



Uprooted Lives

Immigrating can be daunting at the best of times, but add HIV to the mix and the difficulties multiply. Increasingly, AIDS service organizations are called upon to help newcomers deal with the challenges—and the isolation

BY DIANE PETERS

WHEN MARIA APPLIED TO CANADA FOR LANDED IMMIGRANT status in 2002, she was asked to take a blood test. It came back positive for HIV. But the mother of two was already personally familiar with the illness. Her teenage son had contracted it from a blood transfusion in Southeast Asia at the age of 5.

The boy had been born in Canada, back when Maria was living here in the 1980s with her then husband. In Southeast Asia, reaction to her son's HIV status was so bad that when he was initially diagnosed Maria and her children were thrown out of her parents' home, where they had been living. And later, when her son was in his teens, taunting at school left him contemplating suicide. Canada

was a solution. To get the health care her son needed and to leave behind the powerful stigma in the community, Maria chose to return her family to Canada. But a problem remained; while her son and daughter had a legal right to be here, Maria did not.

Thus began years of stress and waiting. While Maria has been living in Toronto since 2002 on a tourist visa, she has to renew it every six months, a hassle at best. And while her children's drugs eventually became fully covered through Ontario Works—a social assistance program—she herself has no basic health care coverage for simply visiting the doctor or getting a blood test.

Variations on Maria's situation abound. Many people living with HIV/AIDS (PHAs) new to Canada struggle to see a doctor, find a pamphlet in a language they can read, get the right meds or manage to pay for them. It's a growing problem, mainly because every year more newcomers to Canada are HIV positive. Of the 15,876 new HIV cases reported in Canada between 1998 and 2004, 467 involved people born in countries where the disease is endemic—spread through the general population mainly through heterosexual sex. And the numbers are on the rise. In 1998, just 34 new HIV diagnoses came from these newcomers, versus 98 in 2004.

Helping these people is a growing priority for AIDS service organizations (ASOs). But the challenges that newcomers face are so numerous and complex that it can be hard to know where to begin. "It's stressful, it's depressing. It's really a lot to handle," Maria says. When she first brought her family back to Canada, even her children were denied full health coverage despite having been born here, because, according to a provincial rule, the mother must have coverage in order for her children to receive it.

At the time, Maria turned to the Alliance for South Asian AIDS Prevention (ASAAP) and the HIV & AIDS Legal Clinic of Ontario (HALCO). Staff at these organizations sorted out the coverage issue for her kids and found her doctors who see her for free. When Maria had to be hospitalized for two weeks in 2003 and the bill came to \$35,000, a social worker at the hospital navigated channels that somehow allowed her to get rid of the entire bill. "You've got to know the right connections," Maria says. "If you don't know them, you're out."

THE COMMON FACTORS

All PHAs new to Canada share common obstacles, the most powerful being stigma. "The stigma can be so great, there are people who are living in fear all the time,"



"Many of my clients tell me that if news of their being HIV positive ever got back to Rwanda or Burundi, it could jeopardize the safety of their family members," says Claire Duchesneau, a social worker at the Montreal Chest Institute's Immunodeficiency Service.

says Rounak Khan, PHA support coordinator with ASAAP. "That can create a barrier in coming out and getting help."

Often, the best places to get help are service organizations devoted to newcomers from certain communities such as Asia, Africa or the Caribbean. But fear of running into someone they know prevents many from accessing these services. Those who brave showing up in public often hide their status, despite the obvious. At the Immunodeficiency Clinic at the Ottawa Hospital, for instance, women in the waiting room often tell each other they're seeing the doctor for a hurt foot or a cold. "It's an HIV clinic. Why don't these women seek support from each other and disclose to each other?" Dr. Paul MacPherson says. "They won't. They're trying to protect themselves."

Some stay silent out of a very real fear, says Claire Duchesneau, a social worker at the Montreal Chest Institute's Immunodeficiency Service, whose clients are mainly African refugees. "Many of them tell me that if it ever got back to Rwanda or Burundi, it could jeopardize the safety of their family members," she says. Disclosure can be an issue, even within families. Many PHAs request meds that don't have to be refrigerated so family members or others in the household won't see evidence of the disease.

Although privacy is critical, it's not always respected by the Canadian immigration system. When HIV and AIDS activist Believe Dhliwayo came from Zimbabwe last October and applied for refugee status, he was sent by Citizenship and Immigration Canada to a clinic for a physical. Right in the middle of the waiting room, a nurse naively asked him personal medical questions, including whether he'd ever had TB, as well as his HIV status. "There wasn't any confidentiality," he recalls. "I could see other people looking at me while I was being asked."

