PrEP and Prejudice

Can personal choice and public health find common ground in pre-exposure prophylaxis?

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“PrEP is not a silver bullet.”

If you speak to a lengthy roster of HIV advocates and researchers about the controversial HIV prevention pill Truvada, you will hear a good handful of them, unprompted, utter this phrase verbatim.

Providing the drug to HIV-negative people isn’t meant as a panacea that will brush aside all other prevention methods, the experts stress. And only time will tell if pre-exposure prophylaxis, or PrEP, will actually help curb the U.S. HIV epidemic, in particular among gay men.

Success on a public health scale depends on whether Truvada ends up in the medicine cabinets of a critical mass of people at high risk for HIV, and if they wind up adhering well to the daily regimen.

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It’s been over two years since Truvada, a common HIV treatment tablet including the antiretrovirals tenofovir and emtricitabine, was approved for use as prevention for the virus. Rivers of ink have been spilled during the past 12 months over PrEP’s apparently tepid uptake. But recent evidence suggests that PrEP is finally starting to catch on among gay men, and that a burgeoning revolution may be upon us.

What is already abundantly clear is that providing HIV-negative people with a drug that may be as much as 100 percent effective at preventing HIV can be powerfully transformative on the individual scale. Out of the dozens (nearly all of them gay men) who shared their stories about being on PrEP for this article, many described life-altering sexual and personal renaissances as, for the first time ever, they discovered what it was like to have sex without fear.

“PrEP makes me feel good about being gay,” says Evan (some of those interviewed preferred to

use their first names only), a 22-year-old full-time sex worker living in Washington, DC. “Growing up gay is still really hard. The first things that we learn about our sexuality are that some people aren’t going to like us, and that we are probably going to get HIV. Taking PrEP has allowed me to step into my sexuality and feel empowered.”

PrEP, he adds, “has led me to accept all gay men as a potential friend, sex partner or life partner regardless of their HIV status.”

Quentin Ergane, 38, who works as a caregiver in a group home for adults with mental illness in Seattle, is perhaps the perfect PrEP candidate. Despite being all too familiar with the alarmingly high rates of HIV among his fellow African-American men who have sex with men (MSM); despite seeing his father, his favorite cousin and his best friend all die of AIDS-related causes; despite an often crippling fear of becoming HIV positive; and despite knowing that condoms could help protect him, he has still used them only haphazardly since his domestic partnership ended in 2009.

“Coming out of 10 years of absolutely not using condoms, and now you’re single and you have to use condoms again, I just didn’t feel like I was getting close to anybody,” Ergane says, adding that decreased pleasure during sex is another key, if less important, factor contributing to his disdain for latex, which is a common refrain among gay men.

“It doesn’t always occur to me in the heat of the moment to put on a condom,” he says. “And also, that set-up is just so unnatural. Do people really stop their intimacy, their connecting, their passion, their everything, and then put on a condom and expect to go back to it on the same level?”

After starting PrEP early this year, “I felt free, finally,” he says. “For the first time since I was a kid, I know my sexuality is not going to be the cause of my death.”

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When gay men describe not using condoms despite intentions to do so, they’ll often use language suggesting this was an accident largely outside of their control: “I slipped.” Some might even describe an almost disembodied state of mind: “I noticed my consistency with condom use had changed.”

Critics may argue that this amounts to a vernacular sleight of hand to deflect justifiable blame for failing to carry through with a rational process. However, as John Guigayoma, a 28-year-old San Franciscan, can attest, sex has a powerful capacity to override such rationality. Like Ergane, Guigayoma found his sexual behavior was running contrary to the HIV prevention ethos he’d been taught—and which, in his case, he was also teaching others. Despite working at a health education outfit, he used condoms sporadically as he wrestled with guilt and shame over a sex life that was making him increasingly unhappy, confused and lost.

“I felt I couldn’t trust myself and that there was something wrong with me,” Guigayoma says. “That just added to all my self-shame: I’m not doing what I’m supposed to do.”

