



Behind the Walls

Living with HIV in prison comes with its own set of challenges, and some aren't the ones you'd expect.

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Douglas Foreman knows firsthand what it is like to live with HIV in prison. At 52, he is a veteran of the Canadian correctional system, incarcerated in 11 different institutions since his first sentence in 1978. A gay man who contracted HIV through sex in the 1980s, Foreman was also diagnosed with hepatitis C virus (HCV) in 1991, although he isn't sure how or when he became infected with it.

That may have happened 32 years ago, during his first year in detention. He was in Quebec's Archambault Institution, at the time a maximum-security penitentiary, when he one day found himself being shot up by a fellow prisoner. "He was sitting beside me and I watched him prepare his hit, then he prepared one for me," recalls Foreman in a telephone interview from his current residence, a medium-security institution in Quebec. "I didn't even know I would shoot up... I would never have known how to."

After more than three decades in the system, Foreman is well aware that being HIV positive in prison comes with its own challenges—ones never faced by people with HIV outside prison or by prisoners who are HIV negative. Access to proper medical care is an obvious concern. As well, the HIV stigma and discrimination common in society can be worse inside prison walls. But Foreman's story points to another issue: Because rates of hepatitis C in Canada's prisons are high and access to prevention tools is

limited, many prisoners with HIV face the heavy health burden of being co-infected with HCV.

According to published data, between two and eight percent of prisoners in Canada are living with HIV, which is at least 10 times higher than the prevalence of the virus in the general population. Even so, Foreman says, "Rates of HIV in prison are much higher than people say. I was in a minimum security prison three years ago where there were 250 prisoners. At a seminar on HIV, I declared who I was and afterwards 25 men came up and told me they were also HIV positive."

HCV infection is even more prevalent, according to official reports, affecting 19 to 40 percent of prisoners, which is at least 20 times the prevalence in the general population. Most prisoners say they became infected with HIV or HCV through sharing needles and equipment to inject drugs. Perhaps Foreman became infected with HCV through that single time he shared a needle. Or perhaps it was through sex—there is mounting evidence that HCV may pass sexually, especially among HIV-positive men who have sex with other men.

Mavis Daniels, 33, is a Cree woman living in Prince Albert, Saskatchewan. She was diagnosed with hepatitis C

in 1996 and with HIV in 2003. Daniels injected drugs for many years before stopping three years ago. She says she contracted HIV through sex with a former partner. The man, a hemophiliac who contracted HIV in the 1980s during a blood transfusion, never told her of his status. She says that after hearing rumours, she asked him, “Are you sick? You need to tell me this.” He said, “No, I’m not. I don’t know who’s telling you this bullshit.” The relationship continued and the couple even decided to try to become pregnant. Eventually, a mutual friend told the truth to Daniels. “My heart jumped because I was already having unprotected sex with him for a year.” An HIV test came back positive.

Daniels has also spent time in prison, twice—once in the late 1990s and again from 2007 to 2009—in Saskatchewan’s Pine Grove Correctional Centre. She is a very real face of some startling statistics, including the fact that the Prairies has nearly half of all HIV-positive federal female prisoners in the country. Aboriginal women in prison are particularly affected—in a 2007 anonymous survey conducted in federal prisons, about one in 10 (or 11.7 percent) Aboriginal female prisoners was HIV positive and a shocking one in two (49.1 percent) was HCV positive.

One of the most important aspects of living with any chronic medical condition, including HIV, is getting good medical care. In Canada, people have the right to “essential health care” while in prison, which includes treatment for HIV.

Generally, HIV-positive prisoners have at least occasional access to specialist care. Barb Bowditch, HIV case manager and consultant with the Prince Albert Hepatitis C Program in northern Saskatchewan since 2006, says that HIV-positive prisoners in the region’s three institutions see an HIV doctor regularly—about every one to three months depending on the institution—either at clinics held in the prison or by being escorted to the Prince Albert clinic. Support and clinical services are offered on an ongoing basis. (Between appointments with the HIV specialist, prisoners can request to see a prison doctor. All requests are evaluated by the prison nursing unit and then forwarded or not.)

