series of *Commissioner’s Directives (CDs)* and *Standing Orders*. These are set at the national level, and are often interpreted and implemented on a regional basis.

Prisoners’ entitlements to health services are addressed in both the *CCRA* and the *Commissioner’s Directives*. The *CCRA* mandates that health care services for prisoners “shall conform to professionally accepted standards.”¹

At present, CSC provides a number of educational and harm reduction interventions for prisoners intended to reduce the transmission of HIV and HCV. They also provide medical services intended to meet the needs of prisoners living with HIV and/or HCV. These interventions will be explored in further detail in the body of the report.

According to CSC, in April 2001 there were 385 women in federal custody in Canada. This represents 3% of a total federal prison population of approximately 13,000

¹ Corrections and Conditional Release Act, section 86(2). Available online at www.canada.justice.gc.ca/en/laws/C-44.6/text.html.6.

people. Aboriginal women comprise 23% of the population of federal women's prisoners, a figure higher than the 17% found among men.²

Various statistics on HIV and HCV seroprevalence among incarcerated women have been produced since the late 1980s. Each of these studies has demonstrated high rates of HIV and/or HCV infection among women prisoners, particularly those with a history of injection drug use. In many cases, the seroprevalence rates among incarcerated women have been found to be higher than those among incarcerated men. For example,

- 2001 CSC figures indicate a 35% increase in known HIV infections among federal prisoners between March 1996 and December 2000. Among federally incarcerated women, the rate of HIV infection in December 2000 was 4.69%. This was significantly higher than the rate for male prisoners of 1.66%. In one institution, the Edmonton Institution for Women, the HIV seroprevalence rate was 11.69%.³
- In 1996, the Burnaby Correctional Centre for Women in British Columbia reported that over 78% of the prisoners tested for HCV between January and August were seropositive.⁴
- A 1995 study conducted at the Kingston's federal Prison for Women found an HCV seroprevalence rate of 39.8%.⁵
- A 1993 study carried out among people entering the Ontario provincial prison system found an HIV seroprevalence rate among women of 1.2%. This rate was higher than that found among men participating in the same study.⁶
- A 1989 study of 248 women in a medium-security provincial prison in Québec found an HIV seroprevalence rate of 7.7%.⁷

These figures clearly indicate that both HIV and HCV infection among incarcerated women are issues of significant concern. They also provide an important context for understanding the findings of this report.

² Correctional Service of Canada. "What was the number of federal inmates on April 29, 2001?" in Basic Facts About Federal Corrections. Available online at www.csc-scc.gc.ca/text/faits/facts07-content05_e.shtml.

³ Correctional Service of Canada. Infectious Diseases Year 2000 (Correctional Service of Canada: Ottawa, February 13, 2001).

⁴ Canadian HIV/AIDS Legal Network. "Info Sheet 1 on HIV/AIDS in Prisons: HIV/AIDS and Hepatitis C in Prisons: The Facts," (Canadian HIV/AIDS Legal Network, Montreal: 2001/2002). Available online at www.aidslaw.ca.

⁵ Ralf Jürgens. HIV/AIDS in Prisons: Final Report (Canadian HIV/AIDS Legal Network/Canadian AIDS Society: September 1996), p.46.

⁶ Canadian HIV/AIDS Legal Network. "Info Sheet 1 on HIV/AIDS in Prisons: HIV/AIDS and Hepatitis C in Prisons: The Facts."

⁷ Ibid.

6. Demographics of Study Participants

The women who agreed to participate in this study were drawn from the populations of 8 federal women's facilities, and 1 provincial women's facility housing a population of federal prisoners. In total, 156 women volunteered to be interviewed for this project. Based upon statistics provided by the Correctional Service of Canada, this number represents approximately 40% of the total population of women federal prisoners.⁸ Section 6 provides a portrait of the women's backgrounds and experiences. In each category, figures reflect only those women for whom information was provided.

Ethnicity, citizenship, and language preference

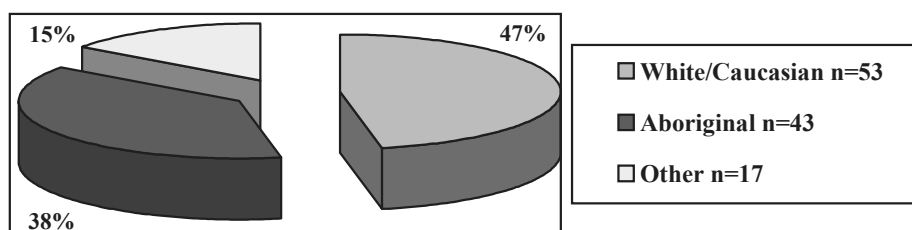
Data was available for 113 women. Of this group, 47% (n=53) identified themselves as White/Caucasian, 38% (n=43) identified themselves as Aboriginal, and 15% (n=17) identified themselves as other ethnicities (i.e., African, Caribbean, German, Dutch Russian). There was insufficient data on ethnicity for 43 women.

Nearly half of all the Aboriginal women in federal custody participated in the study.

According to 2000—2001 CSC statistics, 23% of women incarcerated in federal institutions were Aboriginal.⁹ The percentage of Aboriginal women participating in this study was therefore significantly

higher than that of the prison population as a whole, and represented nearly half (48%) of all Aboriginal women in federal custody.¹⁰

Figure 1 ETHNICITY



For most of the women (n=97), English was the language they read and spoke most frequently, followed by French for 9 participants. Two women read either English or French and spoke the other. Additional languages reported by 9 women included, "Newfie", Cree, Chinese, and Spanish. Thirty-nine women had no data on their language usage.

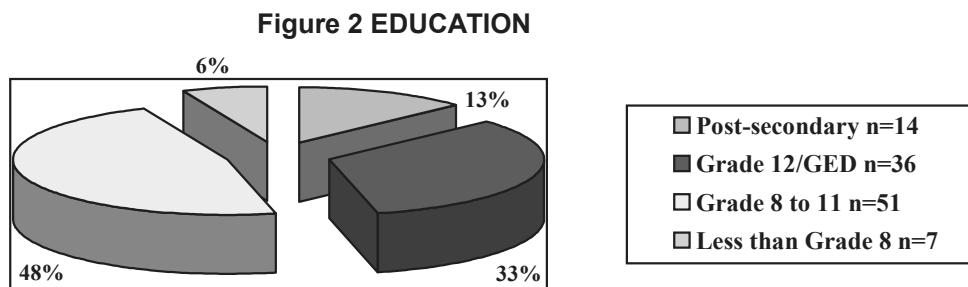
⁸ Correctional Service of Canada. "What was the number of federal inmates on April 29, 2001?" in [Basic Facts About Federal Corrections](#). Lists the total population of women in federal custody as 385.

⁹ Correctional Service of Canada. "What proportion of the federal offender population is Aboriginal?" in [Basic Facts About Federal Corrections](#). Available online at www.csc-scc.gc.ca/text/faits/facts07-content05_e.shtml.

¹⁰ Correctional Service of Canada. "What was the number of federal inmates on April 29, 2001?" in [Basic Facts About Federal Corrections](#). Lists the total population of Aboriginal women in federal custody as 90.

Education

Data was available for 108 women. Of this group, most had between grade 8 and 11 (48%, n=51), followed by those with grade 12 or GED (33%, n=36). Fourteen of the women (13%) had post-secondary education (i.e., college, trade school, university). A further 6% (n=7) listed below grade 8. Data on education was unavailable for 48 women.



Family and marital status

In terms of their family and marital status, there were

- 51 single women (36 with children)
- 21 married women (19 with children)
- 22 identified as common law with an opposite sex partner (15 with children)
- 6 identified as common law with a same sex partner (4 with children)
- 1 identified as living common law, but did not wish to specify the gender of her partner
- 6 were divorced (all with children)
- 4 were separated (3 with children)
- 3 were engaged (2 with children)
- 3 were widowed (all with children).

There was no marital/family data for 41 women.

In total, 88 of the women had children. The women's status of their relationship with their children consisted of state care (n=13), personal care arrangements (i.e., family, friends, n=52), adoption (n=7), adult children (n=11), and/or the children had died (n=3).

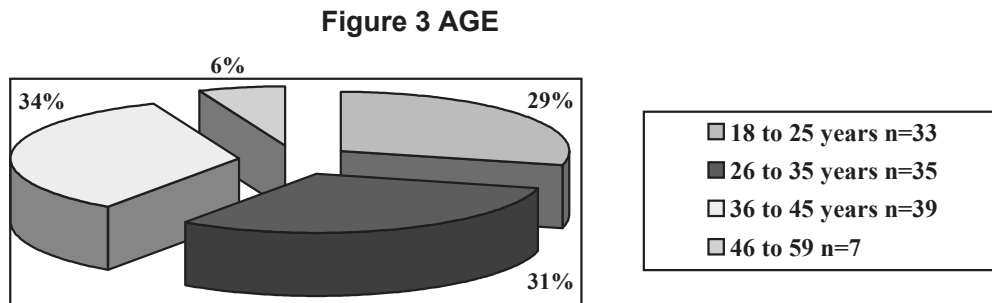
Age

Data on age was available for 114 women.

CSC statistics in 2000—2001 indicate that 56% of federally incarcerated women were between the ages of 20 and 34.¹¹ In this study sample, 60% (n=68) fell between 18

¹¹ Correctional Service of Canada. "What was the profile of the inmate population in 2000-2001?" in [Basic Facts About Federal Corrections](http://www.csc-cc.gc.ca/text/faits/facts07-content05_e.shtml). Available online at www.csc-cc.gc.ca/text/faits/facts07-content05_e.shtml.

and 35. This would indicate that the age range of study participants reflects that of federal women prisoners as a whole.



Sexual orientation

Data was available for 109 women. About one-third of this group (35%, n=55) self-identified as heterosexual. 21% of the women (n=33) self-identified as bi-sexual, 7% (n=11) identified as lesbian, and 2% (n=4) identified as 2-spirited. An additional 6 women listed “other” categories for their sexual orientation, including “try-sexual”, “don’t know”, and “nothing”. Data was unavailable for 47 women.

Length of sentence

In terms of the lengths of sentences that the participants were serving, data was available for 107 women. Of this group

- 71% (n=76) were serving 2 to 5 year sentences
- 11% (n=12) were serving 6 to 10 year sentences
- 5% (n=5) were serving sentences of 10 years or greater
- 13% (n=14) were serving life sentences

One woman was serving less than two years and one woman did not want to identify the length of her term.

CSC statistics for 2000—2001 show that 75% of federally incarcerated women were serving 3 to 10 years, and that 19% were serving life sentences.¹² In this study, 82% of participants were serving 2—10 years, and 13% were serving life sentences. This would indicate that the study sample had a slightly higher percentage of women serving 10 years or less than the prison population as a whole, and a slightly lower percentage of lifers.

Number of years spent in an institution

A large number of women had spent under 5 years in a correctional institution (40%, n=62), with another 10% (n=16) citing 6 to 10 years. Approximately 6% (n=9) had

¹² Ibid.

served 11 to 15 years. Less than 5% were serving more than 15 years (n=3 serving 16 to 20 years, and n=4 serving 21 to 25 years).

Twelve women did not specify the number of years they had served and no data was available for 59 women.

Time spent in young offender, provincial, and/or federal facilities

The women were asked if they had served sentences in any of the following prison systems: young offenders, provincial, and/or federal. Data was available for 94 women.

- 45% (n=42) had previously spent time in the youth system
- 56% (n=53) had previously spent time in the provincial system
- 100% (n=93) had spent time in the federal system

There were no data for 62 participants.

Conclusions

- The study cohort of 156 women represented approximately 40% of all federally incarcerated women in Canada.
- The participation of Aboriginal women in the study was significant. The proportion of Aboriginal women interviewed for the study was much higher than their percentage in the overall prisoner population, and represented nearly half of all Aboriginal women in federal custody.
- The age range of the study cohort reflected that of federal women prisoners as a whole.
- The study cohort sample had a slightly higher percentage of women serving sentences of 10 years or less, and a slightly lower percentage of lifers, than that of the women's federal prison population as a whole.

7. Research Findings

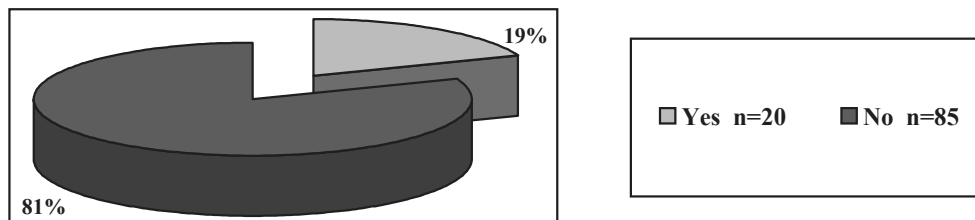
7.1 Risk Behaviours for HIV/HCV Transmission

Numerous studies of Canadian prison populations have documented a significant prevalence of high-risk behaviour for the transmission of HIV and HCV.¹³ This study therefore sought to identify the prevalence and types of risk behaviours evident among federally incarcerated women. The participants were asked questions about their own risk behaviour. Many of the women interviewed reported engaging in some type(s) of behaviour while in prison that might place them at risk for HIV and/or HCV transmission.

Reported incidence of risk behaviour included,

- 27% (n=31 out of 114) of women were tattooing
- 24% (n=25 out of 106) were having unprotected sex
- 19% (n=20 out of 105) were engaging in injection drug use
- 16% (n=18 out of 112) were engaging body piercing
- 9% (n=10 out of 109) were engaging in slashing or other forms of self-injury

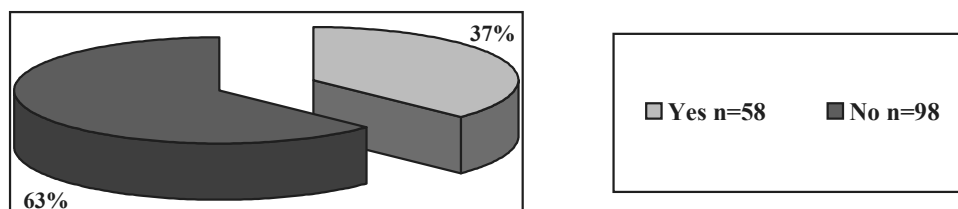
Figure 4 WOMEN REPORTING INJECTION DRUG USE IN PRISON



Sexual activity in prison

46% of the women (n=72 of 156) reported being currently sexually active. Of this group of sexually active women, 81% (n=58 of 72) – 37% of the total women surveyed – reported being sexually active *within* the institution.

