





For People With HIV, 'Test and Treat' Is Key

MICHAEL J. O'LOUGHLIN
Contributor to *Health Progress*

Sam Moore needed help. Diagnosed with HIV in 1997, the New Orleans native kept his health in check with daily medication, something of a miracle considering the devastation HIV and AIDS unleashed on marginalized communities in the 1980s and 1990s.

Though he initially struggled with his diagnosis — he said he was admitted to a psychiatric ward upon learning the news — Moore adapted. But when he returned home to New Orleans in 2017, following the death of his girlfriend, he turned to once-familiar coping methods, including drugs and alcohol, and was soon living on the streets.

When an outreach worker told Moore about Project Lazarus, which provides temporary housing to people living with HIV, he applied for an apartment and moved in a month later.

Staff at Project Lazarus, supported by the Archdiocese of New Orleans, connected Moore, 59, with medical professionals who ensured he had access to the right medications. They helped him find a job and eventually a permanent home. Last year, when Moore suffered a setback, he returned to Project Lazarus, and is waiting for permanent housing. But the community keeps him upbeat.

"Dealing with HIV, you know, you've got the negative people and you've got the positive people," Moore said. "Don't listen to the negative ones. Follow the positive ones."

Moore's story is emblematic of the multiple challenges facing many of the nearly 1.2 million Americans living with HIV.¹ While the HIV and AIDS crisis peaked in the mid-1990s, according to federal data, tens of thousands of people are diagnosed with HIV annually.² About 30,000 people tested positive in 2020, down about 19%

from five years earlier. That is all good news, and while pharmaceutical advances make living with the virus manageable, people from the most marginalized communities continue to struggle with gaining access to appropriate medical care.

At St. Mary's Health System in Lewiston, Maine, the HIV case management clinic has served their rural community since about 2000. The founder of the clinic, Dale Morrell, recognized at the time that while most nonprofits focused on prevention and education, there were few organizations serving people already living with HIV.

The clinic's decision to discern how it could be of service to the community was inspired by the spirit set forth by the Sisters of Charity of Saint-Hyacinthe. They founded the system's first hospital in 1888, having arrived from Montreal to provide health care to the then-sizable French Canadian population.

Early in the HIV clinic's work, patients were frustrated that local doctors seemed to know little about HIV care. Stigma was rampant. Today, much of that has changed, and the clinic connects its patients to nursing professionals and case managers.

Mara Larkin, the clinic's director of care coordination, introduces patients to medical teams and helps them enroll in programs that subsidize their coverage. In terms of accessing care, the clinic considers the whole person, not just their medical realities.

“When you also have transportation issues, when you don’t have housing, when you don’t have access to good food, sometimes it can be challenging to follow a strict medical regimen,” Larkin said. “We try to be a clearinghouse of needs, and when we cannot fulfill them directly, we make referrals to the community.”

With ongoing inequities experienced by people living with HIV in minority and marginalized communities, consideration of all aspects of one’s social determinants of health when providing care remains essential.

ADDRESSING DIVERSE POPULATIONS

Some of the challenges facing an HIV care clinic, like the one at St. Mary’s, may not be entirely apparent when envisioning a rural patient population, such as the one in Maine.

Roughly 6,000 of Lewiston’s 36,000 residents are refugees and asylum-seekers, including many from Angola and Congo.³ St. Mary’s, and its HIV clinic, serve these “new Mainers,” as Larkin calls them, as they adjust to life in a new country. Sometimes, that means helping patients manage the surprise of an HIV diagnosis.

“It can be impossible to get care if you can’t get enough to eat, and you can’t get a roof over your head.”

— DR. TIMOTHY FLANIGAN

The clinic staff helps patients navigate government bureaucracy to see if they are eligible for financial assistance and tries to lessen the stigma still associated with the virus. Some clients have even been skittish about using translators because of fear that their diagnosis will get out into their community. “So, there’s a huge effort with confidentiality, and we are encouraging access in ways that are not self-evident that this is what individuals are accessing,” Larkin said.

In addition to holistic care, including special attention to mental health, the clinic also focuses on a particular challenge related to HIV that would have been difficult to imagine during the earliest days of the crisis: helping people age well while managing life with the virus, a possibility because of incredible advances in HIV treatment options.

One physician, who has worked with patients

with HIV and AIDS for decades, said he never imagined the efficacy of the drugs available today — and the long lives his patients would go on to lead — when he first started practicing in the 1980s.

“Effective treatment for HIV is one of the great advances of modern medical care,” said Dr. Timothy Flanigan, an infectious diseases doctor at The Miriam Hospital and Rhode Island Hospital and a professor of Medicine at the Alpert Medical School at Brown University.

