

PERSONAL NARRATIVE

PrEP and the Judgment of Prevention

Samuel Dubin

Abstract

Medicine sometimes fails to address social, economic, and political determinants of health. But how far beyond clinical encounters should intervention efforts extend? Because prevention efforts can marginalize patients by stigmatizing certain behaviors, interrogating the scope of medicine's prevention obligations is important. Additionally, it is important to distinguish clinician preferences regarding patients' personal behaviors (presumably based on clinicians' hopes for patients' positive health outcomes) from clinician biases expressed (consciously or unconsciously) about those behaviors. I illustrate the urgency of asking how far medicine should be expected to go to prevent disease by sharing how my own medical training has stoked my personal fear of acquiring HIV.

Why I Fear HIV

I fear HIV because of what it would do to my career. I'm an out, gay medical student interested in lesbian, gay, bisexual, transgender, and queer (LGBTQ) health advocacy, so the thought of getting an [HIV diagnosis](#) scares me because I get the feeling, from many different communities of which I am a part, that to get HIV would undermine my credibility and be a blow to my career. To be clear, it is not the health effects of HIV that would set me back. I have access to health care and the resources to take medications to suppress my viral load. I'm probably more likely to die riding my bike in Manhattan than from HIV. Frankly, I would rather have HIV than many other modern-day chronic diseases.

I've come to realize that my fear of HIV has to do with the social authority of medicine. By "social authority," I'm not talking about my grandmother's tacit approval of medicine as the only career she endorsed. (Heaven forbid I pursue a PhD!) Rather, what I mean by fearing medicine's social authority is that I'm more likely to be judged by colleagues for not wearing a condom than not wearing a bike helmet—but not because of statistics on comparative risks of biking and anal sex. It's because of how prevention-based medicine can create stigma by constructing "risky" behaviors as immoral under the banner of health. How could I possibly authoritatively counsel patients on their behavior, how could I help them prevent illness, if they perceived my own choices as poor and my illness as

evidence of moral failure? Who would want me as their physician or trust their health to my expertise if they knew I had HIV and thought I should've known better than to get it?

In short, according to what's typically called victim-blaming logic, those who do not take care of their health deserve the outcomes. Tobacco stigma exemplifies this logic. Isn't your first question when you hear someone has lung cancer, "Well, did they smoke"? The assumption is that people have a social duty to manage their health.

I don't endorse victim blaming; I fear it. I fear what would happen to my career if I lost credibility among my patients because they knew I had HIV. I fear having my patients hear my fear in things I say. And I fear HIV because I think many patients subscribe to a belief in self-responsibility and self-blame for illness—or at least seem to act on this belief. The perception of HIV as a moral failure would render me unqualified to prevent illness in my patients. Living with a chronic acquired health condition, on this line of thinking, makes me a moral failure and therefore an impotent clinician.

I realize that clinical encounters are not about me. I understand that most patients will probably not know my HIV status. And even if I were positive, and they did know, the extent to which they might doubt my clinical skills would certainly be variable. The thought of having my HIV status "outed" or of enduring workplace discrimination because of HIV are very real concerns. But what I dread the most—what would be most compromising to my career—is the exhausting and inevitable dissonance that preaching prevention-based medicine as a physician with HIV would force me to experience. The process of working through this fear prompted me to reflect on the nature of [HIV stigma](#) and what is expected of me as a physician. But I think it's time for medicine to do a little bit of self-reflection, too. I want medicine to ask itself: How does the social authority and cultural status of medicine create stigma and shame around notions of responsibility and health?

My Experience of Stigma

I was stigmatized by members of the health care profession when seeking to alleviate my fear of HIV by taking [pre-exposure prophylaxis](#) (PrEP), a pill that when taken daily reduces the risk of getting HIV to less than 1%.¹ I had just moved to New York City, I was single, and I had access to PrEP. But because my insurance has an enormous deductible—meaning I had to pay out of pocket until I had spent \$3000 on medications alone—PrEP was only free (using a voucher from the copay program that paid up to \$3600 annually) for 6 months. After 6 months, I would be shelling out \$150 to take a pill that, while reducing my risk of HIV, was mainly reducing my anxiety, given that I still used condoms. A price tag on the emotional risks of your sex life creates a bizarre psychology.

Ultimately, I stopped taking PrEP because the costs, financial and other, outweighed the benefits. I had made an informed decision on how to approach the health risks in my life. But to my physician, I was a risk factor. We didn't discuss the complex negotiation of

insurance issues or the pressure I felt from other gay men in New York City to have to be on PrEP. It is a privilege to have access to a physician who prescribed PrEP. But the well-meaning physician made me feel slut-shamed and stigmatized by seeing PrEP as the only option for me because of an intolerable risk of my acquiring HIV. To my physician, prevention-based medicine—"Don't let patients get a disease"—meant pushing PrEP on me. To me, this approach meant stigmatizing my gay identity as inherently risky and fostering insecurity around my identity as a medical trainee. It was then that the social authority of medicine became apparent to me.

I didn't leave my physician feeling empowered by the option of a new HIV-prevention technology. Instead, prevention-based medicine had sent the message I was risky and immoral, that acquiring HIV would be my fault.

To be a good physician, I need to prevent illness. To prevent illness, I need to probe a patient's behaviors. To do that, I need moral credibility. HIV throws a wrench in this tidy equation. These moral mechanics prompt the question: What should change in health care? My physician is not the problem. She was fulfilling her mandate of illness prevention. But this came at a cost to me, a cost that viral load and insurance bills cannot capture or quantify. I don't know how to solve this complex dilemma, but I don't see a conversation happening from which a solution will emerge.

Conversations about how far prevention-based initiatives should extend into someone's private life and the potential for prevention-based stigma must happen simultaneously. To merge these conversations requires a new framework for examining physician authority, analyzing preventative health goals, and considering everything that we know influences health. As public health shows us how many factors other than personal behavior influence health, medicine is being called upon to answer, by PrEP and other means, how much farther than personal behavior it is willing to go. It is time for medicine to tackle the blurred edges to which technology, health prevention, and public health are pushing it.

References

1. Patel P, Borkowf CB, Brooks JT, Lasry A, Lansky A, Mermin J. Estimating per-act HIV transmission risk: a systematic review. *AIDS*. 2014;28(10):1509-1519.

Samuel Dubin is an MD candidate at the New York University School of Medicine in New York City with an expected completion date of spring 2020. He recently completed the Rudin Medical Ethics and Humanities Fellowship. He has been involved in pre-exposure prophylaxis for HIV policy research and outreach.

Citation

AMA J Ethics. 2019;21(6):E536-539.

DOI

10.1001/amajethics.2019.536.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.