Figure 5 WOMEN REPORTING SEXUAL ACTIVITY IN PRISON



¹³ Canadian HIV/AIDS Legal Network. "Info Sheet 2 on HIV/AIDS in Prisons: High-Risk Behaviours behind Bars," (Canadian HIV/AIDS Legal Network, Montreal: 2001/2002). Available online at www.aidslaw.ca.

7.2 HIV and Hepatitis C Prevention Education

The provision of accessible information on HIV and HCV prevention has been identified as a central component of a comprehensive HIV/HCV strategy in the prisons.¹⁴ Therefore, the study sought to identify the level of knowledge of HIV and HCV transmission among the women, and assess their access to prevention information. On this topic, data was available from 118 women.

KNOWLEDGE OF TRANSMISSION

In terms of knowledge of HIV transmission,

- 78% (n=92) had knowledge of transmission from a man to a woman
- 71% (n=84) had knowledge of transmission via sharing of injection equipment
- 67% (n=79) had knowledge of transmission via tattooing and body piercing
- 54% (n=64) had knowledge of transmission from woman to woman
- 35% (n=41) had knowledge of transmission from sharing sharps for slashing or self-injury
- 25% (n=29) had knowledge of transmission through snorting cocaine or smoking crack

Overall, women had less knowledge about transmission of hepatitis C than they did of HIV. The methods of HCV transmission with which women were most familiar included intravenous drug usage (57%, n=67), tattooing and body piercing (54%, n=64), and sexually from man to woman (53%, n=63). Less than 50% (45%, n=53) were aware of transmission from woman to woman, and only one-third (32%, n=38) had information about sharing sharps from slashing or self-injury. Only 27% (n=32) of women had knowledge of transmission from either snorting cocaine or smoking crack. Several women were not aware that bleach was not effective in killing the HCV virus, and 3 women reported concerns about sharing razors and toothbrushes.

ACCESS TO PREVENTION EDUCATION

Women reported receiving HIV and HCV information from a variety of sources, both inside and outside of the institution.

“Prison” or educational workshops offered by the institutions were the most frequently identified sources (42%, n=49), followed closely by community groups such as PASAN, AIDS service organizations, needle exchanges, volunteers, and church groups (37%, n=44). A total of 27 women reported receiving information from health care professionals, consisting of health care (n=7), prison/public health nurses (n=14), and/or doctors (n=6). Pamphlets/written materials and peers were the next most commonly reported sources (with 19 and 18 women respectively listing them). Fifteen women reported having educated themselves about HIV and/or hepatitis C. An additional 12 women reported receiving their information “on the street” or

¹⁴ Prisoners with HIV/AIDS Support Action Network (PASAN). HIV/AIDS in Prison Systems: A Comprehensive Strategy (PASAN, Toronto: June 1992). See also HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons (Correctional Service of Canada, Ottawa: 1994).

“outside”. Eleven women identified television as a source. Other less frequently reported sources for information included school (n=4), family members (n=3), programs in detox or rehabilitation (n=2), and a first aid worker course (n=1).

The most common type of educational material available was pamphlets, reported by 60% of the women. Other materials included videos (19%), posters (18%), and books (13%). Less frequently reported informational sources included the library, workshops, speakers, and newsletters. In general, materials were HIV-related and many women noted having less access to HCV information.

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Despite this wide variety of information sources, many women were dissatisfied with their access to information on HIV and hepatitis C prevention and often felt they were not able to obtain the materials necessary to educate themselves. In fact, 22% of participants (n=35) reported having “none”, “not much”, or being “unsure” about the existence of

any informational materials. While this does not necessarily indicate that such materials were unavailable in the institutions, it does suggest that, at best, the women were not aware of their presence.

Problems were also identified with the format and content of much of the available educational material. Women commonly expressed a desire for more videos or visual presentations, as opposed to written materials, as they felt they were able to learn more effectively from these sources. It was suggested that written materials could be improved by providing more up-to-date information, and by being written in plain, non-medical language.

There was a desire that written materials be made more discreet, and that they not obviously identify themselves as being about HIV or HCV on the covers. In this way, women could read them wherever they wanted without fear that others would notice the content. This would allow women to maintain confidentiality about their status and the information they were trying to obtain. As explained by one woman,

[N]ot all these tiny, tiny pamphlets. [They] get bulky. But a piece of paper with all the information. This PASAN pamphlet is a good sign. And you don't have to write it big for what it is...So you can read it on the bus and when someone comes over says, “Hey”. You know, you can turn and say you're reading the crossword.

“Health care” was also identified as an information source, both in terms of staff and bulletin boards located in and around the health care unit. However, others identified barriers to using the health care unit as an information source. These included locations that were inaccessible, and the need to book an appointment or otherwise obtain permission to attend the health unit. The following woman explains these challenges,

Participant: If you want it, you have to go down to health care and search it out yourself and it's hard to get in the door unless you

have a doctor's appointment. Like, it's impossible to go down there and say, "Can I come in and get some AIDS material to read?"

Interviewer: Would that be the same for hepatitis C as well?

Participant: Yeah, definitely.

In terms of educational programs, access again varied across the system. 29% of women (n=46) did not believe an HIV or HCV educational program was offered at their facility. Again, while this does not necessarily mean that such programs were not available, it does indicate that they were not well promoted, and therefore of limited accessibility.

29% of women did not believe an HIV or HCV educational program was offered at their facility.

The primary health education program provided by CSC is called *Choosing Health in Prisons* (CHIPS), which includes some components on HIV and hepatitis C. CHIPS was identified by 19% of the participants (n=29) as a source of HIV and HCV information. A few of the women who had taken the CHIPS program felt it was too short a program with too much information. The result was it seemed "rushed".

CSC's *Reception Awareness Program* (RAPS) was also mentioned by several women. However, many had not attended the program and were therefore not familiar with its content. The following woman, however, commented upon the content of both CHIPS and RAPS.

Well, there's RAPS and there's CHIPS. I know that a lot of the stuff that's told in CHIPS and RAPS. There's information, but there's not that much. There's also not much of anything for the effects. Like, you know, how it is [for] somebody getting tested for HIV or hep C and it com[es] back negative... There's nothing on counselling, what you went through during the time you're waiting for it.

Another source of HIV and HCV information available to prisoners was community-based AIDS service organizations (ASOs). Study participants identified ASOs as providing programs (often infrequently) in some institutions. Three institutions also held AIDS awareness days or weeks.

Many women discussed peer health programs. Data on this issue was available from 78 women. Of this group, 77% (n=60) identified the benefits of such a program. However, access to peer programs varied between institutions. 54% of the women (n=42) had no access to any type of peer education programs. These responses were spread across 5 different institutions, which indicates this was not simply a localized issue. In fact, several women were not sure what a peer program would contain. While these responses do not necessarily mean the programs were not operating, it again clearly identifies that, at best, women were not aware of – and therefore not accessing or participating in – peer health initiatives.

Although peer health programs were desired by a majority of the women, some raised concerns about program availability, training, selection, and confidentiality.

For those institutions offering peer health programs, variations existed in training and format. Some facilities offered training to several women, while others only trained one or two. In institutions where the number of trained peers was small, some women raised concerns about lack of availability. In other institutions training had only recently been initiated, and these women were unable to comment about its success or effectiveness.

The method of selecting peers was another issue of concern to many women. Seven women reported they did not know how the peer was selected. For those aware of the process, staff was commonly identified as responsible for selection. At one facility, the psychologist, board, and health care unit were involved in the selection process. Few facilities enabled the women themselves to take responsibility for selecting the peers. Three women identified experiencing this type of peer selection.

Other concerns with the peer health program were related to confidentiality and trust. Several women experienced similar feelings to the following woman, *“I don’t think I can trust them. I wouldn’t”*. Another woman explained why she thought this lack of trust existed.

It doesn't seem like they get too much, like, the inmates aren't too much involved in it. I think a lot of girls don't feel comfortable talking to other inmates about it because they're not, they discuss your problems with other people and all of a sudden your problems and stuff are bouncing around...Whereas if you went out in the community they do a program for it. I think you would get a better response. You would have more people participate in it.

Women in smaller institutions also raised the issue of confidentiality where they felt it would not be possible to retain a sense of anonymity when accessing programs or information.

Conclusions

- Women had access to a variety of information sources on HIV, and to a lesser extent HCV.
- Many women felt that they were not able to obtain the information necessary for them to educate themselves.
- CSC health programs such as *Choosing Health in Prisons* (CHIPS) and the *Reception Awareness Program* (RAPS) did not in themselves meet the needs of women regarding HIV and HCV prevention education.
- A majority of women would like to access peer health programs. However, access to these programs was inconsistent and problematic.

Gaps Identified

1. The majority of available information was HIV-related. Information on HCV was less common.
2. There was inconsistent availability and/or awareness of HIV/HCV educational materials and programs.

3. AIDS service organizations provided only infrequent programming for incarcerated women in some institutions.
4. Current provision of peer health programming did not meet the needs of women in many institutions.

Elements of Good Practice in HIV/HCV Prevention Education

1. Informational materials on both HIV and HCV should be available in various forms. Information should be up-to-date, and presented in plain language.
2. Written materials on HIV and HCV such as pamphlets and booklets must be discreet. The content should not be disclosed on the cover.
3. Visual and video educational tools should be more widely utilized and accessible to women.
4. Provision of information on the risk of HCV/HIV transmission via crack and/or cocaine use should be increased.
5. HIV/HCV prevention programs must be widely advertised and promoted to ensure awareness and accessibility.
6. Community-based AIDS and HCV service organizations have an important role to play in complementing health programs provided by CSC.
7. The scientific literature demonstrates that, especially with respect to HIV and AIDS, there is a lack of communication and trust amongst prisoners and prison officials.¹⁵ Therefore, correctional officers should not be present during HIV and HCV prevention programs.
8. Given the concerns about trust and confidentiality identified, the selection and training of participants in CSC's peer education program must be conducted in a manner that maximizes prisoner confidence in the initiative. This should include prisoner involvement in the peer selection process, as well as increased emphasis in the training on confidentiality.

Recommendations

1. CSC, Health Canada, and community-based organizations must ensure that all HIV and HCV prevention education initiatives reflect these elements of good practice.
2. CSC, Health Canada, and community-based organizations must ensure that access to women-specific HIV and HCV prevention education programs and materials be developed and made consistently available throughout the system. Programs must be offered on a regular and ongoing basis.
3. CSC should expand and strengthen the HIV and HCV components of current health programs such as CHIPS and RAPS.
4. Community-based HIV and HCV organizations must increase the provision of prevention education services to incarcerated women.
5. Health Canada must provide funding to assist community groups to provide the services described in point 4, particularly in rural and/or under-served institutions.

¹⁵ Gaston Godin, H el ene Gagnon, Michel Alary, Michel Morissette, Lina No el, "L'accessibilit e aux outils de pr evention de sida pour les personnes incarc er es: le point de vue des agents correctionnels," in Gaston Godin, Joseph Josy-L evy, et Germain Trottier, eds. *Vuln erabilit es et pr evension VIH/Sida. Enjeux Contemporains*. (Sainte-Foy, Qu ebec: Presses de l'universit e Laval, 2002): 73-83.

6. CSC must improve the current implementation of peer health programs, and ensure that access is consistent across the system. CSC staff should work in cooperation with prisoners to ensure that each program is developed and implemented to meet the specific needs of women in each institution.

7.3 Prevention and Harm Reduction Measures

Access to HIV/HCV prevention and harm reduction measures is a key element in preventing the transmission of blood-borne disease within the prison environment. Since 1992, reports published by PASAN, the Expert Committee on AIDS and Prisons, and the Canadian HIV/AIDS Legal Network have all called for the implementation of HIV/HCV prevention and harm reduction measures in prisons.¹⁶

During this time, the Correctional Service of Canada has acted to make available some prevention and harm reduction measures to prisoners. The study sought to assess the current level of access and satisfaction with these existing programs, and identify any areas where additional prevention measures were required.

ACCESS TO CONDOMS, DENTAL DAMS, AND LUBRICANT

Condoms, dental dams, and water-based lubricants have been available in federal prisons since 1992. The purpose of this initiative was to reduce the sexual transmission of infections such as HIV among prisoners. Access to safer sex measures is mandated under Section 16 of CSC *Commissioner's Directive 821*, which states

Non-lubricated, non-spermicidal, latex condoms, dental dams and water-based lubricant, as well as information on preventing HIV and other sexually transmitted diseases, shall be easily and discreetly available to inmates at a minimum of three sites in each institution and in all family visiting units. Appropriate distribution sites are those which inmates routinely attend or through which they pass regularly, such as shower areas and gymnasium, library, school and laundry rooms. No inmate shall be required to make a request for condoms, dental dams or water-based lubricant from any staff member.¹⁷

Participants in the study were asked about the availability of safer sex measures in their institutions. 56% of the women (n=88) provided comment on this issue.

Condoms were more accessible than dental dams or lubrication.

78% (n=69 of 88) reported some access to safer sex measures, with condoms being more readily accessible than dental dams or lubrication. Access occurred in several ways. In

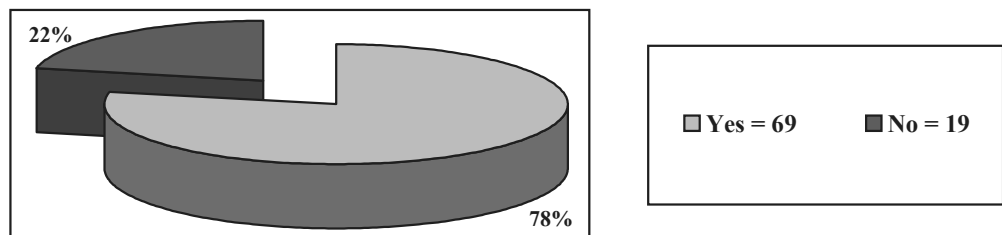
¹⁶ PASAN, 1992. Expert Committee on AIDS and Prisons, 1994. Ralf Jürgens. *HIV/AIDS in Prisons: Final Report* (Canadian HIV/AIDS Legal Network, Montreal: September 1996).

¹⁷ Correctional Service of Canada. *Commissioner's Directive 821*, "Management Of Inmates With Human Immunodeficiency Virus (HIV) Infections", Section 16 (March 4, 1996). Available online at www.csc-scc.gc.ca/text/plcy/cdshtm/821-cde_e.shtml.

some institutions, women received safer sex measures upon admission as part of a “kit”. 22% of the women (n=19) had received condoms and lube in this manner. However, there were no dental dams in these kits.