National data show that about six out of every 10 HIV-positive prisoners is on anti-HIV therapy. In the federal system, people get two weeks’ worth of HIV meds at a time, in blister packs that they keep in their cells. People can start HIV therapy while inside if it’s necessary and if they are ready. At the Prince Albert clinic, Bowditch says, “it’s a decision that’s made by the doctor, the patient and one of the nurses. Some may not want to start HIV meds right away and that’s OK. But, say their CD4 counts are dropping,

we’ll at least start them on Septra and azithromycin” to give them some protection from other infections.

Unfortunately, security can trump health in prison. “For three months,” Daniels recalls, “I complained to nursing staff that something’s wrong with me. I could not eat. Every time I woke up in the morning, I threw up. I told the nurses and they did nothing. I think they assumed that I wanted to make a trip out to the hospital so that someone could come meet me there with drugs.” The situation deteriorated and one morning Daniels had a seizure. “When I woke up in the ambulance they said the sleeping meds collided with my HIV meds, Kaletra and Combivir, and it caused a reaction to the brain.”

Given stories such as Daniels’, prison may not seem like the most obvious place to get healthy, but the stability of the daily routine can make it easier to stick with anti-HIV therapy. It was during her second stay in Pine Grove that Daniels got serious about her anti-HIV therapy. She had been taking it on and off for years, but the dependable routines of prison allowed her to take the medications regularly. Still, a majority

of people on HIV treatment have reported missing at least one day of therapy while in prison. Sometimes they missed because they decided to stop therapy or forgot to refill their prescription, other times because the prison pharmacy did not have the meds in stock or because treatment was interrupted while they were transferred between prisons.

Treating the symptoms and side effects of HIV and HIV treatment is also trickier in prison. Prisoners with HIV—who sometimes take medications such as Gravol (dimenhydratate) to counteract nausea and gabapentin (Neurontin) to treat neuropathy—can be intimidated into handing these over to fellow prisoners who inject them to get high. “What I hear and see is much more abuse of medications. People are injecting garbage like Gravol, and this didn’t used to happen,” says Dr. Peter Ford, a retired HIV specialist with more than 20 years of experience treating prisoners with HIV in federal institutions in Ontario. As a result, prescriptions written by HIV specialists are sometimes ignored by the prison doctors, who have the final say on which prescriptions are filled.

Just as in the wider community, HIV carries stigma in prisons, so many HIV-positive prisoners keep their status secret or at least try to do so. Mooky Cherian, provincial prison program coordinator at Prisoners’ HIV/AIDS Support Action Network (PASAN), an Ontario-based AIDS service organization for HIV-positive prisoners, says that anything, including HIV, that labels someone as weak or vulnerable can lead to problems on the range. During his work in the men’s provincial system in Ontario, Cherian has heard many stories of men



with HIV whose status becomes known and who then face ostracism and aggression from fellow prisoners.

Bowditch says her impression is that the experience in the prisons in northern Saskatchewan is different. “The prisoners are very open about their status within the walls. Probably about eight years ago I heard a lot of this [stories of stigma], but I think people are becoming more comfortable,” perhaps due to a growing awareness of the epidemic in the region.

Stigma combined with the power imbalance inherent in prisons can give rise to the potential for abuse by staff as well. Cherian, who sees clients in several provincial prisons in Ontario, recounts the story of one man who because of his HIV status receives canned nutrition drinks to help him stay healthy. (While needed, these drinks can be a sign to others of the person’s health status.) The man says that guards on occasion take the can from his food tray and drink it in front of him before tossing back the empty can. This kind of intimidation may explain why two-thirds of HIV-positive federal prisoners fear discrimination.

Canada has only one AIDS service organization (ASO) whose sole mandate is to serve prisoners with HIV and advocate on their behalf: PASAN, established in 1991. Because it’s the only one, even though it is officially an Ontario organization, PASAN is often thought of as a federal one. It has also taken on work with hepatitis C-infected prisoners. Other ASOs that have broader mandates—such as the British Columbia Persons with AIDS Society (BCPWA), Centre Action Sida Montréal (CASM) and HIV/AIDS Regional Services in Kingston—provide prison outreach workers.