These government-referred clinics are where many newcomers receive blood tests and later find out, via phone, that they're HIV positive. "They just phone and tell it to you. It's world shattering and there's no counselling," says Khan, who notes that PHAs in this situation are also not given any written information or guidance about where to turn for support.

That support is not always available, however, if you live outside the major centres. Dhliwayo has been staying in Barrie, Ontario, but he has to travel to a Toronto hospital, one hour away, for care. "There's only one doctor here for people with HIV, and he's not taking on any new clients," he says.

Often, immigrants don't realize there are doctors who specialize in HIV/AIDS, and that if their doctor is not well informed, it's important to find one who is. But many Canadians—not just newcomers or those with HIV—have a hard time finding any doctor because of the national shortage.

New Canadian PHAs also struggle with our complex legal and health care system. "It took me three months to figure out where to find services," Dhliwayo says. The problem is compounded when newcomers don't have a firm grasp of English or French. Big city ASOs may have translators and some information printed in languages from Tamil to Cantonese to Creole but, for the most part, very little information for PHAs is available in non-European languages. "You can't have a translator at your side all the time," Duchesneau says. There's so much to read and understand: from printed drug information to travelling directions to what the nurse is telling you at the doctor's office.

Add to these obstacles the strain of moving to a new country. "I'm already stressed that I can't go back to my home," Dhliwayo says. "For me to concentrate enough to go through a thick volume of information, that's a bit of a problem." That stress can turn to depression, further keeping people from taking care of themselves. And stress is compounded by money problems, which almost anyone starting a new life here has. "A lot of them are dealing with immeasurable poverty," Duchesneau says. It's not uncommon for a newcomer to be working more than one job, or collecting a small welfare cheque and sending most of the money home to family. Eating right, taking supplements and exploring complementary medicine are just not options for most people in this situation. As well, it's common for newcomers to postpone taking meds, fearing that the side effects will make them too sick to work or necessitate their having to turn to expensive alternative treatments.

REFUGEE CHALLENGES

While many PHAs apply for protected status in Canada because of the hazards of stigma back home, others have come here because of war, sexism or homophobia. For those who have left home for reasons unrelated to their HIV status, concerns about disclosure remain an issue. "They fear they will be deported because of their HIV, which won't happen, but a lot of people don't know that," says Patrick Truong, support program coordinator for Asian Community AIDS Services (ACAS) in Toronto. This

fear leads some refugee claimants to put off applying for health coverage and taking meds, sometimes until they end up quite ill.

Sometimes the circumstances back home can cause other serious health problems as well. "The average person we see has witnessed multiple deaths and horrific crimes you would not believe," says Duchesneau, who often applies for special health coverage to get African refugees treatment for post-traumatic stress disorder.

Another source of stress can come from the way refugees are treated by others here. "If you are a refugee who is HIV positive, you suffer two stigmas—one related to HIV and the other related to being a refugee, the stereotype that you don't have education and you're on social assistance. Both stigmas together really affect the emotional state of the individual. And that can affect people's treatment and adherence to meds," says Victor Inigo, who works at Toronto's Regent Park Community Health Centre to help refugees and immigrants living with HIV gain access to services.

MacPherson, however, says his refugee patients are usually very committed to taking their drugs, particularly if meds are scarce back home. But significant obstacles remain. He may help refugees build up their immune systems with meds, but sometimes their claims are later rejected and they are sent home. Back home [in Africa], if you're "too well"—usually that means having a CD4 count of more than 200—you are denied treatment because of the scarcity of meds. "We've made them healthy," he says, "and then send them back, virtually disqualifying them from getting meds."

For refugees, finding out the outcome of their claim takes a minimum of a year, but often much longer. Meanwhile, they are eligible for the Interim Federal Health program, which provides health coverage and pays for medications. But, Inigo says, acquiring protected status can take a long time. "I know people who have been waiting 10 years." And there's no way of predicting if a person's claim will be rejected or accepted. "This uncertainty and the long period of waiting are what make the process very hard. It affects the individual in many different ways, not just emotional. They feel no sense of belonging to the community." Until the claim is resolved, people can't truly settle themselves and do what they need to do to stay well long term. "With my clients I've seen that

When Believe Dhliwayo underwent a physical exam while applying for refugee status, a nurse asked him his HIV status in the middle of the waiting room. "There wasn't any confidentiality," recalls Dhliwayo, an HIV/AIDS activist. "I could see other people looking at me while I was being asked."