After admission, access to condoms, dental dams, and/or lube was varied. Methods of distribution included a box that was located outside of the health care unit, in the bathroom, or in the laundry room; a stock in the house or Private Family Visiting (PFV) unit; stored in the first aid kits; and/or a condom dispenser in the hallway, gym, nursery, or bathroom. Another woman reported that a box of condoms was brought to their “house” [unit] once a month.

Figure 6 WOMEN REPORTING SOME ACCESS TO SAFER SEX MEASURES

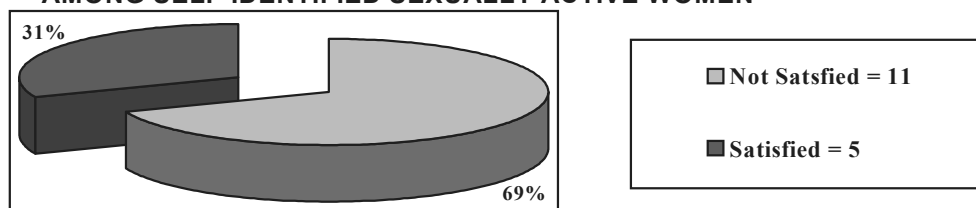


Access to dental dams was much more inconsistent. 17% of women (n=15) reported they had never received any dental dams. Even when dental dams were provided, women expressed concerns. Four women felt the dental dams they received were no good (i.e., too thick) or were unsanitary. This may have been a factor why 2 women reported that dental dams were available but not used as frequently as condoms.

On the face of it, availability of safer sex measures seems quite good, with 69 of 88 respondents identifying some access. However, when these figures are analyzed by reported risk behaviour, a worrying trend emerges.

Of the 88 women responding to the issue of safer sex measures, 18% (n=16) self-identified as being sexually active within the institution. 69% of this group of sexually active women (n=11) indicated dissatisfaction with the current provision and/or accessibility of safer sex measures. Therefore, while the overall data would indicate good access to some safer sex measures (primarily condoms), the group most in need of these measures (i.e., those who are sexually active within the institution) identified significant dissatisfaction with the current situation.

Figure 7 SATISFACTION WITH ACCESS TO SAFER SEX MEASURES AMONG SELF-IDENTIFIED SEXUALLY ACTIVE WOMEN



Therefore, it must be concluded that the true accessibility – and therefore effectiveness – of the current system was less than that suggested by the general data.

The data indicates that there were a variety of reasons why sexually active women faced increased barriers to accessing safer sex measures.

69% of sexually active women indicated dissatisfaction with the current provision and/or accessibility of safer sex measures

There is evidence (n=6) that staff at some facilities actively discouraged sexual activity. One woman reported that she believed she would be sent to segregation if caught having sex. Fear of punitive sanction against consensual sexual activity is a significant barrier to promoting safer sex as it may cause women to avoid accessing safer sex measures for fear of identifying themselves as sexually active.¹⁸

Lack of confidentiality was also identified as an issue. 11% of the women (n=10) said they had to ask either health care staff or correctional officers in order to obtain safer sex measures, and thereby identify themselves as being sexually active – a practice that contravenes *Commissioner's Directive 821*. One woman commented about the difficulty obtaining safer sex measures from staff, saying, “*You always have to argue and fight for them.*”

The result was that many women would simply not ask for protection, as the following woman explained, “*I don't think there's too many people that would go up and ask a guard for that stuff.*”

Concerns were also raised about the irregular nature of distribution, as there was a feeling that some women were able to obtain condoms and dental dams while others were not. Supply was also an issue, as distribution locations were not always stocked, and the dispensing machines or boxes were often empty.

Lack of access to safer sex measures resulted in women engaging in unsafe practices. One such example was washing out and reusing other people's condoms, as one woman reported witnessing.

Conclusions

- Women generally supported the provision of safer sex measures by CSC.
- Condoms, dental dams, and water-based lubricants were not equally and consistently accessible to incarcerated women. Access to dental dams and lubricants was particularly poor.
- While a majority of women had access to some safer sex measures (primarily condoms), access to dental dams and lubricants was much less common.
- Significant barriers existed for sexually active women wishing to access safer sex measures. More than 2/3 of women who identified as sexually active within prison were dissatisfied with access to safer sex measures.

¹⁸ PASAN, p.4.

- Some institutions required women to request safer sex measures from staff, which violates *Commissioner's Directive 821*.

Gaps Identified

1. Access to safer sex measures was generally inconsistent.
2. Access to dental dams and lubricants was particularly problematic.
3. *Commissioner's Directive 821* was not consistently observed across the system.

Elements of Good Practice in the Provision of Safer Sex Measures

1. Adequate supplies of condoms, dental dams, and water-based lubricants must be made equally, consistently, and discreetly accessible within all institutions.
2. Access to safer sex measures should not necessitate making a request to staff, in accordance with *Commissioner's Directive 821*.
3. It is difficult to encourage safer sex practices in an environment that has a punitive ethos towards sexual relationships. Therefore, consensual sexual relationships within the institution must not be cause for increased staff surveillance, harassment, or disciplinary sanction.

Recommendations

1. CSC's policy to provide safer sex measures to prisoners should be continued, and should reflect these elements of good practice in all institutions.
2. CSC must ensure that condoms, dental dams, and water-based lubricants are equally and consistently accessible across the system. Access to dental dams and lubricants in particular must be improved.
3. CSC must ensure that *Commissioner's Directive 821* is observed in all institutions.

ACCESS TO BLEACH

In 1996, the Correctional Service of Canada implemented a bleach distribution program in all institutions. The purpose of this initiative was to provide a harm

reduction option for injection drug users.

Women found bleach useful for reducing the risk of HIV transmission and for personal hygiene.

Participants in the study were asked about the bleach programs in their institutions. 34% of the women (n=53) provided comment on the provision of bleach.

In general, women found bleach useful, both for reducing the risk of HIV transmission and for personal hygiene. Bleach was therefore used for general cleaning and laundry purposes, as well as for cleaning syringes.

The research revealed significant variability in the distribution and availability of bleach across the system. Methods of distribution were different in each institution and included dispensing machines in the gym, bathroom, and/or nursery; distribution

though health care units, or outside health care units; distribution with general cleaning supplies; and availability in first aid kits.

Six women reported receiving bleach upon admission to the institution either as part of a package ("kit") or just as a bottle. The bottles, however, were often not later refilled, nor were instructions provided as to how bleach could be obtained, as indicated in the following dialogue:

Interviewer: Does this institution have a bleach distribution program?

Participant: Yeah.

Interviewer: Do you know how women access it?

Participant: When I came in they gave me a little container of bleach, but that was all.

Interviewer: Do you believe this system works?

Participant: No, because they're not really refilling after. They're not giving you the chance to refill it. They don't say "Bring in your empty bleach bottles" or anything of that sort.

Another method of distribution was the "first come, first serve" basis, which consisted of a few bottles of bleach being left outside of the health care unit. Women commented that they were not able to obtain bleach in these circumstances unless they happened to be one of the first people present when it was handed out. This method of distribution resulted in stockpiling to ensure a personal supply was maintained, especially as it was reported that days, weeks, or even months would pass without the supply being restocked.

The most common methods of bleach distribution involved making a request to health care staff or correctional officers. This was reported by 34% of the women offering comment on the program (n=18). This presented barriers for many women due to a lack of confidentiality, and questioning from staff. The type of questions women were asked can be seen in the following comments on the effectiveness of the bleach distribution system.

Participant: It's very monitored. They ask if you're using it for needles or... or if you're using it to clean. It's very difficult to get.

Interviewer: How do you actually access the bleach?

Participant: You more or less lie.

Interviewer: So you have to ask staff for it, and then lie about what you're using it for?

Participant: Yeah.

Another barrier deterring women from requesting bleach from staff members was the fear of identifying themselves as injection drug users. The ramifications of such a disclosure are highlighted in the following woman's comments:

You have to go ask staff...But, like I said, we haven't had any bleach in our unit for two weeks. You know. So it's not even accessible...You have to go and say what do you need it for... Some staff will just give it to you... Certainly all staff should do that [but] probably less than fifteen percent do. But yeah, you have to specifically say "It's for my rig" and then your fuckin' room is tossed [searched]. You know. Or you're searched, or your visitors are searched, you know?

Another woman commented,

They will put bleach out once a day, and that's it. That's all...Even if they even get it out once a day sometimes you go months with no bleach. Some of the women take the bleach to their laundry. Some of the women would need the bleach for whatever. So they can't determine. And they put a notice saying if you want bleach you got to ask for it and then you go on their list for HIV and so on and so forth. So that sort of cuts that out, cause I ain't coming in with a drug problem or HIV or AIDS or anything else like that. So I don't want to be on their list. So really I haven't seen bleach in awhile. I think the last time I saw it was a couple of months ago.

Concerns about the ramifications of identifying oneself as an injection drug user also related to the fear that it would negatively affect parole eligibility.

Interviewer: How are women accessing [bleach] right now?

Participant: Well, you have to come down...if you need bleach to like clean your counters or to do your clothes, 'cause you don't get that from the stores, contrary to what health care says. If you're a drug addict you can come here and get bleach and they'll give you all the bleach you want. But then your name goes down on the list, and if you're coming up for parole then you're not getting out unless you came out to all the programs....In order to get bleach you have to say you're something you're not in order to get bleach to clean our god damn underwear.

One final concern raised by several women at one institution was that the bleach they were given was diluted.

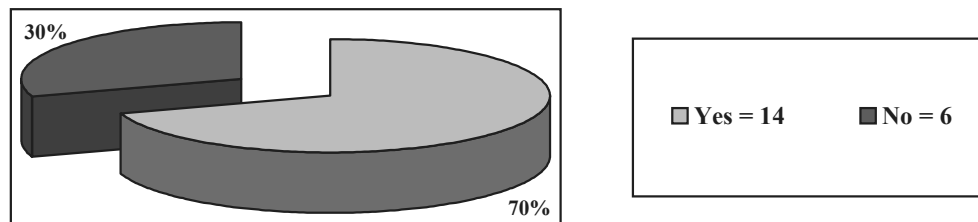
As a result of these barriers, many women were not using the bleach programs at their institutions. In total, 66% (n=35) of women identified problems with bleach accessibility in their institutions.

70% of injection drug users identified problems accessing bleach.

Of particular concern was the significant number of self-identified injection drug users reporting difficulty in accessing bleach. A total of 20 women participating in the study identified themselves as current injection drug users in the institution. Of this group, 14 identified problems with the accessibility of bleach.

Therefore, 70% of the study participants who identified as current injection drug users also identified problems in accessing bleach. This means that the group of women for whom the CSC bleach program is intended faced significant barriers to accessing this harm reduction measure.

Figure 8 SELF-IDENTIFIED IDUs REPORTING BARRIERS TO BLEACH ACCESS



Conclusions

- Women supported the provision of bleach by CSC, and found it useful for cleaning and hygiene purposes and for harm reduction purposes.
- The bleach distribution program as currently administered was failing to meet the needs of incarcerated women. 2/3 of women identified problems with bleach accessibility in their institutions.
- The bleach distribution program as currently administered was specifically failing to meet the needs of injection drug users, the group for whom the program is intended. 70% of current injection drug users identified problems with accessing bleach.
- The need to make a request to staff in order to access bleach created significant barriers for many women.
- In general, the women equated bleach “accessibility” with the availability of a constant supply, and the ability to obtain it without making a request to staff.

Gaps Identified

1. Access to bleach was inconsistent across the system. Current barriers to obtaining bleach resulted in many women not availing themselves of the program.
2. Bleach was often provided in insufficient quantities, which resulted in lack of consistent access and in stockpiling.
3. The need to request bleach from staff in many institutions created significant barriers to access.
4. There is currently no mechanism to monitor the quality of the bleach provided to prisoners (i.e., the age of the bleach, whether it is full strength or diluted).

Elements of Good Practice in the Provision of Bleach

1. Bleach must be made generally and discreetly available to prisoners in various places in the institution.
2. Access to bleach should not necessitate making a request to staff.
3. Bleach must be provided in sufficient quantities to ensure that a constant supply is available, both for cleaning purposes and harm reduction purposes.
4. Full-strength bleach must be provided. Bleach supplies must not be diluted.
5. Fresh supplies of bleach must be maintained to ensure maximum efficacy as a harm reduction measure.
6. Information on the correct use of bleach for harm reduction purposes must be easily and discreetly accessible.

Recommendation

1. CSC's current bleach program must be continued and improved to ensure that it reflects these elements of good practice in all institutions.

ACCESS TO METHADONE

Since 1998, the Correctional Service of Canada has pursued a gradual process of providing methadone for prisoners.¹⁹ Under Phase I of this process, federal prisoners were allowed to maintain a methadone regimen if they were accessing methadone treatment prior to their incarceration. In 2001, CSC conducted a five-year evaluation of its methadone program. It concluded that the provision of methadone had positive post release outcomes for prisoners accessing the treatment, and the program was cost effective.²⁰ In May 2002, CSC completed the implementation of Phase II of its methadone policy, which now makes it possible for qualifying federal prisoners to initiate a methadone program while in custody.

The interviews for this study took place immediately before, and immediately following, the implementation of Phase II. Therefore, many of the women's comments were made before the new policy was in place, or before it was fully functional. Therefore, the information in this report does not provide comment on the new CSC policy. That said, it is useful to review the findings to assess the consistency of the old policy, and to determine to what extent the new policy addresses the concerns identified.

General awareness of the existence of the methadone program was high, with only 5 women not believing the program existed at their facility. However, gaining access to it was challenging in many instances.

It's hard [to get on]. Like you have to be half dead on their doorstep for them to give it to you...I've tried and everybody was willing to give it to me, and I still couldn't get it. I had my addictions

¹⁹ Correctional Service of Canada. Commissioner's Directive 821, "Management Of Inmates With Human Immunodeficiency Virus (HIV) Infections".

²⁰ Sara L. Johnson, *et al.* Institutional Methadone Maintenance Treatment: Impact on Release Outcome and Institutional Behaviour (Addictions Research Centre, CSC: September 2001).

doctor...and he even wrote letters in here, letters saying that methadone would be the most suitable for [me]...'cause I had tried everything...But there was just no way because the new criteria, it's too high...I don't know. It's just too high for what you need, so you just can't get it.

In some facilities, an institutional physician prescribed methadone. However, concerns were raised about the length of time it could take to get an appointment with the doctor, and ultimately the methadone.