Workers from these agencies supply information to prisoners, advocate for access to services within the prison and lend a compassionate ear. To ensure confidentiality to their clients, programs often do not refer to HIV explicitly. Instead, services are offered under the umbrella of sexual health or harm or risk reduction. That way, no one can be sure of a prisoner’s HIV status.

Front-line workers are often involved in organizing social services, health care or housing for prisoners who have been discharged. In Daniels’ case, the system worked well. “Six months before my release date,” she recalls, “I asked Barb [Bowditch] if she could find me a place to stay and a job.” As luck would have it, Bowditch knew the director of the local youth centre where Daniels once worked. A few phone calls and Daniels had work at the centre doing outreach. “What I do here is go out in the outreach van and we give out sandwiches, juice, condoms and needles.”

The Prince Albert clinic also provides health care to people returning to the community, though that can present challenges. “We have their housing information when they get released,” Bowditch says, “but we sometimes lose

them, especially if they are homeless or have an addiction issue. We may see them out on the street and try to connect with them there.”

It’s no surprise that prisoner infection rates for HIV and for HCV are so much higher than those in the general Canadian population. Injection drug use is common in prisons and sharing needles is generally accepted to be the main way HIV and HCV are transmitted there. According to the 2007 national survey, 16 percent of men and 15 percent of women say they have injected drugs while incarcerated. Anecdotal evidence from prisoners puts that percentage higher, often around 30 percent. There’s a multitude of reasons for using drugs: drug dependence, mental health issues, the desire to escape the boredom or difficulty of prison life and pressure from other prisoners. “It’s a stress-filled environment,” Foreman deadpans.

Some people who smoked drugs on the outside begin to inject them while they are in prison because injection does not produce smoke, which might alert the guards. As well, random urine testing for drugs means that some people may switch from smoking marijuana, which can stay in the body for weeks, to injecting drugs like cocaine and heroin, which clear quickly from the body.

Because there is no official access to sterile syringes in prisons, people resort to sharing injection equipment and this increases the risk of HIV or HCV transmission. Given the high rates of HCV in prisons, the danger of co-infection is very real for people living with HIV. Co-infection comes with its own set of medical issues, including faster liver disease progression, more complicated treatment schedules for both HIV and HCV, and lower HCV treatment success rates. Making matters worse, in prisons, care for hepatitis C lags. Only four percent of

HCV-positive prisoners receive treatment. Ironically, as it was for Daniels and her HIV treatment, the routine and structure of prison life can help people succeed with the often year-long regimen of daily pills and weekly injections that make up HCV treatment.

HIV and, with greater difficulty, HCV also pass during sex, and sex is definitely happening in Canadian prisons. In the 2007 survey, 17 percent of male prisoners and 31 percent of female prisoners reported having oral, vaginal or anal sex in the past six months. Almost all reported at least one instance of unprotected sex and a significant proportion said they had sex with someone who was positive for HIV or HCV or whose status they didn’t know. A 2008 ban on tobacco in federal prisons may also be playing an indirect and unexpected role in the increased transmission of HIV. “Tobacco was the jail house currency,” Foreman explains.

Security can trump health in prison.

“Now any tobacco that comes in is sold at astronomical prices. What have taken its place [in everyday bartering] are sexual services.”

Experts realize that reducing HIV and HCV transmission in prisons is going to require programs to reduce the risks associated with injection drug use. Reducing drug use itself is one tactic, and prison programs do exist to help prisoners address their drug dependence. Harm reduction, an approach advocated by many experts and activists, supports such rehabilitation but also acknowledges that injection drug use happens in prisons and encourages looking for ways to make it safer.

