

Gatekeepers of Health

HIV care has improved
dramatically—but
not for everyone

By *David Malebranche*

ON A SWELTERING JUNE DAY IN 2021, Nicole, whose real name has been changed to protect her privacy, walked into an HIV treatment clinic in Atlanta, Ga., expecting something different. She had shouldered a lifetime of discrimination for being both Black and transgender while also dealing with HIV, diabetes and hypertension. She worked as a manager of a fast-food restaurant while parenting several LGBTQ youths. Accessing consistent health care was a daily battle, and Nicole's past interactions with providers had left her feeling discouraged. But she and I had hit it off during a previous telemedicine appointment, so she scheduled a face-to-face visit at the clinic where I worked. As a Black, same-gender-loving physician, I wanted to do better by her.

Despite the amazing scientific advances in HIV care that have taken place since the epidemic began 40 years ago, many people in racially and sexually minoritized communities still fall through the cracks. Some can't afford care, and others can't access it because of job or family demands, lack of transportation or documentation, or other barriers. Many face stigma and discrimination from medical providers themselves. I was determined to do everything I could to change the narrative of Nicole's health-care experiences that day.

She obtained HIV medications through the AIDS Drug Assistance Program, which provides antiretroviral therapy (ART) for the uninsured. To remain eligible for the state-sponsored program, she endured cum-

bersome bureaucratic paperwork, drove 45 minutes each way to the clinic for regular visits and attended required meetings with a benefits counselor every six months. To save money, she filled prescriptions for some of her other conditions at several different local pharmacies. She got her hormones off the street because a previous clinician had refused to prescribe them unless she sought mental health counseling first.

Nicole arrived 30 minutes late for our appointment after a long commute into the city during rush-hour traffic. As we discussed her gender identity, sexual health and romantic partners, I saw a surprised look on her face, suggesting to me that few clinicians had asked her these questions before. Her physical exam was mostly normal,

except for extensive anal warts. "They've been there a long time," she said. "No one knows what to do with them." I imagined some medical providers being so uncomfortable with her being transgender that they bypassed the genital exam altogether.

As we sat together in that sterile exam room, I realized that the medical community had failed her, and it wasn't because of a lack of advances in HIV treatment and prevention. ART has evolved from toxic medications taken multiple times a day to single-tablet regimens with few side effects. We now have bimonthly injections that can maintain full viral suppression. First approved in 2012, preexposure prophylaxis, or PrEP, given as a daily oral pill or bimonthly injection can reduce one's chances of contracting HIV by 90 to 100 percent. Despite these great scientific strides, Nicole wasn't reaping the benefits of this progress.

What's to blame? Many social, institutional and interpersonal medical barriers are. Inequities in housing and food insecurity, access to insurance, and bias and stigma in medical care contribute to persistent racial and ethnic disparities in HIV incidence rates, engagement in care and viral suppression. For Nicole, HIV is just one of many circumstances that make everyday life challenging. America's fragmented and dysfunctional health-care system only makes things worse.

These disparate HIV health outcomes are complicated by a labyrinth of bureaucracy within medical spaces that make it nearly impossible for many to access medications that should be within their reach. This includes cumbersome paperwork to obtain ART if one is uninsured, underresourced clinics and medical staff burnt out from COVID, and institutional policies that prioritize visit numbers and copay billing over patient-centered care. For people living with HIV, these issues within our nation's clinics can make getting and staying on ART a climb that feels insurmountable.

After her exam, Nicole asked, "So, can I get my lab work done?" Unfortunately, because our appointment started late, the technicians had already left for the day. She would have to make another trip. Even our clinic, which worked hard to help those who needed it most, wasn't flexible enough to help her on this occasion. As I watched her



face cloud with disappointment, I feared we would lose her again. I feared that I was failing her, like so many clinicians before me.

Despite my concerns, Nicole told me she left that day feeling encouraged because she felt heard for the first time in eons. We planned to restart her ART, refer her to colorectal surgery to evaluate her warts, explore insurance options with her employer and consolidate all her medications at a single pharmacy. I sent in her hormone prescriptions, confirming what she already knew: there is no universal policy requiring a mental health specialist to approve them.

The burden of improving HIV prevention and treatment is now on the shoul-

ders of our medical systems. As we seek to provide more equitable care, statewide and national policy improvements must be accompanied by changes within health-care systems and clinics: We must enhance case management staff to ensure patients can get to their appointments and understand the processes required to access treatment. We must make sure patients can have necessary blood work done on the day of their checkup appointment. We must develop sensible patient-flow protocols to ensure that people are seen in a timely and efficient manner. Offering patients a diverse range of appointments, such as telehealth, walk-ins and house

calls, can accommodate the fluidity of life. Clinics need to hire staff and providers who reflect the communities served, and they should invest in cultural humility training to reduce bias and stigma in treatment. Modifications at the clinic level, though relatively small compared with sweeping national policies, can have an enormous impact on whether someone living with HIV decides to continue accessing care there or not.

Medical approaches to HIV prevention and treatment have come a long way. These revolutionary breakthroughs can help tackle the current HIV health inequities in the U.S. and ultimately lead to a cure. But this will all be for naught if the medical systems and personnel who are the gatekeepers to these advances act more like health-care barriers than facilitators.

I'd like to tell you that the work we did that day helped Nicole feel more optimistic about trusting medical systems and providers. I'd like to tell you that her future clinic appointments went smoothly and didn't require repeat visits. I'd like to tell you that she found her voice with her employer, obtained private insurance through her job and is now receiving care for all her medical issues. I'd like to tell you she is being treated by other medical staff with the dignity and respect she deserves.

But I can't. She missed our next appointment, and by the time the clinic was able to reschedule her, I had stopped working there. Truth is, patients fall out of care more often than we like to admit, sometimes because of a revolving door of clinical providers entering and leaving these settings. I took solace in knowing that we had connected that day and that I did my best to give her the medical care she deserved. Perhaps our interaction restored her faith in human connectedness—a dynamic that may alleviate some of the harm inflicted by broken and discriminatory health-care systems. Nicole came to our appointment expecting something different. I hope she now realizes that something different is possible.

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