Sarit Golub, MPH, PhD, a psychologist at Hunter College in New York City who is studying gay men’s use of Truvada, says a major benefit of PrEP is it “separates the act of HIV prevention from the act of the potential encounter,” allowing the rational mind more of a chance to run the show.

“I can’t trust myself to use a condom,” Ergane says, “but I can trust myself to take this pill every day.”

“PrEP helped me take control,” says Guigayoma, who went on Truvada a year ago. Reducing his HIV risk with medication has given him a chance to take stock of his life and take better care of himself holistically. Part of that process has been forgiving himself for preferring latex-free sex. “Maybe there’s not something wrong with me,” he resolved. “Maybe this is just the way that I want to live my sex life.”

Such a sex life includes a greater overall risk of sexually transmitted infections (STIs) when compared with one that’s faithful to condoms. PrEP advocates are hoping that the minimum twice-yearly STI screenings the Centers for Disease Control and Prevention (CDC) advises for those on Truvada will lead to earlier diagnoses and that subsequent treatment will counterbalance the lack of latex. Nevertheless, such cavalier attitudes toward condoms are causing deep-seated concern and even fury among some in the gay community.

“It’s not surprising that people might think I am irresponsible,” Guigayoma says. “But it’s more responsible to acknowledge the reality of our sex lives and provide people with workable options than it is to dictate a particular pre-vention tactic.”

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Quentin Ergane

Approved to treat HIV since 2004, Truvada has a long track record supporting the notions that it’s generally safe and well tolerated, and that clinicians can easily monitor for any development of kidney dysfunction or reduction in bone density—the two major potential long-term side effects. The question of drug resistance may be unsettled, however.

Research from the iPrEx trial (see sidebar below) showed that no one who contracted HIV during the study developed drug resistance. But most participants were tested for HIV monthly, whereas anyone who keeps to the CDC’s minimum requirement for PrEP will receive only quarterly HIV screens—giving the virus more time to mutate.

Another worry is that PrEP may lead gay men to increase their sexual risk-taking, a phenomenon known as risk compensation. The argument is often framed as an either/or between Truvada and

condoms—go on the pill, drop the latex—although in reality overlap in use appears common. Such strict dualistic thinking dovetails with the popular line that “condoms have failed” gay men—a defeatist claim that fails to acknowledge that without latex HIV rates likely would be catastrophically worse.

Other typically overlooked elements in this debate are the many behavioral practices gay men also use to reduce HIV risk, and which may factor into risk compensation, such as: “seropositioning,” in which the positive partner is the bottom, or receptive, person; “serosorting,” in which men attempt to have sex with partners of the same serostatus; favoring oral sex over anal sex; or having the top (insertive partner) pull out before ejaculating.

None of the PrEP studies have shown any evidence of risk compensation. Actually, in both the placebo phase and the open-label extension of iPrEx, the volunteers, all of whom received risk-reduction counseling, trended toward less risky behaviors. But as the gay world begins to discover PrEP, a different story may start to emerge.

In a wintertime interview, iPrEx head researcher Robert M. Grant, MD, MPH, a professor at the University of California, San Francisco, was adamant that Truvada does not lead to risk compensation. But by summer he acknowledged that he was starting to hear anecdotes to the contrary.

Those looking for such a story need look no further than PrEP’s unofficial poster boy: Damon Jacobs, a Manhattan therapist who has earned the title by recounting his experiences on Truvada in dozens of media outlets. Unbridled in his enthusiasm for this form of HIV prevention, he’s been unapologetic about shifting from inconsistent condom use to an almost entirely latex-free existence since starting PrEP.

There proved no shortage of people sharing their own PrEP experiences for this article who reported engaging in varying degrees and various types of risk compensation. Some went on Truvada for the express purpose of ditching condoms. Quentin Ergane, for one, is now enjoying being the bottom in sex more often. John Guigayoma uses condoms less frequently. However, both men are having fewer sexual partners these days.