They made me wait twelve days in here, sick, before I saw the doctor. And the nurses are the one[s] that put you on the doctor's list. So the doctor doesn't know you're here. She would've put me on a week before, but...the nurses said, "No, no, it's not important enough now. We'll put her to see the doctor next time." Right. So you're sitting there sick and they won't give you nothing. So the nurses, you know, say, "Oh, you look fine, You're healthy." because I'm still chubby from when I got out.

This lengthy waiting period was also evident for those women who were already on methadone when they entered the prison.

There was a lack of understanding regarding the selection criteria for the methadone program. This resulted in many women (n=19) being unsure of how the program

There was a lack of understanding regarding the selection criteria for the methadone program.

operated or how women accessed it. In addition, there was a perception of bias within the selection process. A few women felt the selection criteria was too lenient because some 18-year old women were on the program. Another woman was worried that if she asked to be placed on methadone it

would be perceived as drug seeking behaviour and she might be penalized when applying for parole. A final concern related to the methadone program was the level of dosage received. Two women felt the level was either too low or too high and was not being regulated appropriately

Despite these identified concerns with the program, 6 women commented about the positive benefits of the program and how it was helping those who needed it. As well, 2 women felt that the program was accessible to those who needed it.

Conclusions

- The provision of methadone by CSC was supported by most women.
- General awareness about the existence of the methadone program was high. However, there was confusion about the selection criteria and the process by which women could access the program.
- There was a desire that methadone initiation be made available. This finding would support CSC's decision to implement Phase II of its methadone policy.

Gaps Identified

1. Lack of opportunity to initiate methadone treatment while in prison. [This gap has been addressed by the implementation of Phase II of CSC's methadone policy.]
2. Prisoner awareness of the application process for the methadone program was inconsistent.
3. There was some concern about delays in seeing physicians to prescribe methadone, and delays in accessing methadone.

Elements of Good Practice in the Provision of Methadone

1. Assessment criteria for methadone maintenance must be consistently applied within each institution, and across the system.
2. Information on the application process and selection criteria must be made clear and widely available to prisoners.
3. Access to/denial of access to a methadone program must not be used punitively or as a disciplinary measure.
4. Delays in accessing methadone related medical services must be minimized.
5. All medical staff must be provided adequate and ongoing training and support to assist them in managing the program.

Recommendations

1. CSC policy to provide methadone access to prisoners, including methadone initiation, should continue.
2. CSC should monitor the implementation of Phase II of its methadone policy to ensure that it reflects these elements of good practice in all institutions.

ACCESS TO STERILE SYRINGES

Numerous Canadian studies have demonstrated that the sharing of syringes for injection drug use creates a significant risk of HIV and HCV transmission within prisons.²¹

As outlined in Section 7.1, 20 women (19% for whom risk behaviour information is available, and 13% of the total study cohort) identified themselves as injection drug users within the institution. Given the lack of access to sterile syringes/syringe exchange within Canadian federal prisons, this creates an environment where the sharing of syringes is common.²²

At present, CSC provides bleach to prisoners as a harm reduction measure for cleaning used syringes. However, bleach is suboptimal at best in preventing disease transmission, as it is less than 100% effective in killing HIV and is of very limited

²¹ Canadian HIV/AIDS Legal Network. "Info Sheet 2 on HIV/AIDS in Prisons: High-Risk Behaviours behind Bars."

²² Ibid.

efficacy in killing HCV.²³ Given the problems in the current provision of bleach, as described above, it is clear that the bleach alone is far from a comprehensive response to the risk of disease transmission in prisons via the sharing of injection equipment.

Although the study contained no question specifically addressing syringe exchange or distribution, the issue was raised consistently by the women themselves during the course of the interviews.

A total of 32 women (16% of the total cohort) identified the need for needle exchange during their interviews. Given that needle exchange was not an issue introduced by the interviewers, this may well be a low estimate of total number of women interested in having access to a syringe exchange program. The number of women who identified the need for needle exchange is in fact much greater than the number who self-identified as current injection drug users.

In November 1999, CSC's internal *Study Group on Needle Exchange Programs* issued a report recommending that the federal prison system pilot test five needle exchange projects, one in each region of Canada (including one women's institution).²⁴ However, the recommendations of that report were never implemented, and to date CSC does not provide sterile syringes to prisoners.

Conclusions

- Injection drug use was common in women's prisons, with 1 in 5 women self-identifying as injecting within the institution.
- Current CSC harm reduction measures are insufficient to address the risk of disease transmission through sharing of injection equipment.
- Many women identified the need to distribute sterile syringes in prisons.

Gap Identified

1. Lack of availability of sterile syringes to incarcerated injection drug users.

Recommendation

1. CSC should act upon the recommendations of the 1999 *Final Report of the Study Group on Needle Exchange Programs*, and pilot test needle exchange projects in all five regions of Canada, one of which must be in a women's institution.

ACCESS TO SAFER TATTOOING AND BODY PIERCING MEASURES

Tattooing is a popular prison art form among both men and women. Many talented tattoo artists operate in Canadian prisons, and many thousands of people receive

²³ Canadian HIV/AIDS Legal Network. "Info Sheet 5 on HIV/AIDS in Prisons: Prevention: Bleach", (Canadian HIV/AIDS Legal Network, Montreal: 2001/2002). Available online at www.aidslaw.ca.

²⁴ Study Group on Needle Exchange Programs. "Final Report of the Study Group on Needle Exchange Programs" (Correctional Service of Canada, Ottawa: October 1999).

tattoos while incarcerated. In a 1995 CSC survey, 45% of federal prisoners reported receiving a tattoo while in prison.²⁵

Because the practice of tattooing is prohibited in federal prisons, it is necessarily an activity that occurs in secret. Although under proper conditions, tattooing is a perfectly safe activity for both customer and artist, in prisons tattooing happens in often unhygienic conditions using inadequate homemade tools.²⁶

Tattooing is the most common risk behaviour identified by study participants.

In the prison environment, tattooing and body piercing pose a high-risk of HIV and HCV transmission via the reusing and sharing of tattooing/piercing needles and tattoo inks.

As outlined in Section 7.1, 31 women (27% for whom risk behaviour information is available, and 20% of the total study cohort) identified themselves as being involved in tattooing within the institution. Tattooing was in fact the single most common risk behaviour identified by the study participants. The related practice of body piercing was identified by 18 women (16% for whom risk behaviour information is available, and 12% of the total study cohort).

Thirty-six women – nearly one-quarter of the total cohort – expressed interest in participating in a program on safer tattooing and body piercing.

Conclusions

- Tattooing and body piercing were common in women's prisons.
- Women expressed significant interest in information and materials to practice tattooing and body piercing safely.
- Current CSC prohibition of these practices, along with a failure to provide the measures necessary to practice them safely, creates an environment where the risk of disease transmission is increased.

Gaps Identified

1. Lack of availability of measures and materials to practice tattooing and body piercing safely.
2. Prohibition of tattooing increases risk of unsafe/unsanitary practices.

Recommendations

1. CSC should eliminate current prohibitions and penalties for tattooing.
2. CSC policy should be changed to designate tattooing as a hobby-craft activity within all institutions.
3. CSC must make harm reduction measures, as well as appropriate materials to practice tattooing and body piercing safely, available to prisoners.

²⁵ Correctional Service of Canada. 1995 National Inmate Survey: Final Report. (Correctional Research and Development, Ottawa: 1996).

²⁶ Rick Lines. Pros & Cons: A Guide to Creating Successful Community-based HIV/AIDS Programs for Prisoners. (PASAN, Toronto: 2002). p.72.

ACCESS TO SAFER SLASHING/CUTTING INFORMATION

A recent CSC study, *Women Offenders who Engage in Self-harm: A Comparative Investigation*, describes self-injury as “as a coping mechanism to relieve stress and gain control over one’s environment.”²⁷ The report characterizes the scale of self-injurious behaviour among incarcerated women as very significant.

It has been estimated that almost half of all women inmates have made a previous suicide attempt...[T]he percentage would likely be much higher if other forms of self-harm were considered.²⁸

According to the Canadian Association of Elizabeth Fry Societies, 59% of federally sentenced women have reported that they have engaged in self-injurious behaviour.²⁹ One common form of such self-injurious behaviour is slashing or cutting, whereby a woman deliberately cuts or slashes her body with a “sharp” (a sharp object such as a piece of broken glass).

As outlined in Section 7.1, 10 women (9% for whom risk behaviour information is available, and 6% of the total study cohort) identified themselves as being involved in slashing/cutting within the institution. Given the fear associated with disclosing such information, it can be fairly assumed that the actual number of women involved in this practice is higher.³⁰ This assumption would be supported both by the Elizabeth Fry Society, and by the above CSC report’s conclusions that a significant percentage of incarcerated women engage in self-injury.

Slashing/cutting presents a risk of HIV and HCV transmission through the sharing of “sharps”, or implements used to cut the skin.³¹ This is also an area where some women (n=6) identified the need for information on safer slashing/cutting. This represents a gap in existing prevention information.

Conclusions

- A small [within the context of this study] yet still significant number of women self-identified as being involved in slashing/cutting and other forms of self-injury within the institution. Given other reports on self-injury among incarcerated women in Canada, it may fairly be assumed that the figures found in this research represent an underestimation of the prevalence of the practice.
- Women identified a lack of information on safer slashing/cutting as a gap in current harm reduction educational materials.

²⁷ Cherami Wichmann, *et al. Women who Engage in Self-harm: A Comparative Investigation*. Correctional Service of Canada (February 2002). p.6.

²⁸ *Ibid*, p.2.

²⁹ Canadian Association of Elizabeth Fry Societies. “Fact Sheet: Human and Fiscal Cost of Prison” (Canadian Association of Elizabeth Fry Societies, 2002). Available online at www.elizabethfry.ca/eweek02/factsht.htm.

³⁰ *Ibid*.

³¹ *Ibid*. p.147.

Gap Identified

1. Lack of availability of information on safer slashing/cutting and other forms of self-injury, as well as safer alternatives to self-injurious behaviour.

Recommendation

1. CSC and community-based organizations should develop and make accessible information on safer slashing/cutting and other forms of self-injury, as well as safer alternatives to self-injurious behaviour.

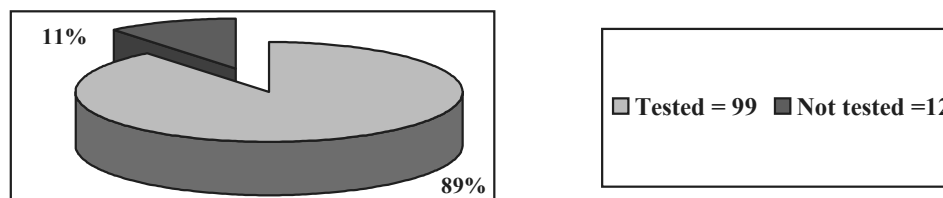
7.4 Testing and Confidentiality

TESTING FOR HIV AND HCV

Testing for HIV and HCV is available on a voluntary basis in all federal prisons through prison health units, and in some cases through external public health nurses. There is no mandatory HIV or HCV testing of prisoners in Canada.³²

The uptake of both HIV and HCV testing by women in this study was very high. The vast majority of the women (89%, n=99 with data available for 111) had been tested for HIV while in prison. This is a greater percentage than those who had received testing in the community (64%, n=74 with data available for 117). Women accessed testing both on admission, and upon request during the course of their sentences.

Figure 9 WOMEN WHO HAD RECEIVED HIV TESTING IN PRISON



A large majority of women had also received HCV testing in prison (78%, n=77 with data available for 99). This is again greater than the percentage of women who had accessed the testing in the community (62%, n=64 with data available for 117).

10% of the women who received HIV testing in prison did so because they believed testing was mandatory.

While this high uptake of testing services is positive, the data identified several issues of concern regarding testing procedures. For example, 10% of the women who received HIV testing in prison did so because they believed testing was mandatory (n=11). This number was spread between 4 separate institutions, which would indicate a systemic concern.

³² Correctional Service of Canada. Commissioner's Directive 821, "Management Of Inmates With Human Immunodeficiency Virus (HIV) Infections", Sections 9—11 (March 4, 1996). Available online at www.csc-scc.gc.ca/text/plcy/cdshtm/821-cde_e.shtml.

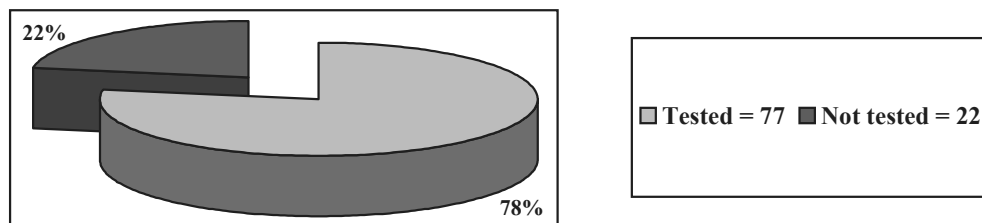
The data on pre- and post- test counselling was also a source of concern.

The purpose of pre- and post- test counselling is both educational (to provide information about the benefits of testing, types of risk behaviour) and therapeutic (to ensure that a person can make the best possible informed decision about whether or not to test, to discuss the consequences of a positive or negative test result and possible sources of support).³³ Pre- and post- test counselling is considered a component of best practice in HIV testing. Such counselling is mandated under Sections 12 and 13 of *CSC Commissioners Directive 821*, which states

12. All [HIV] testing shall be preceded by a period of counselling by health services staff regarding the possible implications of the test and test results.

13. Following testing, HIV seropositive inmates shall receive counselling from medical staff and shall have access to the full range of available institutional and community counselling services.³⁴

Figure 10 WOMEN WHO HAD RECEIVED HCV TESTING IN PRISON



Despite CSC policy, 64% of the women for whom data is available on this issue (n=34 of 53 women) – 34% of all women receiving HIV testing – indicated they had received no counselling as part of their HIV testing. These figures were spread across 7 institutions, which would indicate that this is not an isolated issue.

For example, some women reported that the institution did not provide negative test results.

When it's blood work day, you go down and you get the blood work done. If it's negative you don't get a phone call. You never see the information unless you ask. You never see it. You just take their word. There are some women in here that nobody has phoned.

³³ Hepatitis C Council of New South Wales. "Pre & post test counselling". (NSW Health Department, Australia: April 2002). Available online at

www.hepatitisc.org.au/information/Pre%20&%20post%20test%20counselling.pdf

³⁴ Correctional Service of Canada. *Commissioner's Directive 821*, "Management Of Inmates With Human Immunodeficiency Virus (HIV) Infections", Section 12 and 13 (March 4, 1996). Available online at www.csc-scc.gc.ca/text/plcy/cdshtm/821-cde_e.shtml.

