Dealing With HIV-Related Discrimination or Stigma in a Health Care Setting

Many people living with HIV face discrimination—or are otherwise made to feel uncomfortable—at doctors' and dentists' offices, hospitals and other health care settings.

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Alora Gale thought that by the late 2000s, most—if not all—medical providers understood that HIV does not survive long outside the body and cannot reproduce outside a human host. "Even in 2008, a quick Google search would've answered this question," says Gale, 40, a Seattle-area resident who was born with HIV and formerly ran BABES, a longtime peer group for women living with HIV. But that year when she spoke to her longtime ophthalmologist about having LASIK surgery to improve her vision, the ophthalmologist consulted a LASIK-performing colleague who warned that Gale's HIV "could become airborne and infect everyone in the room," Gale recalls. On that basis, she was deemed ineligible for surgery.

"That's the BS my doctor accepted and brought back to me," she says. Despite being a longtime advocate for people living with HIV, she says she was so "shocked, dismayed and bewildered in that moment" that she just walked out without saying a word. "When things like that happen in a trusted space, it just hits differently, and I wasn't ready to fight back."

But that soon changed. Gale called her ophthalmologist and asked to have her records transferred to a different provider. Didn't she want to try to talk through it first? "Absolutely not," she says. She felt the claim was so far-fetched that the doctor should have researched it to learn that it wasn't true.

Gale ultimately didn't get the LASIK surgery for a variety of reasons. But the incident with her ophthalmologist echoes recent tales of many people living with HIV who say that even in this era, when it is known that people with HIV on antiretroviral medication with a suppressed viral load cannot transmit the virus sexually (never mind casually, such as in a medical setting), they still encounter problematic incidents in health care settings. These range from acts of outright discrimination to moments during which providers and their staff betray their ignorance and anxiety about HIV in ways that make patients living with the virus feel uncomfortable.

For example, a study done in 2006—well into the era when HIV transmissions routes were clearly

understood—found that roughly half of skilled nursing facilities in the Los Angeles area refused to treat people with HIV, despite the fact that such refusal is unlawful under the Americans with Disabilities Act (ADA), which classifies HIV a disability. And a 2022 European study found that people with HIV were experiencing the same levels of stigma in health care settings as they had a decade earlier. Even though 83% of health care workers who did not specialize in HIV knew that medically suppressed (undetectable) HIV cannot be transmitted (this is known as Undetectable Equals Untransmittable, or U=U.) 40% said they would still be nervous about drawing blood from someone with HIV.

So how can you respond to what you believe to be discrimination by a health care provider—whether a primary care physician, a dentist or a hospital staffer—based on your HIV status? Better yet, how can you prevent it in the first place? To start, read our tips for patients and providers.

But first, it's important to understand the difference between outright discrimination and comments or behavior that may feel strange or uncomfortable. More often than not, the problem is a result of a staffer's ignorance or thoughtlessness—or, in some cases, HIV-related fear or stigma.

"There's a legal difference," says Demetre Daskalakis, MD, who recently became chief medical officer at New York City's LGBTQ-serving Callen-Lorde clinics after long stints heading up infectious-disease response in New York City and at the Centers for Disease Control and Prevention (CDC). "Discrimination means outright refusal of care or being given subpar or unequal care or service based on a demographic or medical characteristic, like your race, gender or having HIV."

This is serious and unlawful, and addressing it properly requires careful consideration. Ultimately, it's up to you whether to hold a health setting accountable or, for your own peace of mind, simply walk away.

But health staffers sometimes say or do things in front of patients with HIV that do not constitute outright discrimination, says Daskalakis, but that are "weird or annoying" and often put the burden of education on the patient. Take Sonya Jean Millman, 54, a health worker in Baton Rouge, Louisiana, diagnosed with HIV in 2017. She says that, once, right after she told a health clinic receptionist that she was living with HIV, the receptionist "sanitized her hands in front of me, twice, while handing back my insurance card." Millman didn't say anything to her—and acknowledges that the receptionist might have done that with all patients—but it still left her feeling dirty and stigmatized because of her HIV status.

Millman recalls another incident after she'd had a colonoscopy when "two drops of my blood hit the floor," and two nurses rushed in "with gloves up to their elbows and a bunch of sanitizer"—a response that she felt was extreme and stigmatizing. This time, says Millman, a longtime HIV peer educator, she approached the health center's leaders to ask whether they might be interested in HIV 101 training for staff led by her in partnership with her job at the time and a local nursing

school. The health center happily agreed. “So stigmatizing me actually turned into an opportunity to educate,” she says.

Those incidents, she says, were similar to another time when a health care staffer wrote “HIV+” prominently on her chart and left it in a place where anyone, including other patients, could see it, which violates HIPAA, the federal health privacy law.

But other cases go well beyond discomfort and cross into outright discrimination. In 2020, for example, Michael Mitchell, 62, of Atlanta, who was diagnosed with HIV in 2005, had an experience similar to Gale’s. He was told flat-out by an ophthalmology practice that it wouldn’t perform LASIK surgery because he had HIV. As justification, the practice cited guidelines that had not been updated since it was established around 2011 that people with undetectable HIV cannot transmit the virus.

Enraged, Mitchell contacted the Office of the Attorney General, who told him that the refusal was a clear violation of the ADA. But then, says Mitchell, the practice filed for bankruptcy, selling the business to a new one that did not assume liability for prior lawsuits. (Perhaps not so coincidentally, Mitchell adds, the new practice was owned by the same ophthalmologist who owned the old one.)

Mitchell ultimately had his LASIK surgery done elsewhere, without incident. Still, he’s glad he looked into action against the original office, even though the matter wasn’t resolved. He wasn’t seeking money, he says, “I wanted them to change their policy.”
