The HIV treatment cascade – patching the leaks to improve HIV prevention

By James Wilton and Logan Broeckaert

We have known for years that antiretroviral therapy can significantly improve the health outcomes of people living with HIV. More recently, research has revealed the important role that antiretroviral therapy plays in preventing the transmission of the virus. As HIV treatment and prevention have converged, attention has turned to how well we are engaging people living with HIV in the continuum of services, including testing, care and, ultimately, effective treatment. The concept of an HIV treatment cascade has emerged as a way to identify gaps in the continuum, which are preventing people from realizing the treatment and prevention benefits of antiretroviral therapy.

This article takes a closer look at the cascade, why it’s important for HIV prevention and how it can be improved.

Steps in the HIV treatment cascade

Antiretroviral therapy is normally considered successful when it reduces the viral load of a person living with HIV to undetectable levels. Research shows that people who have an undetectable viral load in their blood are more likely to live a long and healthy life\(^1\) and are less likely to pass HIV to others.\(^2\) [For more up-to-date information see the CATIE statement on the use of antiretroviral treatment (ART) and an undetectable viral load to prevent the sexual transmission of HIV.]

For a person living with HIV to achieve an undetectable viral load, they need access to a continuum of services: HIV testing and diagnosis, linkage to appropriate medical care (and other health services), support while in care, access to antiretroviral treatment if and when they are ready, and support while on treatment. This sequence of steps is commonly referred to as the HIV treatment cascade or the HIV care cascade. Unfortunately, the cascade isn’t seamless and some people “leak” out and are lost at each step, due to barriers to getting tested, staying in care, and starting or adhering to antiretroviral treatment. These barriers include:

- poor access to services;
- stigma and discrimination;
- poverty, food insecurity and homelessness; and
- mental health and addiction issues.\(^3\)

As a result of these leaks at different points in the continuum, only a small proportion of people living with HIV are engaged in all the steps needed to achieve an undetectable viral load. For example, in the United States it is estimated that only 19% to 28% of people living with HIV have an undetectable viral load (see Figure 1).\(^4,5\)

Figure 1. Engagement in the HIV treatment cascade in the United States
There are currently no official estimates for the number of people engaged in the treatment cascade in Canada; however, preliminary data suggest that there are also significant leaks in the cascade in Canada and that the proportion of people with an undetectable viral load may be similar to that in the United States (although it likely varies across regions and for different populations).

**UPDATE:** New [2014 estimates of the HIV treatment cascade in Canada](#) were released in 2016. It is estimated that in 2014, 80% of people living with HIV were diagnosed, 76% of people diagnosed were on treatment, and 89% of people on treatment had an undetectable viral load. This means that, overall, an estimated 54% of people living with HIV in Canada had an undetectable viral load in 2014.

**Patching the cascade to improve treatment and prevention**

Poor engagement of people living with HIV with healthcare and social services limits the effectiveness of our HIV programs and our response to the HIV epidemic. Increasing the number of people engaged at all levels of treatment and care may both improve the health of people living with HIV and reduce new HIV transmissions. Increasing engagement in the cascade requires programs that address the multiple barriers.

However, we do not know what the “ideal” cascade should look like and aiming to get everyone living with HIV on successful treatment is not realistic, nor would it be ethical. It’s critical that efforts to better engage people in services do not come at the cost of individual rights and that we make sure clients and patients are ready and willing to take each step. To ensure informed consent, the risks and challenges that come with testing positive for HIV and starting treatment need to be explained to clients and patients before they make these important decisions.

Let’s take a look at each step of the cascade, its importance for treatment and prevention, and how we might be able to better engage people in each step.

**HIV testing and diagnosis**

An estimated 26% of people living with HIV in Canada do not know they have HIV. Reducing the number of people who are unaware of their HIV status requires increased uptake and frequency of HIV testing.

Increasing the frequency and rates of HIV testing will help diagnose people sooner after they have become infected with HIV. Currently, many people in Canada are not learning about their HIV status until late in their HIV disease, when they start to develop symptoms or opportunistic infections. At this point, antiretroviral treatment can help improve their health, but not as effectively as when treatment is started earlier. Furthermore, research suggests that a disproportionate number of HIV transmissions originate from people who are unaware of their HIV status because they are less likely to take measures to prevent transmitting the virus to others and are more likely to have a higher viral load, particularly if they have recently become infected and are in the acute stage of HIV.
Earlier diagnosis is therefore important for both the health of a person living with HIV and for preventing the transmission of the virus.