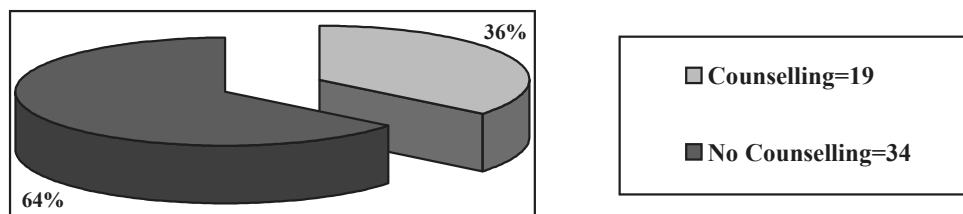
A few women reported receiving minimal pre- and post- test counselling, consisting of a few questions. One woman explained,

They basically took my blood. They asked, "Why do you feel you need it?" and I think they asked one or two questions.

Another woman was simply asked how she would respond to a positive result.

All they asked me was if my test came back positive for HIV how would I feel. How would anybody feel, right? But after I tested positive for hep C, like the nurse, I didn't feel comfortable with her, so I didn't talk to her about it but I don't know about the HIV.

Figure 11 PROVISION OF PRE- AND POST- HIV TEST COUNSELLING



A few women also expressed concern that it took many weeks or months to receive their test results.

A smaller number of women expressed satisfaction with the pre- and post- test counselling they had received. One participant spoke of an "open door" at the facility.

They ask you there and then the nurse also calls you back again just to sit down and talk to you and answer any questions if you want it done. If you say "No" she'll say "OK. I'll get back to you in a couple of days, to let you think it over if you want and if you decide not to she says my door is always open."

Another woman felt all her questions had been answered:

Interviewer: Do you know if pre- and post- test counselling is available for women who want to be tested for HIV?

Participant: Yeah. When I went and talked to [the nurse] I asked her all those questions and she said "If your tests were to come back positive, we'd do the test again just to make sure. And then we also sit down and answer any questions, and we'll give you all the information that you need."

Women who had access to an external public health nurse expressed particular satisfaction with the service they had received. In these cases, the women felt that

the process was more confidential, the results were received more quickly, and that there was easier access to follow-up counselling and information.

Conclusions

- The uptake of both HIV and HCV testing services by women prisoners was very high.
- Provision of pre- and post- HIV test counselling was very inconsistent. 2/3 of the women reported no counselling as part of their testing.
- 1 in 10 women tested for HIV did so because they believed it to be mandatory.
- Women able to access external public health nurses for testing were very satisfied with the service.

Gaps Identified

1. Pre- and post- HIV test counselling was not consistently provided.
2. *Commissioner's Directive 821* does not mandate that post-test counselling be conducted following an HIV negative test result, which contravenes best practice in the community.
3. Some women experienced significant delays in receiving their test results.
4. There was confusion as to whether HIV testing was voluntary or mandatory.
5. Anonymous HIV testing was not available as an option.

Elements of Good Practice in the Provision HIV/HCV Testing

1. Pre- and post- test counselling must be a mandatory component of HIV/HCV testing practice in all institutions. This must include clear explanation of the voluntary nature of such testing.
2. Various testing options should be available, including anonymous testing and testing using external public health nurses.
3. Delays in providing HIV and HCV test results should be minimized.

Recommendations

1. CSC should ensure that the provision of HIV and HCV testing for prisoners reflects these elements of good practice in all institutions.
2. *Commissioner's Directive 821* should be amended to require pre- and post-test counselling be a mandatory component of testing practice across the system, regardless of test result.
3. CSC and public health departments/community health centers should continue collaboration in providing testing services, and expand wherever possible.
4. CSC should provide the option of anonymous HIV testing for women prisoners.

CONFIDENTIALITY

The issue of confidentiality in prisons is multi-faceted, and was evidenced in various ways in the research findings. The most obvious relates to the security of personal information such as medical records, and the related concerns about keeping one's

health information a private matter. However, the study findings demonstrated other ways that confidentiality must be considered when addressing the issue of HIV and HCV in prisons. Many of these might not be specifically identified as “confidentiality” issues by the women themselves, but upon analysis are clearly related to concerns about privacy.

The fear of being “seen” to access HIV and HCV programs and services is evident in almost every area.

Perhaps most significant is the degree to which confidentiality considerations influenced women’s decisions about whether to access or participate in HIV/HCV prevention and care programs. This fear of being “seen” to access HIV and HCV programs and services – and the fear of the resulting stigma – was evident in almost every area in this report. A related concern was that of identifying oneself as being involved in risk behaviours in the institution – such as sex or injection drug use – that discouraged women accessing prevention measures.

Study findings relating to issues of confidentiality or privacy are evident in every section of this report. Some examples include,

PREVENTION EDUCATION

- The desire that HIV/HCV prevention education pamphlets and booklets be made more discreet.
- The desire that HIV and HCV educational pamphlets not obviously state their content on the cover, as this would allow women to access them and read them without disclosing their interest in the topic.
- Concerns about privacy/trust in accessing Peer Health Counsellors.

PREVENTION AND HARM REDUCTION MEASURES

- Lack of confidential access to safer sex measures and bleach. In particular the barriers identified in institutions where accessing these measures necessitated making requests to staff, thereby identifying oneself as involved in prohibited activities.
- The fear that requesting bleach from staff would result in cell searches and other punitive actions against the women.
- The equation of “accessibility” of harm reduction measures with the lack of staff involvement in obtaining them.

HIV AND HCV TESTING

- The significant satisfaction expressed by women who were able to access external public health nurses for testing. A major factor in this satisfaction was the feeling that the process was more confidential, as it did not directly involve CSC staff.

COMPLEMENTARY AND ALTERNATIVE THERAPIES

- The fear that accessing these therapies would draw unwanted attention to the women obtaining them.

SPECIAL DIETS

- The fear that receiving a special diet singles women out for unwanted scrutiny from other prisoners and staff.

COUNSELLING AND SUPPORT

- The significant satisfaction expressed by those women who were able to access external public health nurses and/or community-based organizations. A major factor in this response was the feeling that these services provided greater confidentiality.

It is therefore evident that the issue of confidentiality was integrally linked to satisfaction with services, and affected decisions about participation in or access to programs. This is a significant finding, as it demonstrates the degree to which the

Confidentiality must be addressed as a central element in the design and implementation of all HIV/HCV programs and services as an essential element of good practice.

issue of confidentiality must be addressed as a central element in the design and implementation of all HIV/HCV programs and services in prisons. It is an essential element of good practice.

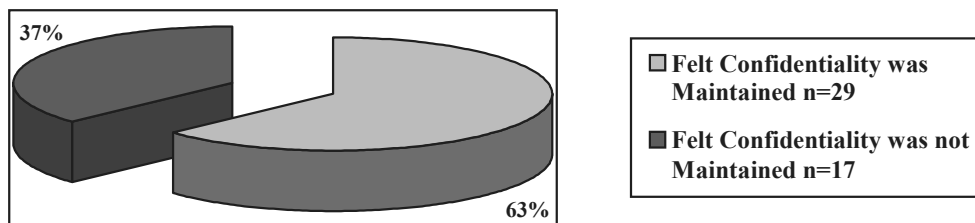
In addition to the findings above, 46 women discussed the issue of confidentiality in more direct terms.

63% of this group (n=29) felt that confidentiality was maintained in the institutions. However, of the

17 women who felt confidentiality was *not* maintained, nearly half (n = 8) were either HIV positive or HCV positive. This would indicate that women living with HIV and/or HCV had greater fears about confidentiality, and/or were more likely to have experienced a confidentiality breach while in prison.

Specific areas where women highlighted concerns about confidentiality included the distribution of medications (i.e., lining up to receive medications); the scheduling of HIV/HCV testing services (i.e., always on the same day/time); the accessing of complementary or alternative therapies; the accessing of special diets; the accessing of peer counsellors [see Section 7.2]; and the accessing of safer sex measures and bleach from staff [see Section 7.3]. Each of these activities had the potential for singling a woman out, and provoking questions from prisoners and staff about why she was accessing such services.

Figure 12 CONFIDENTIALITY IN PRISONS



Concerns were also expressed about confidentiality being violated by staff talking to each other and prisoners talking to each other.

Women who had access to external public health nurses felt this offered greater privacy, as medical information was maintained by an outside source.

Conclusions

- The issue of confidentiality is multi-faceted, and was a central issue underlying many aspects of HIV and HCV programs and services in prisons.
- Issues related to confidentiality and privacy were integrally linked to satisfaction with programs and services, as well as their accessibility.
- Confidentiality was a central element of good practice in all HIV and HCV programs and services within the prison environment.
- Women were generally satisfied with the level of institutional confidentiality.
- Women living with HIV and/or HCV were generally dissatisfied with the level of institutional confidentiality.
- Breaches of confidentiality occurred both from staff and other prisoners.
- Women who had access to an external public health nurse felt this service offered greater confidentiality than did the prison health unit.

Gaps Identified

1. Methods of providing health services such as testing, the distribution of medications, and the provision of special diets, etc. can potentially compromise women's confidentiality.
2. Issues of confidentiality were not always considered in structuring HIV/HCV education programs, medical services, and support counselling.
3. Confidentiality breaches by staff were reported.

Elements of Good Practice in Promoting Confidentiality

1. Confidentiality is an essential element of good practice in the provision of all HIV/HCV programs and services, and is not limited solely to the provision of medical services.
2. Maximizing confidentiality and privacy should be addressed as a central element in the design and implementation of both correctional and community-based programs.
3. Providing choice in HIV/HCV programs and medical services – including correctional, public health, and community-based sources – can improve access by increasing prisoner confidence in the confidentiality of services.
4. Proactive policy guidelines and staff training are an important element of promoting institutional confidentiality on HIV and HCV. Such policy should include clear procedures and sanctions for confidentiality breaches.

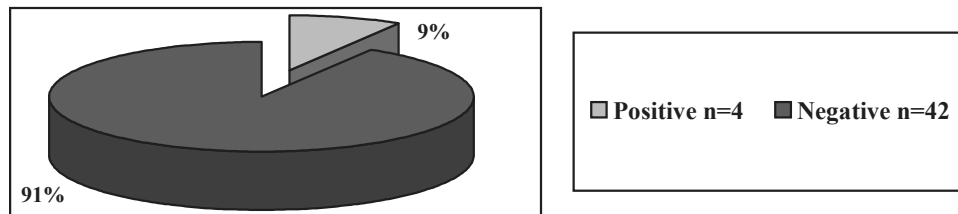
Recommendations

1. CSC, public health departments, community health centers, and community-based organizations should ensure that all HIV and HCV programs and services reflect these elements of good practice in all institutions.
2. CSC should make every effort to improve the level of institutional confidentiality, particularly in the case of HIV and HCV infection. This must include improving the security of medical information, and the revision of routine health services such as testing procedures, medical appointment scheduling, and the medication distribution that have the potential to inadvertently disclose confidential information.
3. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV services, and expand wherever possible.

7.5 Medical Care and Treatment

There was significant dissatisfaction with the level, availability, and quality of CSC health services. Satisfaction/dissatisfaction with medical services was an issue addressed by 46 women. Of this group, only 9% (n=4) indicated that their experience in accessing health care was positive.

Figure 13 EXPERIENCE WITH HEALTH SERVICES



The negative experiences identified by the women fell into several specific areas.

ACCESS TO HIV/HCV MEDICAL SERVICES

Women expressed mixed experiences in accessing basic HIV/HCV medical services. Levels of satisfaction with existing services varied between institutions, and often within institutions. The two most common concerns identified were accessing blood work and accessing physicians/specialists.

Access to routine blood work (i.e., to test liver functioning, for viral load testing, to measure blood sugar levels) was a common problem identified by 33% (n=15) of the women. This group was spread across 5 different institutions, which would indicate a broader systemic concern.

The need to request blood work, rather than have it performed as a matter of routine, was a common theme mentioned by many women, as was the waiting time between taking the blood and receiving the results. In some cases, results were available in a

Aboriginal women more frequently reported a lack of access to blood work.

week. In others it took three months or longer. In some cases, a lack of routine blood testing resulted in significant delays in accessing care.

Some of the Aboriginal women noted an apparent inequality in access to medical care, and a few commented that regular blood work was available to “*some women*”. Women who identified as Aboriginal more frequently reported a lack of access to regular blood work. 53% of the women reporting this problem (n=8 of 15) were Aboriginal women.

Satisfaction with current access to physicians and specialists was similarly mixed. While some women identified positive experiences in their care, and regular access to physicians and testing when needed, others (34%, n=17), identified problems. Of this group, 41% (n=7 of 17) were Aboriginal women.

The following exchanges illustrate some of inconsistencies in access identified in the research.

Interviewer: Do women in this institution have a choice of the type of medical care they receive and do they receive regular testing?

Participant: Yeah. He [the physician] comes in and we talk about it. When you're hep C, they hook you up with this specialist right away and they do regular blood work and liver biopsy.

However, the following HCV positive woman at the same institution expressed a very different experience.

Interviewer: Do you receive regular blood work to test your liver?

Participant: I didn't even know anything about that, 'cause when I came in here she told me I had to do a liver thing and I said “OK” and then I had to request it myself. I had to tell them.

Interviewer: They don't encourage you to get regular liver testing?

Participant: No. It's too much stuff, in my opinion anyway, for them to be doing all the blood work. It's too much for them.

Delays in accessing appointments with specialists were a barrier identified by 20% (n=9) of the women.

You have to put in a request and then like, maybe three weeks from now when you're on the list then you get to see him. But by then the problem's gone, or it's not bothering you anymore.

Another woman identified a lack of staff escorts for medical appointments as a source of delay.

They can put me on the list, but then it depends when a guard can take me. There's a shortage of staff and it can take months.

While hepatitis C specialists were reported to be more readily accessible than others, several women reported not being able to see one, or facing problems doing so. In some instances there was a lack of knowledge of the availability of specialists, and some women (n=5) were not sure whether any options were available at all.

A final concern identified was the lack of access to female physicians at some institutions. Women not wanting to be examined by male doctors therefore faced significant barriers to care, as described by one woman, *“They are male doctors [and] I won’t do it. I won’t. I haven’t had one [examination] since I went back. I won’t. I refuse.”*

Conclusions

- There was an overall dissatisfaction with the quality and accessibility of medical services.
- Women’s experiences in accessing basic medical services varied significantly across the system, and often within institutions.
- Aboriginal women faced increased barriers in accessing blood work, and more often identified problems accessing physicians as desired.