Flanigan, who is also a Catholic deacon, said an individual with HIV can stop viral replication and actually reverse their disease, allowing the immune system to repair itself. The treatment that makes that possible, Flanigan said, is “highly effective, very straightforward and has very few side effects.”

So does that mean the challenge of HIV is over?

“The answer is no,” Flanigan said, “because individuals with HIV struggle with so many different, overlapping conditions which are so hard to overcome.”

Those challenges form “overlapping epidemics,” he said, and often include substance use disorders, including alcohol dependency, as well as mental health issues and a lack of access to basic necessities.

“It can be impossible to get care if you can’t get enough to eat, and you can’t get a roof over your head,” Flanigan said.

Then there is internalized stigma.

Catholic health care workers serving people with HIV should remember that “one of the great gifts of our faith is that each of us is a child of God,” Flanigan said. “We may have this or that illness, but that doesn’t define who we are.”

Helping patients accept that, however, can be challenging, but it’s essential if access to care is a priority.

“Putting your hand on their shoulder and telling them that our medications are phenomenally good, that we are going to provide care for you, that you are not going to walk this journey alone,” Flanigan said, “gives that person hope.”

Hospitals can help underresourced patients connect with clinics affiliated with the Ryan White HIV/AIDS Program, a federally funded program that serves low-income people with HIV.⁴

“For anybody providing medical care, it’s



important that they feel comfortable providing HIV testing, HIV screening, as well as HIV prevention,” Flanigan said.

Sometimes testing and screening is most effective when it takes place not in a clinic, but out where people live.

Atlanta, like other Southern cities, has struggled to combat stubbornly high rates of HIV.⁵

Mercy Care, which traces its roots to Catherine McAuley, founder of the Sisters of Mercy, reaches out to residents in Greater Atlanta to provide rapid HIV testing and to connect people newly diagnosed with the virus to proper health care.

Andrea Steward manages the HIV prevention and treatment for Mercy Care. In recent years, she has hosted testing events at music festivals, in retail spaces and at local universities. These included Morehouse College, where Mercy Care offered testing on World AIDS Day, commemorated each December 1.

The mobile testing process is straightforward — completed in about five minutes — but following up with patients who test positive can be difficult. Obstacles include patients who lack cell phones and email addresses; transportation challenges; and maintaining vital education, especially when it comes to medical adherence.

“It’s really important to make sure that they’re taking their medication accurately, because we want to make sure they don’t become resistant to a medication,” Steward said.

UNDERSTANDING VARIED COMMUNITY NEEDS

HIV affects different communities in unique ways. That means hospitals and health systems have to consider how they interact with individuals from particularly marginalized communities.

Helping health care workers understand those communities, and their unique needs, is the goal of Sean Cahill, PhD, the director of health policy research at The Fenway Institute, a secular non-profit organization based in Boston that focuses on LGBTQ health and those living with HIV.

“Transgender people live in our society, they have health care needs, they need access to health care, just like everybody else,” Cahill said. “And they need care that’s nondiscriminatory, culturally

responsive, affirming and clinically competent.”

According to a 2017 report, coauthored by Cahill, “transgender women of all racial and ethnic backgrounds are 49 times more likely to be HIV-infected than the general population” and they “are less likely than other (HIV-positive) populations to adhere to their antiretroviral medications.”⁶

With ongoing inequities experienced by people living with HIV in minority and marginalized communities, consideration of all aspects of one’s social determinants of health when providing care remains essential.

Transgender women report high incidences of negative experiences in health care settings, the report states, in part because of decades of social injustice, leading to hesitation when it comes to managing HIV. Those kinds of experiences can be mitigated by training.

Cahill said hospitals can do simple things to help LGBTQ patients feel welcome, like display rainbow or transgender flags in common spaces and advertise in LGBTQ media. But then, Cahill said, institutions have to “walk the talk.” That means asking patients their preferred names and pronouns, for example, to alleviate some anxiety.

One goal must be paramount for health care workers if there is any hope for the epidemic to wind down, according to several HIV experts.

“The most important way to prevent transmission is to get people who are infected on treatment,” said Dr. Jon Fuller, SJ, a Jesuit priest who provided HIV care at Boston Medical Center from 1987 until his retirement in 2021.

Fuller called the advent of modern pharmaceuticals such as pre-exposure prophylaxis (PrEP), medications that reduce the chance of someone contracting HIV through sex or IV drug use, miraculous. But remaining undetectable is the key.

