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Investigating where patients go when they leave HIV care

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- Previous research has found HIV-positive Canadians stop attending follow-up HIV appointments at rates between 11% and 24%.
- Alberta researchers find that many patients “lost to follow-up” are seeking healthcare outside HIV services, often in hospital emergency rooms.
- This research has implications for programs that seek to re-engage patients in HIV care.

Potent combination anti-HIV therapy (ART) can reduce levels of HIV in the blood (viral load) to very low levels that cannot be detected with routinely used tests. These low levels are commonly called “undetectable.” Keeping HIV at such low levels with ART is associated with improved health. This effect of ART is so powerful that researchers in Canada and other high-income countries expect that many HIV-positive people who continue to take ART every day and keep regular clinical and laboratory appointments will have a near-normal lifespan.

Studies have found another benefit of ART that comes from achieving and maintaining an undetectable viral load: [The sexual spread of HIV does not occur.](#)

These twin benefits of ART and an undetectable viral load (improved health and the prevention of HIV transmission) are so profound that the Joint United Nations Programme on AIDS (UNAIDS) has encouraged countries, regions and cities to engage with their populations so that the following goals are achieved by 2020:

- 90% of people with HIV know their infection status
- 90% of people diagnosed with HIV are taking ART
- 90% of people taking ART have an undetectable viral load

To help achieve these goals (often shortened to [90-90-90](#)) it is essential for there to be more opportunities for HIV testing accompanied by supportive counselling and, in cases of a positive test result, swift referral to care where an offer of ART can be made.

Dropping out of HIV care

Research in the United States suggests that a large proportion of HIV-positive people— perhaps as high as 40% in some cases—drop out of care. According to researchers at the Southern Alberta Clinic (SAC), figures from several studies in larger Canadian provinces suggest that dropout rates are between 11% and 24%, depending on the clinic/region surveyed. Researchers label people who have dropped out of care as “lost to follow-up” (LTFU).

Not surprisingly, studies have found that people who drop out of HIV care are at heightened risk for developing serious HIV-related complications and dying.

What's more, researchers at SAC who have reviewed studies published in the past several years have found that “innovative approaches to facilitate reengagement in HIV care, including intensive outreach, patient navigators and use of case managers, have shown modest benefits.”

In Alberta

Researchers at SAC sought to find out where patients who dropped out of HIV care went to receive their non-HIV care, as these could potentially be places where they may be helped to re-enter HIV care.

To find out more about where patients who were LTFU went for non-HIV care, the researchers accessed Alberta's comprehensive and province-wide electronic health record (EHR). They reviewed information collected by the EHR between January 2010 and August 2014 on patients who had gone more than one year without a visit to SAC.

According to the researchers, there were a total of 1,928 patients registered at SAC. However, 178 (9%) patients dropped out of HIV care at SAC. Further analysis revealed that some patients had moved out of the province, others sought HIV care elsewhere and a small portion had died. By the end of the study, many participants who were residing in Alberta had returned to HIV care. However, analysis of the EHR data revealed that 29 (16%) patients who left SAC had no further contact with HIV care yet sought non-HIV care in Alberta.

These 29 patients had many contacts—a total of 188 (at least six per person)—with the medical healthcare system for care unrelated to HIV during the study period. The majority of these contacts (nearly 70%) occurred in the Emergency Departments of hospitals. In 25 cases, hospitalization was required. The remaining participants interacted with hospitals and community clinics for their non-HIV care.

Implications of the study

According to the researchers, “an important implication of this finding is that health-care based reengagement efforts, such as medical or social service referral, will miss this population [who are LTFU]” because it depends on patients visiting the HIV clinic to receive such referrals.

There may be an alternative method of finding out more about patients who are LTFU. The Southern Alberta researchers drew attention to research from Seattle, Washington, where an HIV clinic collaborated with local health departments and made use of a care linkage specialist for outreach. The Seattle researchers were somewhat able to re-engage patients into care and find out why they appeared to disengage in care. In the Seattle study, the majority of patients who stopped visiting the HIV clinic did so because they had been sent to prison or had moved out of the region or sought care at other HIV clinics. Furthermore, the Seattle researchers stated the following: “The ongoing movement of patients between correctional settings and community, between different geographic areas, and between different clinical care sites is a challenging issue for both clinic and health department-based relinkage interventions to address.”

The Emergency Department

Research from Baltimore, Maryland, suggests that intensive efforts to help HIV-positive people who enter the Emergency Department link to care can be effective. According to the Alberta researchers, such intensive interventions can include “physically escorting patients to an HIV clinic or in-person interaction with an HIV specialist.” However, the Baltimore researchers noted that interventions to help patients in the Emergency Department link to and stay in care often required additional funding because the services of “multidisciplinary non-Emergency Department staff” were required.

What is needed

Based on the findings from their regions and their review of other studies related to patients who are LTFU, the Alberta researchers call for studies to better understand why some HIV-positive patients drop out of HIV care. They add that while focusing on HIV-positive patients who seek care from Emergency Departments may help to re-engage many who are LTFU, such attempts will not find patients who have disengaged with the healthcare system altogether.

The main issue raised by the Alberta researchers—dropping out of HIV care—is important and can affect the health and well-being of some HIV-positive people as well as the ability of cities and regions to reach the UNAIDS 90-90-90 targets.

Technical notes about the EHR

The EHR database captures visits to Emergency Departments, urgent care facilities, community clinics and more than 90% of lab tests and prescriptions for Alberta residents (regardless of HIV status). According to the Alberta researchers, at the time of the study there were some “rural and private community providers who are not yet

contributing to the provincial [data] platform and represent sources of uncaptured data in the EHR.” The EHR is also linked to registries in the province so that deaths can be incorporated into the database. However, it is possible, likely even, that the EHR database has limitations (it was not designed for the purpose of the present study). It is possible that some patients who left the care of SAC were in care in other parts of the province with clinics not yet registered with the EHR.

Resources

[British Columbia researchers study HIV treatment interruptions and their consequences](#) – *CATIE News*

[CATIE statement on the use of antiretroviral treatment \(ART\) to maintain an undetectable viral load as a highly effective strategy to prevent the sexual transmission of HIV](#)

[Canada’s progress towards global HIV testing, care and treatment goals](#) – *CATIE News*

[Going beyond current ideas about the cascade of HIV care](#) – *CATIE News*

[90–90–90 - An ambitious treatment target to help end the AIDS epidemic](#) – UNAIDS

[Progress on Ontario’s HIV care cascade](#) – *CATIE News*

[Alberta—Reducing deaths by strengthening the HIV Treatment Cascade](#) – *CATIE News*

[Gaps in British Columbia’s HIV treatment cascade](#) – *CATIE News*

[The HIV treatment cascade – patching the leaks to improve HIV prevention](#) – *Prevention in Focus*

[The Engagement Cascade](#) – *The Positive Side*

[Health navigation](#) – *The Programming Connection*

[Linkage to care](#) – *The Programming Connection*

[The routine offer of HIV testing in primary care settings: A review of the evidence](#) – *Prevention in Focus*

[The HIV testing process](#) – CATIE fact sheet

[HIV testing technologies](#) – CATIE fact sheet

—Sean R. Hosein

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