Gaps Identified

1. Access to medical services was inconsistent.
2. Barriers existed in accessing routine blood work. These included difficulty in accessing regular routine testing, and delays in receiving results.
3. Aboriginal women experienced increased barriers in accessing some medical services.
4. Delays in accessing medical specialists existed in many institutions.
5. There was a lack of access to female physicians in some institutions, which resulted in some women refusing or avoiding care.

Elements of Good Practice in Promoting Access to HIV/HCV Medical Services

1. The standard of medical care provided to prisoners must be comparable to that available in the community.
2. Adequate financial and human resources should be provided to prison medical units to enable them to meet the above objective.
3. Annual training should be provided for medical staff to enable them to keep their skills and knowledge current with emerging best practice. This is particularly true in the areas of HIV and HCV care and treatment.
4. Prisoners should be empowered to play an informed and proactive role in decisions made about their health care.
5. Choice should be provided in access to medical services and practitioners – including both correctional and external health service providers.
6. Delays in access to physicians and medical specialists should be minimized.
7. Management of prison health services should be removed from the responsibility of correctional services. According to UNAIDS, “Experience in a

range of prison systems has shown that health care in prisons can be delivered more effectively by public health authorities than by prison management.”³⁵

Recommendations

1. CSC should ensure that the provision of HIV/HCV medical services reflects these elements of good practice in all institutions.
2. CSC and community-based HIV/HCV organizations should provide accessible medical information to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about their health care.
3. CSC should work to minimize barriers to accessing blood work. This is particularly true for Aboriginal women, and for women living with diseases such as HIV, HCV, and/or diabetes where regular blood testing is a crucial diagnostic tool and component of health care provision.
4. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV services, and expand wherever possible.
5. CSC should provide female physicians in all women’s institutions.
6. The Government of Canada and the provincial Ministries of Health should negotiate transfer of management of prison health services from CSC to provincial health authorities.

ACCESS TO PAIN MANAGEMENT MEDICATION

Chronic pain can be a symptom of both HIV and HCV infection. As a result, access to effective pain management is a common health concern for people living with these diseases. The study sought to collect information on women’s access to pain

Only one woman reported feeling she had a voice in the selection of her pain management.

medication. Data on this topic was available on 24 women, all of whom self-identified as HIV positive, HCV positive, or dual infected. .

Pain medication available to the women consisted predominantly of over-the-counter drugs such as “Motrin”, “Tylenol”, “Ibuprofen”, “Bufferin”, and “Advil”. Only 2 women were receiving prescription pain

medications. Ten women had not received any pain management medications at all.

Barriers to accessing pain management were common in all institutions. As described by these women,

Participant 1: They don't give nothing for pain here.

Participant 2: [It's] not very good. Girls get sick and they can't even walk. They're so sick and they don't give them nothing.

A common theme expressed by many women was a lack of information, input, and consultation in the development of their pain regimen. For example, 42% of the

³⁵ Joint United Nations Programme on HIV/AIDS (UNAIDS), *Prisons and AIDS: UNAIDS technical update*. (Joint United Nations Programme on HIV/AIDS, Geneva: April 1997). p.7. Available online at www.unaids.org.

women (n=10 of 24) reported having no choice in their pain medication selection. 29% (n=7) did not know what pain medications they were given (if any). Two women reported being chronic injection drug users who had been told they were not allowed to receive any pain medications. Only 1 woman reported feeling she had a voice in the selection of her pain management.

A related issue, particularly for women living with HIV and/or HCV, was a lack of access to medications for relief of the sometimes severe side effects of HIV and HCV therapies. Of the 28 women who identified this as an issue, only 14% (n=4) reported receiving any type of medication for side effects. Two of these women had been given "Gravol", 1 woman received "Tylenol", and another had been given "Aspirin". Nine women were not sure what medications were being given for side-effects.

There was also evidence that women were not always properly informed about side-effects (real and imagined) of HIV and HCV therapies. In one extreme instance, 10 women in one facility reported discontinuing their hepatitis C medications due to concerns about believed side effects. Their concerns had started after noticing one woman losing her hair.

I know that the women that were on it were having symptoms before they took the medication. While they were taking the medication they turned those women into a state of hysteria, telling them things that were happening to them as a result of the medication. So they stopped taking it. Like some woman was losing her hair. She was losing her hair before she took the damn medication. But during the course of taking the medication she was like three months into it, her hair was still falling out and they were going, "Oh, that's a side effect." So she stopped taking it.

Conclusions

- Access to pain management was a significant concern for women living with HIV and/or HCV.
- Barriers to accessing pain management existed for women living with HIV and/or HCV in all institutions.
- Over-the-counter medications were the most commonly accessed medications for pain. Prescription pain medications were much less common.
- Barriers existed to accessing medications to relieve the side-effects from HIV and HCV therapies

Gaps Identified

1. Lack of access to prescription pain management.
2. Barriers to accessing pain management for illegal drug users.
3. Lack of access to medications to relieve side-effects of HIV/HCV therapies.
4. Lack of information, input, and consultation reported by many women in the development of their pain regimen.

Elements of Good Practice in the Provision of Pain Management

1. Access to pain management medications – including prescription narcotic medication – must be provided in a non-discriminatory fashion.
2. History of illegal drug use should not preclude access to pain management.
3. Ongoing training should be provided for health care staff and physicians on the relationship between HIV and HCV infection and chronic pain, and on current best practice in the management of HIV/HCV related pain.
4. Prisoners should be empowered to play an informed and proactive role in decisions made about a pain management plan.

Recommendations

1. CSC should ensure that equitable access to pain management for women living with HIV and/or HCV is available in all institutions, and that the provision of pain management medication reflects these elements of good practice.
2. CSC and community-based HIV/HCV organizations should provide accessible information on pain management to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about pain management options.
3. CSC should ensure equal access to medications for the relief of side-effects in all institutions. This should include ensuring that information and consultation is provided to women living with HIV and/or HCV to assist them in making informed choices about their options.

ACCESS TO COMPLEMENTARY AND/OR ALTERNATIVE THERAPIES

Many people living with HIV/AIDS use of a variety of complementary or alternative therapies – including traditional Chinese herbs and acupuncture, vitamins and other supplements, massage, and spiritual healing – to address HIV and its related symptoms.³⁶ The study sought to assess women’s access to such “non-mainstream” health promotion options. Data on this topic was available on 25 women. Of this group, 60% (n=15) self-disclosed and living with HIV, HCV, or both.

Overall, access to complementary therapies was limited, and consisted primarily of vitamins (n=25). A smaller number (n=8) of women had access to alternative therapies such as chiropractors, massage, and reflexology.

Significant barriers were identified in accessing vitamins, the most common being the cost. While some women had their vitamins prescribed by a physician, and were therefore provided them by the prison health unit, more than half of the women taking vitamins had to purchase them themselves through the canteen or through outside sources. Given the limited financial resources available to most prisoners, this situation created a major barrier, as described by one participant.

³⁶ Yvonne J. Bryson, MD. “Complementary Therapies in HIV Disease” in *Improving the Management of HIV Disease*, Vol. 4, No. 3 (International AIDS Society, USA: September 1996). Available online at www.ama-assn.org/special/hiv/library/readroom/other96/abrams.htm

You get...say \$69 dollars. They take off 10%. That goes into your savings. And then you take off a dollar for the inmate welfare fund. If you have cable [TV], they take off four dollars for cable. So that leaves you somewhere around \$55. That goes into your current account. That is where all your spending comes out of for outside shopping, for photographs, for anything like that. Then out of that account you stipulate how much you are going to spend on canteen and you say, "I want \$50 taken out of my pay for my canteen". So they'll take \$50 out of your \$58 leaving you \$8 dollars in your current and put it [\$50] into your canteen. So whatever you don't spend...on canteen goes back into current. So you figure a bottle [of vitamins] In this place will probably be around \$15...If I remember rightly you have to take it two times a day...One to two pills. So you would be taking 30 pills a week roughly. Right? In a jar there are maybe 100. So that would last you three weeks. We only do shopping once a month. She would have to buy 2-3 bottles. So you are looking at \$30-\$35 just on that one thing. So she would have to decide if she needs her milk thistle or soap. They provide soap from the store, but maybe that is not the kind she can use. So she has to buy her own soap. Or laundry detergent because we don't trust that stuff that they give us. That is \$14 for a big box. You can only make transfers of \$500 a year. So what if she needs pantyhose...know what I mean. You can't live.

Several of the women (n=4) who disclosed themselves as being either HIV positive or HCV positive also identified confidentiality concerns in accessing complementary or alternative therapies. Among this group, there was a feeling that to access such therapies was to "centre yourself out", which they did not perceive being safe to do.

Conclusions

- Access to complementary and/or alternative therapies was a significant concern for women living with HIV and/or HCV.
- The most commonly accessed complementary therapy was vitamins. Access to alternative therapies were less common.
- The majority of women accessing complementary and/or alternative therapies were living with HIV, HCV, or both.
- Some women expressed confidentiality concerns about accessing complementary and/or alternative therapies for fear of being singled out.

Gaps Identified

1. The need for many women to purchase vitamins themselves lead to significant barriers in access due to the prohibitive cost.
2. Lack of access to other forms of complementary or alternative therapies.
3. The potential for disclosure of serostatus by virtue of receiving complementary and/or alternative therapies.

Elements of Good Practice in the Provision of Complementary and/or Alternative Therapies

1. Access to complementary and/or alternative therapies should be available to all women living with HIV and/or HCV as a health promotion measure. In practice, it is preferable to improve access for all prisoners, regardless of serostatus, as this would minimize confidentiality concerns for women living with HIV and/or HCV who would otherwise be singled out by receiving them.
2. Where women are receiving complementary or alternative therapies (such as vitamins), they should be provided in as discreet a manner as is possible.

Recommendations

1. CSC should ensure that the provision of complementary and/or alternative therapies reflects these elements of good practice in all institutions.
2. CSC should make vitamins available without charge to all prisoners requesting or prescribed them as part of a broader health promotion initiative.
2. CSC should not limit free access to vitamins solely to women living with HIV and/or HCV as this creates confidentiality concerns. The more common vitamin access becomes, the less it singles out individual women for scrutiny.
3. CSC and community-based HIV/HCV organizations should provide greater information on complementary and/or alternative therapies, particularly for those women living with HIV and/or HCV.
4. CSC should expand the availability of complementary and alternative therapy options for women living with HIV and/or HCV.

DIET AND NUTRITION

Access to a well balanced and health diet is an important element of health promotion for people living with HIV and/or HCV. Diet is also an integral component of the proper use of some HIV therapies.³⁷ Therefore, the study sought information on women's satisfaction with the standard of diet and nutrition. Data on this topic was available for 32 women.

21 women identified poor food quality as an issue. All were living with HIV and/or HCV.

In general, women were unsatisfied with the quality of food provided and experienced limited access to special diets. 66% of the women (n=21 in 5 different facilities) identified poor food quality as an issue. Significantly, all of these women were living with HIV and/or HCV.

Common concerns identified included the use of powdered milk instead of real milk, a scarcity of greens and fresh vegetables, and the frequent serving of prepared foods that tended to be very greasy and fatty. Some women also identified a difficulty in accessing pure water (water not containing sodium).

As the following woman living with HCV explains, it was difficult to obtain a well-rounded or proper diet.

³⁷ Lines, p.81.

[We] don't have proper food, you know? They should have a dietician that goes off to the cooks and tell[s] them again about the guide, the food guide. That's what they should do. But they're not doing that. They should do something like that because we're not getting proper food, you know? It's just grease and fatty food, you know? I don't need that. No. I need bran. Especially with my liver, 'cause you need high fiber. And you gotta drink lots of water and stuff. I mean I get fruit, vegetables, but something has to be done.

Given the importance of proper nutrition for promoting the health of people living with HIV and/or HCV – and for the optimal use of some HIV anti-retroviral therapies – the issue of diet and nutrition takes on added significance. One woman stated,

I know a girl, a girlfriend of mine who's just starting a bout of anti-virals...I'm at the point where I could be starting them too. But I don't think this is the place to be starting them, a big bout of medication, because [for] a lot of those you're supposed to have five small meals with them.

Two women decided not to take medications for HIV or HCV due to a lack of access to a diet appropriate to offset the side-effects of the medications.

At some facilities, special diets were available upon request from the health unit. These primarily fell into the categories of lactose free and vegetarian diets. However, even where special diets were available, women often reported difficulty accessing them. Information on the availability of special diets was inconsistent, as was knowledge of how to request them. Some women living with HIV and/or HCV also identified confidentiality concerns about accessing special diets, feeling that receiving different meals would single them out. One woman reported having problems even getting a diabetic diet, as sugar was often added to foods. Some women also identified difficulties accessing nutritional supplement drinks such as “Boost”.

However, some institutions appeared to provide a better dietary standard. For example, 8 women in 2 institutions felt the food supplied was good and they had access to special diets as needed. One facility had also recently made improvements to its diet for people living with hepatitis C. This indicates an inconsistency in the provision of proper diets from region to region.

Conclusions

- The standard of diet and nutrition provided was generally seen as unsatisfactory in most institutions.
- Women living with HIV and/or HCV in most institutions strongly identified the need for an improved standard of diet and nutrition.
- Standards of diet and nutrition were inconsistent across the country. Some institutions were seen to provide a good diet, while others were not.
- Access to special diets was inconsistent across the country. Some institutions were seen to provide good access, while others were not.

- Information about the availability of special diets and how to access them were inconsistent.

Gaps Identified

1. Inconsistent standards of diet and nutrition provided across the system.
2. Inconsistent access to special diets across the system.
3. Lack of information about the availability of special diets and the procedure for requesting them in some institutions.
4. Difficulty in accessing nutritional supplement drinks in some institutions.
5. The potential for disclosure of serostatus by virtue of receiving special diets and/or nutritional supplement drinks.

Elements of Good Practice in the Provision of Diet and Nutrition

1. The diet for all women living with HIV and/or HCV should meet or exceed those set in the *Therapeutic Nutrition Guidelines in HIV/AIDS*. In practice, it is preferable to improve the overall dietary standards for all prisoners to meet the *Guidelines* as this will minimize confidentiality concerns for women living with HIV and/or HCV who would otherwise be seen to be receiving different meals.
2. Special diets for women living with HIV and/or HCV should be easily and consistently available. This should include access to nutritional supplement drinks.
3. Where women are receiving special meals or nutritional supplements, they should be provided in as discreet a manner as is possible.
4. Information on the availability of special diets, and the process for requesting them, should be widely available.
5. Accessible information on the importance of diet and nutrition as a health promotion strategy should be made available to women living with HIV and/or HCV to assist them in making informed decisions about their diet.