Agencies that work with HIV-positive people in prisons

Prisoners' HIV/AIDS Support Action Network (PASAN)

416.920.9567 or 1.866.224.9978

(accepts collect calls from prisons in Canada)

www.pasan.org

Centre Action Sida Montréal Femmes (CASM)

514.495.0990

netrover.com/~casm

HIV/AIDS Regional Services, Kingston

613.545.3698 or 1.800.565.2209

www.hars.ca

Prince Albert Hepatitis C Program, Saskatchewan

HIV Case Manager – 306.960.4157

HIV Outreach Nurse – 306.765.6541

Hepatitis C Nurse – 306.765.6545

British Columbia Persons with AIDS Society (BCPWA)

604.893.2200 or 1.800.994.2437

www.bcpwa.org

Resources for people in prison

Cell Count – PASAN's magazine for and by prisoners; published four times a year, this bulletin is the only newsletter in Canada providing an uncensored forum for prisoners and young offenders to explore and share their own experiences, ideas and fears about HIV/AIDS. Contact PASAN to subscribe.

Prisoners' calendar – available through the CATIE Ordering Centre, www.catie.ca or 1.800.263.1638

Articles from *The Positive Side* with more info

“Path to Healing” (Winter 2010 issue) – inspiring stories of HIV-positive Aboriginal people from the Prairies

“Double Duty” (Spring 2008 issue) – HIV/HCV co-infection

“Hep C on the Radar” (Spring/Summer 2010 issue) – sexual transmission of hepatitis C

Additional reading from the Canadian HIV/AIDS Legal Network

Under the Skin: A People's Case for Prison Needle and Syringe Programs. 2010.

Clean Switch: The Case for Prison Needle and Syringe Programs in Canada. 2009.

These two publications are available at www.aidslaw.ca or through the CATIE Ordering Centre at www.catie.ca or 1.800.263.1638.

Needle and syringe programs seem an obvious solution, yet the Canadian prison system has not allowed their introduction. A zero-tolerance policy for drugs in prisons precludes any activity that would acknowledge drug use. It's true that other prevention and harm reduction measures—condoms, dental dams, bleach for needles—are in place. Douglas Foreman applauded their introduction into prisons in the early 1990s, but there's still a long way to go. For example, bleach can kill HIV—though Cherian points out there is no evidence that it is effective at killing HIV in the makeshift syringes normally found in prisons—but is not effective at killing HCV. What's more, research shows that even approved prevention tools are not consistently available in Canadian prisons.

As well, tattooing with improvised machines and unsterile equipment is common in prisons and carries the risk of transmitting HIV and HCV. A pilot prison tattooing program started in mid 2005 by Correctional Service of Canada was shut down in December 2006 by the then newly elected federal government, even though a draft report of an evaluation said the program had potential to reduce the risk of transmission.

For national-level research and advocacy about HIV in prisons, the Canadian HIV/AIDS Legal Network has long been at the forefront, holding conferences and producing important documents. “As a legal organization, we can focus on research and policy analysis and advocate for the health and human rights of people in prison in a way that complements the work of grassroots organizations,” says Sandra Ka Hon Chu, co-author of two of the organization's detailed reports on the need for needle and syringe programs in prisons. (See resources listed at left. The two reports contain many stories of prisoners living with HIV.)

While getting needle and syringe programs into prisons would help slow the spread of HIV and HCV, it might be the growing rates of hepatitis C that finally convince authorities to address the problem. Ford, the HIV specialist whose groundbreaking early research drew attention to the prevalence of HIV in Canadian prisons, argues that HCV is so rampant inside that it amounts to a “new epidemic.” In November 2009 he traveled to Ottawa to educate members of the federal Standing Committee on Public Safety and National Security about these issues. “What we're looking at,” he told the committee, “is a problem with a communicable blood-borne disease Corrections is going to find itself looking after people with terminal liver failure, and this is a very expensive prospect.”

For her part, Daniels has not yet taken treatment for hepatitis C. A few years ago, her friend begged her to wait until she was in a more stable place in her life before considering to undertake the often-grueling treatment. She thinks the time has come and has started talking with her doctor and collecting information. As for Foreman, he is also fighting to be treated for HCV. While both his HIV and HCV infections are critically important, he knows that, untreated, it's the HCV he acquired back in 1991 that poses the greatest risk to his health. +