These are some of the interventions being used in Canada to promote HIV testing and diagnose people earlier:

- Campaigns to improve awareness of HIV risk and encourage people to get tested regularly. Campaigns such as *Get on it* in Ontario, *Find out where you stand* in Montreal, and *What’s your number?* and *Hottest at the Start* in Vancouver encourage gay men and other men who have sex with men to test regularly for HIV. Some of these also aim to improve awareness of acute HIV infection and its role in HIV transmission.

- Improving access to more acceptable types of HIV testing, such as point-of-care (POC) antibody testing and peer testing, to increase options for people who want to get tested. For example, POC testing is now more widely available in large Canadian cities. Peer outreach and testing in gay bathhouses is offered by some organizations, such as Toronto’s *Hassle Free Clinic*. In Montreal, the *SPOT Project* offers gay men anonymous HIV rapid testing and counselling as well as a full range of tests for sexually transmitted infections (STIs) from a storefront site.

- Improving access to tests that have shorter window periods and can detect HIV infection earlier than antibody tests. These tests can help identify people in the acute stage of HIV infection. For example, P24 antigen testing has been used in Ontario since 2010 and a *pilot study using nucleic acid amplification (NAAT) testing* is currently underway in Vancouver.

- Making HIV testing a routine part of healthcare to increase the number of people offered an HIV test. For example, Vancouver is scaling up HIV testing; primary care facilities, acute care hospitals and a few dental clinics in the city are now routinely offering HIV tests to patients.

- Integrating HIV testing with testing for other STIs. Some organizations, such as the *Hassle Free Clinic*, offer an HIV test to anyone seeking STI testing. This greatly increases opportunities for HIV testing since people are more likely to seek testing and treatment for other STIs than for HIV.

- Enhanced partner notification services to better identify and diagnose people who may have been exposed to HIV. Some regions, such as Vancouver, are re-examining how they perform partner notification to improve the effectiveness of the service.

**Linkage to care and support**

Linking people who receive a positive diagnosis to accessible and culturally appropriate care and support services is important to ensure that people living with HIV enter the next step of the treatment cascade. Research shows that delays in linkage to medical care after HIV diagnosis are associated with faster disease progression. Interventions that currently improve linkage to care in Canada include the following:

- Referral systems that link people diagnosed with HIV into care. For example, the Manitoba HIV program, which provides a wide range of integrated care and support services at two sites in Winnipeg, has a referral line for people who test positive. This line can be used by the healthcare provider who performed the test to refer newly diagnosed individuals to the Manitoba HIV program for care.

- Improved outreach interventions. For example, the *STOP Outreach Team in Vancouver* uses case-management to connect people with complex needs to the most appropriate service or program and ensures strong engagement in care before discharging them from the team’s caseload.

**Retention in care and adherence support**

Once linked to care, a person needs to be supported and monitored and receive counselling to determine when they are ready and eligible to start treatment. Once a person decides to start treatment, remaining in care is important so a person can be supported with adherence and receive ongoing viral load monitoring to ensure that their treatment is working.

Appropriate care and support for people living with HIV may include a wide range of services in addition to medical care, such as mental health and addiction services, adherence support, affordable housing and prevention counselling. These services can improve the quality of life of people living with HIV, address the underlying reasons people may drop out of care or find it difficult to adhere to treatment, and improve sexual well-being. Research shows that a combination of medical care and additional types of care and support improve the health outcomes of
people living with HIV and make them less likely to engage in behaviours that can lead to HIV transmission.

Recently, the International Association of Providers of AIDS Care released guidelines for healthcare providers that contain 37 evidence-based recommendations to improve retention in care and adherence to antiretrovirals.

Interventions and services are offered across Canada that keep people engaged in care and help them access treatment, adhere to their medications and prevent the transmission of HIV.

- Intensive case management approaches can improve engagement in care by providing tailored support to individuals who need it. For example, the Manitoba HIV program proactively follows up with people who entered the program but have been lost to care and provides highly individualized services to people who have a history of lapses in care.