Recommendations

1. CSC should ensure that its provision of diet and nutrition to women living with HIV and/or HCV reflects these elements of good practice.
2. CSC should review its dietary standards for prisoners living with HIV and/or HCV to ensure it is consistent with the *Therapeutic Nutrition Guidelines in HIV/AIDS*.
3. CSC should ensure that a consistent standard of diet and nutrition is provided in all regions.
4. CSC should ensure that information on the availability of special diets is made more accessible.
5. CSC and community-based HIV/HCV organizations should provide accessible information on diet and nutrition to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about their diet.
6. CSC should ensure that barriers to accessing nutritional supplements are minimized, particularly for those women living with HIV and/or HCV.

7.6 Support, Counselling, and Information

In general, there were four separate groups from whom the women identified receiving support and/or counselling – prison health care/medical staff, community-based groups, Elders, and correctional officers.

Despite these options, women generally expressed the opinion that greater and more varied support services – including both group and individual counselling – were needed. One illustration of this is the fact that 10 women reported not receiving any support from any of these groups, and one other woman was not sure what would have been available to her. This indicates that gaps exist in the current structures.

However, the most significant gap was evident in services specifically for women who were living with HIV and/or HCV. For these women (n=20), very little support was reported. Only 1 of the 20 women reported feeling she was receiving good support, and another said she felt she was having her questions answered. Twelve women

Only 1 of 20 women living with HIV and/or HCV reported feeling she was receiving good support.

reported not receiving any additional support around their HIV/HCV infection, and 14 were not aware of any HIV/HCV related support services. This indicates a significant gap in the availability and accessibility of HIV and HCV support services for incarcerated women.

Conclusions

- Although support and counselling services were available from a variety of sources, women generally felt that the current programming did not meet their needs.
- Women living with HIV and/or HCV strongly identified a lack of support and counselling services.

Elements of Good Practice in the Provision of Support, Counselling, and Information

1. The standard of HIV/HCV support and counselling services provided to prisoners should be comparable to that available in the community.
2. Choice should be provided in access to HIV/HCV support and counselling services and practitioners – including both correctional and external/community-based service providers.
3. Access to HIV/HCV support and counselling from both correctional and external/community-based services should be consistent across all institutions.
4. HIV/HCV support and counselling services of both correctional and external/community-based sources must be available on a consistent and reliable basis within each institution.
5. Delays and barriers to accessing support and counselling services should be minimized.
6. All HIV/HCV related support, counselling, and information services should be provided in a discreet and non-identifying manner that maximizes the confidentiality of women accessing the services.

Recommendations

1. CSC, Health Canada, public health departments/community health centers, and community-based organizations should ensure that all support and counselling services reflect these elements of good practice.
2. CSC, Health Canada, public health departments/community health centers, and community-based organizations must ensure that support and counselling services are expanded to meet the identified needs of incarcerated women.
3. CSC, Health Canada, public health departments/community health centers, and community-based organizations must ensure that support and counselling services for women living with HIV and/or HCV are expanded and made consistently accessible in all institutions.

Support Received from Prison Health Care/Medical Services

Prison health care/medical services were the single largest source of support, counselling, and information on HIV and HCV identified by the women. Data on this issue was available from 141 women.

Prison medical services were the largest source of support, counselling, and information on HIV and HCV.

Most women reported positive experiences using prison health care and found health staff to be very helpful. This response was evident in all regions. Thirty-four women felt that the prison health service had been very helpful when utilized. A few women reported that, in particular, at least one nurse or doctor in health care had been helpful and made them feel comfortable.

This is all kind of new to me. I just found out a couple of weeks ago so I don't know if it's really sunk in yet. It helps to talk to the girls in here too, and the nurse has been very helpful. I feel comfortable with her.

Seven women reported having their questions answered and addressed when raised. However, some others explained that staff with more lived experience would be helpful to provide less “book” answers.

Interviewer: Was it helpful?

Participant: Yeah it was helpful, but again, we need someone to come in and sit down and talk to the women from experience.

Interviewer: Have you found the same thing?

Participant 2: Yeah.

Sixteen women had never asked for support because they felt medical care staff was too busy or they had simply never thought to ask them. Another 5 women reported not having any questions to ask. Four women reported they would not use health

care as a resource and another 4 reported they did not trust staff because of misinformation they had received.

Despite this overall positive response, there were some areas of concern identified. Accessibility was one, in that some institutions required appointments to go to the health care unit to ask questions. Several women reported they could not simply visit the health unit, but must have an appointment booked in advance. As appointments could often be difficult to obtain, or take some time to schedule, this delay meant in some cases that by the time the appointment arrived, the question had been forgotten. Women serving longer sentences had a perception that their waits were longer than those of women with shorter sentences, and that their requests were often put off in favour of women being released sooner.

A small number of women (n=2) reported rude or disrespectful treatment from nurses. One woman who was an intravenous drug user felt she had been "looked down upon" by the doctor because of her drug use.³⁸

Several other women felt they were given vague or different answers.

Especially specific ones... I still don't know the answer to this question. How long is the window period? Like, I've been in for nine months. I've been tested twice for HIV. Negative both tests. So, am I clean? I don't have to get tested again? I keep asking this. I keep getting different answers.

A lack of education was also mentioned at one facility where the staff was reported to be very young.

In terms of women living with HIV and/or HCV, 60% of this group (n=12 of 20) obtained support from various health care practitioners (i.e., nurse, alcohol and drug counsellor, psychologist, health care staff). Access to group and individual counselling through health services was mentioned by a few of these women (n=4). However, 1 woman commented that even though health care knew she had hepatitis C, they did not contact her and she instead had to approach them for information.

As discussed in other sections, women who were able to access external public health nurses for HIV and HCV issues were very satisfied with the service.

Conclusions

- Prison health care/medical services was identified as the single largest source of support, counselling, and information for all women, regardless of HIV/HCV status.
- Some barriers existed to accessing health care staff for support, counselling, and information. These included the perception that health care staff were too

³⁸ This would be a concern that is also documented by other researchers. See Gilles Bibeau et Marc Perreault, *Dérives montréalaises: À travers des itinéraires de toxicomanies dans le quartier Hochelaga-Maisonneuve* (Montréal: Boréal, 1995) and Claire Lahaie, "Prévention de la transmission - Au front - Une expérience novatrice," dans Gaston Godin, Joseph Josy-Lévy et Germain Trotter, eds. *Vulnérabilités et prévention VIH/Sida: Enjeux contemporains* (Sainte-Foy, Québec: Presses universitaires de l'université Laval, 2002): 257-264.

busy to provide assistance, and the need in some institutions for appointments to visit the health unit.

- Women preferred health care staff to have a well-rounded knowledge of HIV and HCV issues.
- Women able to access external public health nurses for information and counselling were very satisfied with the service.

Gap Identified

1. Barriers to accessing prison health care units for information or support exist – or are perceived – in some institutions.

Recommendations

1. CSC should ensure that all support and counselling services provided by prison health care/medical staff reflect the elements of good practice.
2. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV support and counselling services, and expand wherever possible.
3. Given their primary role in providing HIV/HCV related information and support services to incarcerated women, CSC should ensure that all prison health care/medical staff receive annual training on HIV and HCV issues to support them in maintaining current knowledge.
4. CSC should ensure that barriers deterring women from accessing health care staff for information and support on HIV and HCV are minimized.

Support Received from Community-based Groups

Community-based groups and organizations were another sector from which women identified receiving support. Data on this issue was available from 120 women.

Thirty-three women who had access to community groups identified very positive experiences. Comments such as “*you build this rapport with these people*” and “*they answer questions I didn’t know I had*” were made by several women. Of these 33 women, 10 were Aboriginal and 10 were self-identified injection drug users. This may indicate that these populations, who often face additional barriers within the institution, benefit more significantly from access to community-based programs.

Twelve women identified that the information they received from community-based organizations was very helpful. Factors such as the availability of experienced people and educational resources were identified as sources of satisfaction with community-based services, as the following woman explains:

It’s kind of nice to have someone come in that’s been there, not just like a health professional. You feel a little more at ease with someone who knows the way you’re feeling.

Women expressed difficulty accessing community-based groups that did not accept collect phone calls.

Five women had not attended any of the community group sessions at their facility. Thirteen women had never asked community groups about HIV and/or hepatitis C, partly because in some cases only church groups had attended.

The largest concerns women raised revolved around obtaining access to community groups. Thirty-three women from 5 different facilities reported that no

community groups were currently coming to their institution, and another 15 participants reported contact with only a few (i.e., church groups, university research teams, public health, PASAN).

As discussed in Section 7.2, AIDS service organizations (ASOs) were identified as providing services on only an infrequent basis in some institutions. In terms of women living with HIV and/or HCV, only 30% (n=6 of 20) received assistance from community-based health organizations (i.e., ASOs, PASAN, People With AIDS Society, Hepatitis C Society). This would indicate a significant gap in some regions in terms of community-based services specifically intended for incarcerated women living with HIV and/or HCV. Some women expressed further difficulty in accessing community-based groups that did not accept collect phone calls.

Overall, women had very positive experiences with community groups, and desired greater access to them. 62% of the participants (n=96) expressed the preference to have community groups host support programs and services. This clearly indicates a significant level of trust and confidence in community-based services, which is also evident in the positive feedback that the women gave about services provided by external public health nurses.

Conclusions

- Women generally had very positive feedback on the value of community-based programs. They identified greater levels of trust with community-based services, and confidence in the information provided.
- A majority of women preferred that community-based groups host support programs, rather than correctional services.
- Access to community-based services – particularly from AIDS service organizations – was inconsistent across the country. This was particularly true for women living with HIV and/or HCV.
- Women wanted more access to community-based programs than was available.

Gaps Identified

1. Inconsistent provision of services to incarcerated women by community-based organizations, particularly by AIDS service organizations.
2. Inconsistent provision of services to incarcerated women living with HIV and/or HCV by community-based organizations, particularly by AIDS service organizations.
3. Difficulty accessing some community-based groups, particularly organizations

that did not accept collect phone calls.

Recommendations

1. Community-based organizations should ensure that all support and counselling services reflect the elements of good practice.
2. Access to community-based services must be increased and made consistent across the country. This is particularly true for services provided by community-based HIV and HCV organizations. This necessitates increased commitment from community-based HIV and HCV organizations to providing services for incarcerated women, increased cooperation from CSC to accommodate community-based programs, and increased funding from Health Canada to support these services, especially at more isolated institutions.
3. Community-based HIV and HCV organizations must ensure that they accept collect calls from prisoners.

Support Received from Elders

Elders were identified as another source of support and counselling. Data on Elder services was available from 15 Aboriginal women.

Most Aboriginal women reported being able to access to Elders as often as needed. One woman commented,

I go twice a week I see the Native Elder.

A woman at another institution identified that Elder services were in place, although it had taken some amount of effort to establish access.

Well it took us awhile to get a Native Elder. You can only access what is available in here except at your own expense.

Aboriginal women living with HIV and/or HCV desired that Elders have greater knowledge about HIV and hepatitis C. They felt that this would allow the Elders to be more effective in understanding their experiences.

Interviewer: Do the Elders know much about hep C?

Participant: No, they don't know because a lot of these Elders, they come from the community and I think a lot of them need to be educated on the stuff cause they don't know.

In discussing HIV and HCV services, another Aboriginal woman said,

Participant: A lot of the Elders here they believe that disease isn't a Native way to resolve something, and I'm Native so...

Interviewer: You wouldn't talk to the Elders about those issues?

Participant: No.

In total, 47% (n=7 of 15) desired that their Elders have more knowledge on HIV and HCV issues.

Conclusions

- Aboriginal women generally expressed good access to Elders.
- Aboriginal women living with HIV and/or HCV desired that Elders be able to provide more information on HIV and HCV.

Gap Identified

1. Lack of specific HIV/HCV knowledge among some Elders.

Recommendation

1. Elders should seek to expand their knowledge on HIV and HCV in order to meet the needs of Aboriginal women living with HIV and/or HCV.

Support Received from Correctional Officers

Data on support received from correctional officers/guards was available from 73 women.

With minor exceptions, correctional officers were not viewed as a source for support of information on HIV and HCV.³⁹

The majority of the women (n=45, 62%) had never asked correctional officers for information about HIV or hepatitis C, for a variety of reasons. Approximately half had not thought about asking them. Others did not feel staff would have the information they desired, and therefore did not bother to ask. 19% of the women (n=14) had asked, but found the information they received either inaccurate or not available. Some women reported asking several staff questions, and then comparing the answers received. 12% (n=9) reported that when they had asked questions of correctional officers, the staff had felt uncomfortable and did not want to talk about the subject. A few women (n=4, 5%) had asked questions of correctional officers and reported they were knowledgeable and had answered their questions.

Conclusions

- Women did not view correctional officers as a source of support or information on HIV and HCV.
- Many correctional officers were unable or uncomfortable providing information on HIV and HCV when asked.

Gaps Identified

1. Lack of comfort in approaching correctional officers for HIV/HCV information.

³⁹ See also Godin, *et al.*

2. Lack of education on HIV/HCV issues among many correctional officers.

Recommendation

1. CSC should improve provision of training on HIV and HCV for correctional officers. Emphasis should not be limited to workplace safety issues.

8. Conclusion

Unlocking Our Futures represents the most comprehensive research project of its kind in Canada to date. Its findings present an important opportunity for policy-makers and health service providers to review the experiences of federally incarcerated women regarding HIV and HCV programs and services on a national basis.

The good practice recommendations contained in this report are intended as a tool to assist the Correctional Service of Canada, Health Canada, public health departments, community health centres, and community-based organizations assess what is working, what is not working, and what gaps still exist in our collective response to the HIV and HCV crisis in the Canadian prison system. Our task must now be to meet those needs by expanding access to those programs and services identified as good practice, and implementing new programs where current responses are either insufficient or non-existent.

However, the findings of this study have implications beyond the needs of the 156 women interviewed. Many of the issues raised and needs identified are equally as relevant to provincially incarcerated women, and provincial ministries of correctional services and health – as well as community-based organizations – must also consider these findings and adapt their programs and services accordingly. Similarly, many of the practices or policies identified are of relevance to federally incarcerated men, and must be taken into consideration in improving the response to HIV and HCV in male federal institutions.

