TREATMENT TURNS 20

The transformative impact of antiretroviral therapy—on the epidemic, HIV care and what it means to live with the virus.

By Darien Taylor

Twenty years ago the lives of people with HIV suddenly changed. Since the early 1980s, we had been living in the shadow of death, watching as friends, lovers and entire communities got sick and died. Our doctors tried to treat the opportunistic infections that occurred as our immune systems weakened; we marched in the streets to demand political action, more funding and better treatment; AIDS service organizations sprang up to offer support; and hospices and care teams were assembled for the dying. But there was little we could do to stop the progression of this terrible disease we knew so little about.

By 1996 more than 4.6 million people worldwide had died from AIDS, more than 10,000 of them in Canada. And some 35,000 cases of HIV had been reported to the Public Health Agency of Canada.

Then, in what seemed like a moment, HIV became a chronic, manageable illness that—given access to good care and treatment—people could live with for many years.

The end of AIDS?

It took place before our eyes like theatre. In July 1996, at the XVI International AIDS Conference in Vancouver, one researcher after another spoke of a new concept: highly active antiretroviral therapy, or HAART—a combination of three or more drugs that targeted HIV at different stages of replication, to halt the virus in its tracks. Treatment activists like myself who took pride in knowing all about the development of new drugs were caught off-guard, unprepared, as the game-changing importance of the new combination therapies dawned on us, while we craned our necks to watch the presentation screens in the conference auditoriums. These combinations—or “cocktails,” as they were called—coupled with the new technology of viral load testing, were enabling people with HIV to achieve an undetectable viral load, meaning that the level of HIV in their bodies was so minimal that it could not be detected with the available technologies.

I remember meeting a colleague at the airport after the close of that whirlwind conference and giddily telling her that we were witnessing “the end of AIDS.”

Hit early, hit hard!

“Hit early, hit hard!” became the battle cry in the fight against AIDS. Jubilant researchers boldly predicted that the remarkable ability of HAART to slow down the replication of HIV might result in a cure. All HIV in the body might be killed over time by these new combinations—the “eradication theory.” (Unfortunately, they were wrong.)

That same momentous year, a clinical trial established that AZT-based therapy delivered during pregnancy and
labour and later to the newborn could reduce mother-to-child transmission by two-thirds. Subsequently, the use of combination therapy in pregnancy further lowered this risk. Combined with the routine offer of HIV testing to pregnant women, most jurisdictions in Canada now see very few infants born with HIV.

**Sober second thoughts**

But these life-saving treatments came with some considerable challenges. In our rush to embrace these miraculous drugs, we tended to at first ignore their side effects, the complex dosing schedules and food restrictions, the handfuls of pills—sometimes in the neighbourhood of 30, spaced out over the course of every day...and night. Without strict adherence, drug resistance could occur, limiting one’s treatment options for the future.

Then people with HIV began to notice strange patterns of fat redistribution on their bodies: hard fat accumulating on their belly (“crix belly”) or between their shoulders (“buffalo hump”) and loss of fat on their face and limbs. These profound side effects—a syndrome that would become known as lipodystrophy—further “marked” people with HIV.

In the initial euphoria of combination therapy, many people with relatively high CD4 counts, myself included, started taking these drugs. When my CD4s were above 500 I began taking a combination that included the protease inhibitor ritonavir (Norvir). I tolerated the diarrhea but as the fat on my upper arms began to disappear, I decided to go off therapy, preferring to wait until my immune system showed signs of weakening. Moving away from the mantra of “hit hard, hit early,” the consensus on when to begin therapy became more conservative, recommending that people start therapy when their CD4s were around 300, unless their viral load was exceptionally high or they developed opportunistic infections.

What happened to people with HIV became known as “the Lazarus effect.” Like the biblical character Lazarus, who was miraculously raised from the dead, people living with HIV were essentially being raised from their deathbeds by these new therapies. Many of us experienced “survivor’s guilt,” the philosophical puzzle of “why me?” after having seen so many die only to find that we had been spared and granted a new lease on life.

There were economic and social repercussions, too. Many of us had been forced to give up our plans for the future, education and careers, had lost loved ones by the dozens and had ourselves been sick for years. It took real courage to re-engage with the world at large again, to go back to work and to risk falling in love again. For me, as someone who had been lucky enough to stay employed throughout these years of uncertainty, my big commitment was a mortgage on a small house in Toronto’s rather down-at-the-heels Parkdale area. I hoped to be around to pay it off—and in three years I will have.

In the meantime, researchers were working to develop new drugs with fewer side effects. Successive generations of combinations slowly became easier to take.

With clinical trials such as the SMART trial, which started in 2001, the HIV community began to realize that there was going to be no reprieve from strict adherence to the medication regimens. No structured treatment interruptions, no “drug holidays,” only relentless day-in, day-out adherence. And so it remains to this day.

**The meaning of “undetectable”**

In 2008, a group of physicians in Switzerland released the controversial Swiss Statement. It held that HIV-positive people posed “no risk” to their sex partners if they had an undetectable viral load for at least six months, were on ART and had no sexually transmitted infections. Though the Swiss Statement had many detractors who questioned the scientific evidence informing it as well as its application to the sex lives of gay men, it heralded the current period of treatment (now commonly called ART) when research has confirmed that ART can indeed greatly reduce the chance of transmitting HIV when one’s viral load is suppressed. In addition to huge health benefits for HIV-positive individuals, we learned that HIV treatment could also be used to prevent HIV.

These findings have led to the development of pre-exposure prophylaxis (PrEP), perhaps the most promising HIV prevention strategy since the condom. With PrEP, taking the antiretroviral drug Truvada daily enables people who are HIV negative to have safer sex with partners who are HIV positive. In HIV-negative people who take it, Truvada acts to prevent HIV from gaining entry to their immune system. Though guidelines for the use of Truvada for PrEP continue to stress the importance of using condoms, some HIV-negative men and women experience difficulties in using condoms consistently, and Truvada provides them with additional protection.
The pendulum swings...again

As antiretroviral drugs have become easier to take with the advent of one-pill-once-a-day regimens with few side effects (such as Atripla in 2006) and we have gained a better understanding of the effects of chronic inflammation on the body caused by the ongoing presence of HIV, we began to re-examine the question of when to start treatment. Recently, results from the START trial showed the significant health benefits of beginning soon after diagnosis, even if your CD4 count is still high, signaling the revision of treatment guidelines.

The next 10 years

Unfortunately, ART does not cure HIV. Nor does it eliminate much of the immune dysfunction and inflammation that over time can lead to heart and bone disease, neurocognitive problems and other health concerns. The search for answers to these problems will likely lead researchers beyond the realm of ART.

Challenges still remain in identifying people who are HIV positive, ensuring that they stay in care, receive treatment and are able to maintain an undetectable viral load. Though our conference rallying cries may insist that no one be left behind when it comes to treatment access, the fact is that throughout Canada many individuals and communities are left behind when it comes to HIV testing and accessing good treatment—Aboriginal people, refugees, people with mental health issues, people who use drugs, people in small towns and rural areas who must travel great distances for care. Equitable access is an important—and surely an achievable—hurdle to overcome in the next 10 years.

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- A Doctor’s Perspective: Care Then and Now—Dr. Philip Berger
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- PHA Perspectives: You + ART
- The Push for Access—Tim McCaskell
- The Evolution of HIV Treatment—Sean Hosein
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- Treatment Timeline
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