RESOURCES

AIDS SERVICE ORGANIZATIONS

- African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), www.accho.ca
- Africans in Partnership Against HIV/AIDS (APAA), 416.924.5256, www.apaa.ca
- Alliance for South Asian AIDS Prevention (ASAAP), 416.599.2727, www.asaap.ca
- Asian Community AIDS Services (ACAS), 416.963.4300, www.acas.org
- Asian Society for the Intervention of AIDS (ASIA), 604.669.5567 www.asia.bc.ca
- Black Coalition for AIDS Prevention (Black-CAP), 416.977.9955, www.black-cap.com
- Canadian HIV/AIDS Legal Network, 416.595.1666, www.aidslaw.ca
- Centre of Resources, Interventions and Services in Sexual Health (CRISS), 514.855.8991, www.criiss.org
- Centre for Spanish Speaking Peoples AIDS Support Program, 416.925.2800, www.spanishservices.org
- Committee for Accessible AIDS Treatment, 416.364.2261, www.regentparkchc.org/CAAT.htm
- Group d'Action pour la Prévention de la transmission du VIH et l'Eradication du Sida (GAP-VIES), 514.722.5655, www.aihc.ca/CCRI/gapvies.html
- HIV & AIDS Legal Clinic of Ontario (HALCO), 416.340.7790, www.halco.org
- Women's Health in Women's Hands, 416.593.7655, www.whiwh.com

MULTILINGUAL HIV TREATMENT INFORMATION

Fact sheets in Asian and African languages: languages.catie.ca, www.acas.org/treatment or call CATIE at 1.800.263.1638

People working to get immigrant status in Canada often deal with immigration consultants. Some are “quite bad,” Truong says. Scams happen often, with consultants charging exorbitant fees for things like filling out basic forms for health coverage. “Especially for people who come into the country illegally, there’s always a chance they can be cheated.”

HELP IS AVAILABLE

Since Canada’s immigration and refugee system does not cater to PHAS, ASOs fill in the gaps. People at these organizations call the federal and provincial governments directly to clear up coverage issues, they contact pharmaceutical companies to get free meds, and they find or develop information in different languages and source translators. Khan even takes her clients to the doctor personally when they need extra support.

These groups are constantly looking for ways to better serve newcomers. At the Montreal Chest Institute, Duchesneau and her staff have started following the news in Rwanda and Burundi, as events there affect their clients here. “It took us years to understand what religion meant to our clients,” Duchesneau says. “Now we hold a mass at the hospital once a month just for women from Africa who have HIV.”

Sharing information has become a new mandate for many of these groups. Large city groups often receive calls from smaller centres, and they send off pamphlets in various languages and offer advice.

In Toronto, the Ethnoracial Treatment Support Network has been formed, which brings together ACAS, ASAAP, the Black Coalition for AIDS Prevention, the Centre for Spanish Speaking Peoples, Africans in Partnership Against HIV/AIDS and CATIE. One of their projects is to develop a peer-based counselling system to provide multilingual treatment information and support to new immigrants and refugees living with HIV.

The HIV/AIDS and Immigration Services Access Project is another collaboration looking at ways to improve services for newcomers and suggest changes to Canada’s immigration system. They want immigration-referred doctors to deal with testing and disclosure more sensitively; a complete information package to be given to all PHAS newly arrived in Canada; and to send out the message, as strongly as possible, that HIV is a treatable illness, not a death sentence. Helping newcomers stay well with HIV/AIDS will be an ongoing challenge, no matter how dedicated service providers are or how the rules change. Yet, despite everything, many newcomer PHAS do overcome their difficulties and receive treatment. Most work when they can, volunteer to help others and still find the energy to assist family back home. “People who come here are highly resourceful,” MacPherson says. “They didn’t survive this long without being really smart.” +

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once a person is accepted, everything changes. They really move on and make huge changes and long-term decisions.”

IMMIGRANT CHALLENGES

In addition to all the stresses of living with HIV in a new country, many immigrants feel they need to prove their value to Canada, so they work numerous jobs and refuse social assistance even when they’re sick.

But there are also people trying to immigrate to Canada who, like Maria, already live here—sometimes illegally—but are waiting for status. Many are refugees who have had their claims rejected. For these people, there are even more barriers to staying well.