9. Good Practice Recommendations

HIV/HCV PREVENTION EDUCATION

Elements of Good Practice

1. Informational materials on both HIV and HCV should be available in various forms. The information must be up-to-date, and presented in plain language.
2. Written materials on HIV and HCV such as pamphlets and books must be discreet. The content should not be disclosed on the cover.
3. Visual and video educational tools must be more widely utilized and accessible to women.
4. Provision of information on the risk of HCV/HIV transmission via crack and/or cocaine use must be increased.
5. HIV/HCV prevention programs must be widely advertised and promoted to ensure awareness and accessibility.
6. Community-based AIDS and HCV service organizations have an important role to play in complementing health programs provided by CSC.
7. The scientific literature demonstrates that, especially with respect to HIV and AIDS, there is a lack of communication and trust amongst prisoners and prison officials.⁴⁰ Therefore, correctional officers should not be present during HIV and HCV prevention programs.
8. Given the concerns about trust and confidentiality identified, the selection and training of participants in CSC's peer education program must be conducted in a manner that maximizes prisoner confidence in the initiative. This should include prisoner involvement in the peer selection process, as well as increased emphasis in the training on confidentiality.

Recommendations

1. CSC, Health Canada, and community-based organizations must ensure that all HIV and HCV prevention education initiatives reflect these elements of good practice.
2. CSC, Health Canada, and community-based organizations must ensure that access to women-specific HIV and HCV prevention education programs and materials are developed and made consistently available throughout the system. Programs must be offered on a regular and ongoing basis.
3. CSC should expand and strengthen the HIV and HCV components of current health programs such as CHIPS and RAPS.
4. Community-based HIV and HCV organizations must increase the provision of prevention education services to incarcerated women.
5. Health Canada must provide funding to assist community groups to provide the services described in point 4, particularly in rural and/or under-served institutions.
6. CSC must improve the current implementation of peer health programs, and ensure that access is consistent across the system. CSC staff must work in

⁴⁰ Godin, *et al.*

cooperation with prisoners to ensure that each program is developed and implemented to meet the specific needs of women in each institution.

CONDOMS, DENTAL DAMS, AND LUBRICANT

Elements of Good Practice

1. Adequate supplies of condoms, dental dams, and water-based lubricants must be made equally, consistently, and discreetly accessible within all institutions.
2. Access to safer sex measures should not necessitate making a request to staff, in accordance with *Commissioner's Directive 821*.
3. It is difficult to encourage safer sex practices in an environment that has a punitive ethos towards sexual relationships. Therefore, consensual sexual relationships within the institution must not be cause for increased staff surveillance, harassment, or disciplinary sanction.

Recommendations

1. CSC's policy to provide safer sex measures to prisoners must be continued, and should reflect these elements of good practice in all institutions.
2. CSC must ensure that condoms, dental dams, and water-based lubricants are equally and consistently accessible across the system. Access to dental dams and lubricants in particular must be improved.
3. CSC must ensure that *Commissioner's Directive 821* is observed in all institutions.

BLEACH

Elements of Good Practice

1. Bleach must be made generally and discreetly available to prisoners in various places in the institution.
2. Access to bleach should not necessitate making a request to staff.
3. Bleach must be provided in sufficient quantities to ensure that a constant supply is available, both for cleaning purposes and harm reduction purposes.
4. Full-strength bleach must be provided. Bleach supplies must not be diluted.
5. Fresh supplies of bleach must be maintained to ensure maximum efficacy as a harm reduction measure.
6. Information on the correct use of bleach for harm reduction purposes must be easily and discreetly accessible.

Recommendation

1. CSC's current bleach program must be continued and improved to ensure that it reflects these elements of good practice in all institutions.

METHADONE

Elements of Good Practice

1. Assessment criteria for methadone maintenance must be consistently applied within each institution, and across the system.
2. Information on the application process and selection criteria must be made clear and widely available to prisoners.
3. Access to/denial of access to a methadone program must not be used punitively or as a disciplinary measure.
4. Delays in accessing methadone related medical services must be minimized.
5. All medical staff must be provided adequate and ongoing training and support to assist them in managing the program.

Recommendations

1. CSC policy to provide methadone access to prisoners, including methadone initiation, must be continued.
2. CSC should monitor the implementation of Phase II of its methadone policy to ensure that it reflects these elements of good practice in all institutions.

STERILE SYRINGES

Recommendation

1. CSC should act upon the recommendations of the 1999 *Final Report of the Study Group on Needle Exchange Programs*, and pilot test needle exchange projects in all five regions of Canada, one of which must be in a women's institution.

SAFER TATTOOING AND BODY PIERCING MEASURES

Recommendations

1. CSC should eliminate current prohibitions and penalties for tattooing.
2. CSC policy should be changed to designate tattooing as a hobby-craft activity within all institutions.
3. CSC must make harm reduction measures, as well as appropriate materials to practice tattooing and body piercing safely, available to prisoners.

SAFER SLASHING/CUTTING INFORMATION

Recommendation

1. CSC and community-based organizations should develop and make accessible information on safer slashing/cutting and other forms of self-injury, as well as safer alternatives to self-injurious behaviour.

TESTING FOR HIV AND HCV

Elements of Good Practice

1. Pre- and post- test counselling must be a mandatory component of HIV/HCV testing practice in all institutions. This must include clear explanation of the voluntary nature of such testing.
2. Various testing options should be available, including anonymous testing and testing using external public health nurses.
3. Delays in providing HIV and HCV test results should be minimized.

Recommendations

1. CSC should ensure that the provision of HIV and HCV testing for prisoners reflects these elements of good practice in all institutions.
2. *Commissioner's Directive 821* should be amended to require pre- and post-test counselling be a mandatory component of testing practice across the system, regardless of test result.
3. CSC and public health departments/community health centers should continue collaboration in providing testing services, and expand wherever possible.
4. CSC should provide the option of anonymous HIV testing for women prisoners.

CONFIDENTIALITY

Elements of Good Practice

1. Confidentiality is an essential element of good practice in the provision of all HIV/HCV programs and services, and is not limited solely to the provision of medical services.
2. Maximizing confidentiality and privacy should be addressed as a central element in the design and implementation of both correctional and community-based programs.
3. Providing choice in HIV/HCV programs and medical services – including correctional, public health, and community-based sources – can improve access by increasing prisoner confidence in the confidentiality of services.
4. Proactive policy guidelines and staff training are an important element of promoting institutional confidentiality on HIV and HCV. Such policy should include clear procedures and sanctions for confidentiality breaches.

Recommendations

1. CSC, public health departments, community health centers, and community-based organizations should ensure that all HIV and HCV programs and services reflect these elements of good practice in all institutions.
2. CSC should make every effort to improve the level of institutional confidentiality, particularly in the case of HIV and HCV infection. This must include improving the security of medical information, and the revision of

routine health services such as testing procedures, medical appointment scheduling, and the medication distribution that have the potential to inadvertently disclose confidential information.

3. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV services, and expand wherever possible.

MEDICAL CARE AND TREATMENT

Elements of Good Practice

1. The standard of medical care provided to prisoners must be comparable to that available in the community.
2. Adequate financial and human resources should be provided to prison medical units to enable them to meet the above objective.
3. Annual training should be provided for medical staff to enable them to keep their skills and knowledge current with emerging best practice. This is particularly true in the areas of HIV and HCV care and treatment.
4. Prisoners should be empowered to play an informed and proactive role in decisions made about their health care.
5. Choice should be provided in access to medical services and practitioners – including both correctional and external health service providers.
6. Delays in access to physicians and medical specialists should be minimized.
7. Management of prison health services should be removed from the responsibility of correctional services. According to UNAIDS, “Experience in a range of prison systems has shown that health care in prisons can be delivered more effectively by public health authorities than by prison management.”⁴¹

Recommendations

1. CSC should ensure that the provision of HIV/HCV medical services reflects these elements of good practice in all institutions.
2. CSC and community-based HIV/HCV organizations should provide accessible medical information to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about their health care.
3. CSC should work to minimize barriers to accessing blood work. This is particularly true for Aboriginal women, and for women living with diseases such as HIV, HCV, and/or diabetes where regular blood testing is a crucial diagnostic tool and component of health care provision.
4. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV services, and expand wherever possible.
5. CSC should provide female physicians in all women’s institutions.
6. The Government of Canada and the provincial Ministries of Health should negotiate transfer of management of prison health services from CSC to provincial health authorities.

⁴¹ Joint United Nations Programme on HIV/AIDS (UNAIDS).

PAIN MANAGEMENT MEDICATION

Elements of Good Practice

1. Access to pain management medications – including prescription narcotic medication – must be provided in a non-discriminatory fashion.
2. History of illegal drug use should not preclude access to pain management.
3. Ongoing training should be provided for health care staff and physicians on the relationship between HIV and HCV infection and chronic pain, and on current best practice in the management of HIV/HCV related pain.
4. Prisoners should be empowered to play an informed and proactive role in decisions made about a pain management plan.

Recommendations

1. CSC should ensure that equitable access to pain management for women living with HIV and/or HCV is available in all institutions, and that the provision of pain management medication reflects these elements of good practice.
2. CSC and community-based HIV/HCV organizations should provide accessible information on pain management to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about pain management options.
3. CSC should ensure equal access to medications for the relief of side-effects in all institutions. This should include ensuring that information and consultation is provided to women living with HIV and/or HCV to assist them in making informed choices about their options.

COMPLEMENTARY AND/OR ALTERNATIVE THERAPIES

Elements of Good Practice

1. Access to complementary and/or alternative therapies should be available to all women living with HIV and/or HCV as a health promotion measure. In practice, it is preferable to improve access for all prisoners, regardless of serostatus, as this would minimize confidentiality concerns for women living with HIV and/or HCV who would otherwise be singled out by receiving them.
2. Where women are receiving complementary or alternative therapies (such as vitamins), they should be provided in as discreet a manner as is possible.

Recommendations

1. CSC should ensure that the provision of complementary and/or alternative therapies reflects these elements of good practice in all institutions.
2. CSC should make vitamins available without charge to all prisoners requesting or prescribed them as part of a broader health promotion initiative.
3. CSC should not limit free access to vitamins solely to women living with HIV and/or HCV as this creates confidentiality concerns. The more common vitamin access becomes, the less it singles out individual women for scrutiny.

4. CSC and community-based HIV/HCV organizations should provide greater information on complementary and/or alternative therapies, particularly for those women living with HIV and/or HCV.
5. CSC should expand the availability of complementary and alternative therapy options for women living with HIV and/or HCV.

DIET AND NUTRITION

Elements of Good Practice

1. The diet for all women living with HIV and/or HCV should meet or exceed those set in the *Therapeutic Nutrition Guidelines in HIV/AIDS*. In practice, it is preferable to improve the overall dietary standards for all prisoners to meet the *Guidelines* as this will minimize confidentiality concerns for women living with HIV and/or HCV who would otherwise be seen to be receiving different meals.
2. Special diets for women living with HIV and/or HCV should be easily and consistently available. This should include access to nutritional supplement drinks.
3. Where women are receiving special meals or nutritional supplements, they should be provided in as discreet a manner as is possible.
4. Information on the availability of special diets, and the process for requesting them, should be widely available.
5. Accessible information on the importance of diet and nutrition as a health promotion strategy should be made available to women living with HIV and/or HCV to assist them in making informed decisions about their diet.

Recommendations

1. CSC should ensure that its provision of diet and nutrition to women living with HIV and/or HIV reflects these elements of good practice.
2. CSC should review its dietary standards for prisoners living with HIV and/or HCV to ensure it is consistent with the *Therapeutic Nutrition Guidelines in HIV/AIDS*.
3. CSC should ensure that a consistent standard of diet and nutrition is provided in all regions.
4. CSC should ensure that information on the availability of special diets is made more accessible.
5. CSC and community-based HIV/HCV organizations should provide accessible information on diet and nutrition to women prisoners living with HIV and/or HCV to increase their ability to participate in decision-making about their diet.
6. CSC should ensure that barriers to accessing nutritional supplements are minimized, particularly for those women living with HIV and/or HCV.

SUPPORT, COUNSELLING, AND INFORMATION

Elements of Good Practice

1. The standard of HIV/HCV support and counselling services provided to prisoners should be comparable to that available in the community.

2. Choice should be provided in access to HIV/HCV support and counselling services and practitioners – including both correctional and external/community-based service providers.
3. Access to HIV/HCV support and counselling from both correctional and external/community-based services should be consistent across all institutions.
4. HIV/HCV support and counselling services of both correctional and external/community-based sources must be available on a consistent and reliable basis within each institution.
5. Delays and barriers to accessing support and counselling services should be minimized.
6. All HIV/HCV related support, counselling, and information services should be provided in a discreet and non-identifying manner that maximizes the confidentiality of women accessing the services.

Recommendations

1. CSC, Health Canada, public health departments/community health centers, and community-based organizations should ensure that all support and counselling services reflect these elements of good practice.
2. CSC, Health Canada, public health departments/community health centers, and community-based organizations must ensure that support and counselling services are expanded to meet the identified needs of incarcerated women.
3. CSC, Health Canada, public health departments/community health centers,

SUPPORT RECEIVED FROM PRISON HEALTH CARE/MEDICAL SERVICES

Recommendations

1. CSC should ensure that all support and counselling services provided by prison health care/medical staff reflect the elements of good practice.
2. CSC and public health departments/community health centers should continue collaboration in providing HIV/HCV support and counselling services, and expand wherever possible.
3. Given their primary role in providing HIV/HCV related information and support services to incarcerated women, CSC should ensure that all prison health care/medical staff receive annual training on HIV and HCV issues to support them in maintaining current knowledge.
4. CSC should ensure that barriers deterring women from accessing health care staff for information and support on HIV and HCV are minimized.

SUPPORT RECEIVED FROM COMMUNITY-BASED GROUPS

Recommendations

1. Community-based organizations should ensure that all support and counselling services reflect the elements of good practice.
2. Access to community-based services must be increased and made consistent across the country. This is particularly true for services provided by community-based HIV and HCV organizations. This necessitates increased

- commitment from community-based HIV and HCV organizations to providing services for incarcerated women, increased cooperation from CSC to accommodate community-based programs, and increased funding from Health Canada to support these services, especially at more isolated institutions.
3. Community-based HIV and HCV organizations must ensure that they accept collect calls from prisoners.

SUPPORT RECEIVED FROM ELDERS

Recommendation

1. Elders should seek to expand their knowledge on HIV and HCV in order to meet the needs of Aboriginal women living with HIV and/or HCV.

SUPPORT RECEIVED FROM CORRECTIONAL OFFICERS

Recommendation

1. CSC should improve provision of training on HIV and HCV for correctional officers. Emphasis should not be limited to workplace safety issues.