The concept of getting people with HIV onto antiretroviral therapy treatments, to suppress an individual’s viral load to the point where it is undetectable, is referred to as HIV Undetectable=Untransmittable (or U=U). It

means that the person cannot spread the virus, thus making it untransmittable. The results are twofold, protecting a person's own health and slowing the spread of HIV.⁷

"If you've got HIV suppressed, and you're otherwise in good shape, with good nutrition and exercise, you can live a life expectancy that's going to be determined by your other medical conditions, not by HIV," Fuller said. "Not only will you be taken care of, but the epidemic will stop spreading."

While longer-lasting injections are now available, most PrEP medications have to be taken daily.⁸ That can be difficult for people experiencing various crises, especially challenges associated with housing or mental health. And while Fuller is encouraged that PrEP is becoming more accessible and widely used by gay and bisexual men, as well as transgender women, he laments that Black and Hispanic communities are unable to access the medication at the same rate as gay, white men.⁹

OVERCOMING OBSTACLES FOR BETTER HEALTH OUTCOMES

Back in New Orleans, the executive director of Project Lazarus, Susanne Dietzel, PhD, sees firsthand how similar inequities plague the population she serves, including Moore.

Some are widespread in many communities and can be intertwined, such as not being able to secure appointments with physicians, cognitive disabilities and unstable housing that make taking a daily medication difficult.

Others are more localized, but no less challenging.

"At the beginning of every hurricane season, we always say to our residents, 'We want to make sure that everyone has at least a 30-day supply of their drugs in hand,'" Dietzel said. "If we have to mandatorily evacuate, we want to make sure that they have all of the necessary information that they need to access their drugs somewhere else."

But Project Lazarus fills one specific need that nearly everyone interviewed for this story said remains essential to helping people with HIV access care.

"Housing is health care," Dietzel said. "Stable housing encourages people to have their drugs in a regular place at all times."

"Housing and nutrition are absolutely critical,"

she said. "You take one of those out of the equation, then someone's health status declines rather rapidly."

MICHAEL J. O'LOUGHLIN is the national correspondent for *America: The Jesuit Review*, author of *Hidden Mercy: AIDS, Catholics, and the Untold Stories of Compassion in the Face of Fear* and host of *America's* podcast series "Plague."

NOTES

1. "HIV Basics: Basic Statistics," Centers for Disease Control and Prevention, June 21, 2022, <https://www.cdc.gov/hiv/basics/statistics.html>.
2. U.S. Statistics, HIV.gov, October 27, 2022, <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics/>.
3. Cynthia Anderson, "Refugees Poured into My State. Here's How It Changed Me," *The Christian Science Monitor*, October 28, 2019, <https://www.csmonitor.com/USA/2019/1028/Refugees-poured-into-my-state.-Here-s-how-it-changed-me>.
4. "The Ryan White HIV/AIDS Program: The Basics," Kaiser Family Foundation, November 3, 2022, <https://www.kff.org/hiv/aids/fact-sheet/the-ryan-white-hiv-aids-program-the-basics/>.
5. Ellen Eldridge, "On World AIDS Day, Georgia Leads the Nation in New HIV Cases – And Atlanta Is a Hot Spot," GPB, December 1, 2022, <https://www.gpb.org/news/2022/12/01/on-world-aids-day-georgia-leads-the-nation-in-new-hiv-cases-and-atlanta-hot-spot>.
6. Connor Volpi and Sean Cahill, "Retaining Transgender Women in HIV Care: Best Practices in the Field," The Fenway Institute, 2018, https://fenwayhealth.org/wp-content/uploads/TFIR46_RetainingTransgenderWomenInHIVCare_BestPractices_web.pdf.
7. "HIV Undetectable = Untransmittable (U=U), or Treatment as Prevention," NIH, <https://www.niaid.nih.gov/diseases-conditions/treatment-prevention>.
8. "FDA Approves First Injectable Treatment for HIV Pre-Exposure Prevention, U.S. Food and Drug Administration, December 20, 2021, <https://www.fda.gov/news-events/press-announcements/fda-approves-first-injectable-treatment-hiv-pre-exposure-prevention>.
9. Benjamin Ryan, "PrEP's Promise to Change the Course of HIV Has Succeeded — But Only for White Gay Men," *NBC News*, March 18, 2023, <https://www.nbcnews.com/nbc-out/out-health-and-wellness/preps-promise-change-course-hiv-succeeded-only-white-gay-men-rca75438>.

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

www.chausa.org

HEALTH PROGRESS®

Reprinted from *Health Progress*, Summer 2023, Vol. 104, No. 3
Copyright © 2023 by The Catholic Health Association of the United States