- Maximally assisted therapy (MAT) programs deliver daily treatment and support services to their clients. For example, the Positive Outlook Program at Vancouver Native Health Services and the MAT program at the Downtown Community Health Centre in Vancouver both provide assistance with daily treatment adherence and comprehensive support to their clients.

- Peer navigator programs train HIV-positive peers to offer services to people living with HIV who face multiple barriers to engagement. For example, Positive Living BC’s peer navigators provide tailored support to people who need it. They do this through community outreach and at the Immunodeficiency Clinic at St. Paul’s Hospital.

- Programs that offer psychosocial supports, such as housing and food security programs, can reduce structural barriers to engagement in HIV care and treatment. For example, La Corporation Félix Hubert d’Hérelle in Montreal, the SHARP Foundation in Calgary, and many others across the country offer housing and housing supports to people living with HIV. A Loving Spoonful in Vancouver offers 1,200 meals a week to people living with HIV.

- Programs that support people living with HIV to live healthy sexual lives and incorporate prevention as part of their overall health and well-being. For example, the Poz prevention program at Toronto People With AIDS Foundation provides peer consultations, training for service providers and group discussions on sexual health and HIV prevention.

What can you do?

Public health authorities, healthcare providers and frontline service providers all have a role to play in making services more accessible and providing people with ongoing care.

Patching the leaks in the cascade may require new interventions and new partnerships and/or the re-conceptualization of how services are integrated and linked with other services. It may also involve changing how services are evaluated.

Key questions to ask yourself and your organization are:

- How can your organization better engage people living with HIV in the treatment cascade?
- What additional services could your organization provide to improve engagement in one or more steps of the cascade? Can you learn from what other agencies have done? Would it work in your region?
- What initiatives or partnerships could you develop to connect people living with HIV to your services? What initiatives or partnerships could you develop to connect your clients with other relevant services in your community?
- How can you evaluate whether your clients are entering the next step of the cascade?

As we work to improve engagement in the treatment cascade, it is critical that human rights are respected and that people living with HIV and at risk of HIV are empowered through information to make decisions about testing and treatment that are right for them. This includes information about the legal requirement to disclose prior to some sexual activities.

Improving HIV treatment and prevention

Each step in the cascade is important for improving the health of people living with HIV and preventing new transmissions. The idea of a treatment cascade is useful for conceptualizing how services are linked and for
identifying gaps that need to be addressed. At the same time, it has several shortcomings. First, it represents care for people living with HIV as a linear process, which we know isn't always the case. For example, a person living with HIV may fall out of care or stop treatment for various reasons, they may move backwards or forwards at different points along this continuum, or they may receive healthcare for many years without starting treatment. When developing programs and services, we need to take these realities into account. Secondly, the concept of a treatment cascade does not include prevention as a component of an effective response. As a model of care for people living with HIV, it indirectly reinforces the false view that the responsibility for HIV prevention rests solely with people living with HIV. In fact, prevention is a shared responsibility and all people, regardless of serostatus, have an important role to play. Additionally, treatment as a mechanism for prevention is only one of several effective prevention strategies, all of which, when appropriately combined will provide a more effective response to the HIV epidemic than any one strategy alone. We should no longer do prevention work in isolation of those working in HIV testing, treatment, care and support, as they are all reinforcing elements of an effective response to HIV.

While each organization has a role to play in improving care for people living with HIV, we also need to look at the issue from a systemic level. How can we, as policymakers, service providers, healthcare providers and people living with HIV, improve services for people living with and at risk of HIV? We need to identify gaps and ways to improve care in conjunction with the community, to ensure that a person can effectively navigate their way within the healthcare system. Fragmented, stand-alone programs and services need to be linked to ensure that people living with and at risk for HIV have access to services that can support their care.

In September 2013, CATIE will host a national forum called New Science, New Directions in HIV and Hepatitis C. This forum will provide an opportunity for frontline workers to come together to learn about new directions in service provision, share programming experiences and strategize about developing more integrated approaches to treatment and prevention.

Resources

CATIE statement on the use of antiretroviral treatment (ART) and an undetectable viral load to prevent the sexual transmission of HIV

Treatment Update – HTPN 052: The trial that changed everything

Prevention in Focus – Detecting HIV earlier: Advances in HIV testing

Prevention in Focus – Recently infected individuals: A priority for HIV prevention

Prevention in Focus – The STOP HIV/AIDS Project: Treatment as prevention in the real world

References

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Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.