Time will tell how common risk compensation turns out to be. A crucial question is whether those who take increased risks will also take their meds. A combination of widespread risk compensation and spotty PrEP adherence could push HIV rates in the wrong direction. And if risk compensation among people taking Truvada influences similar behaviors in others, HIV rates could rise among the non-PrEP users.

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“PrEP works if you take it,” according to researcher Robert Grant.

Indeed, no one in iPrEx or its open-label phase contracted HIV while taking Truvada four or more days a week. But even if Truvada does offer bulletproof protection, we still don't know if it will reduce the stubbornly consistent 50,000 new HIV cases in the United States each year.

A key to tailoring PrEP for wide-spread success, according to Anthony Fauci, MD, director of the National In-stitute of Allergy and Infectious Diseases, is for the public health field to stop the "false kidding of oneself that HIV is 'an equal opportunity employer.'"

Nearly two-thirds of U.S. HIV cases transmit through gay sex. In fact, MSM amount to the only risk category that hasn't recently turned the tide: While heterosexuals and injection drug users have seen rates fall in recent years, gay and bisexual men's rates have only risen, especially among the young.

This isn't to say that all gay men should immediately start popping a blue pill every day. There is still a wide spectrum of risk within the community. Consider the estimate that perhaps as little as 2.5 percent of sexual encounters between men involve one partner ejaculating inside the other's rectum—the act by far the most likely to transmit the virus.

Arguably the most effective way to harness PrEP's power is to target it toward HIV-negative men who aren't using condoms consistently, and especially to those who are likely to be the bottom when another guy ejaculates inside him. (This prioritized demographic would exclude men in a monogamous relationship with either another HIV-negative man or with a positive guy who has a suppressed virus and is in regular HIV care.)

"My focus is not helping the worried well get access to PrEP," says Jim Pickett, director of prevention advocacy at AIDS Foundation of Chicago.

With such a priority in mind, the July results from iPrEx's open-label phase are encouraging: Those at higher risk for the virus were both more likely to go on PrEP and were more likely to adhere. However, overall adherence was dramatically lower among younger participants.

Hopefully, PrEP's benefits will extend beyond the individuals taking Truvada. According to Demetre Daskalakis, MD, MPH, the new assistant health commissioner of New York City's Bureau of HIV/AIDS Prevention and Control, "PrEP, if given to the right population at risk, really isn't just prevention of HIV, but specifically it's prevention of acute HIV."

Indeed, during the first six to 12 weeks of infection—a period known as the acute phase—viral loads skyrocket, which makes HIV much easier to transmit. During this phase, a person might feel perfectly fine and continue engaging in the kind of high-risk sex that exposed him to the virus in the first place, thus helping the virus wind its way through "sexual networks." So ultimately PrEP can operate as a wire cutter that breaks the chain.

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John Guigayoma

As for getting PrEP to a critical mass, much has been made of the estimate from Truvada's manufacturer, Gilead Sciences, that only about 2,300 people are taking PrEP. But that figure has many often-overlooked limitations: It only reflects data through September 2013; it was culled from just 55 percent of U.S. pharmacies; and it excludes the thousands currently taking PrEP through studies.

Numerous health care providers contacted for this article reported that, since the media buzz started in 2013, they've seen 2-, 5-, even 20-fold up-swings in prescriptions.

"We've really had a tremendous amount of interest," says C. Bradley Hare, MD, the director of HIV care and prevention services at Kaiser Permanente Medical Center in San Francisco, where 250 patients are on PrEP, compared with 40 a year ago. "It's been growing and sustained over the last year."

Why would potential PrEP candidates choose not to take it? For starters, there are possible insurance barriers (though PrEP is generally covered), concerns about side effects (founded or unfounded), an unwillingness to take a daily drug, and fear of being stigmatized as a promiscuous barebacker. But a major roadblock for gay men might be their own lack of awareness that PrEP could benefit them personally.

Daskalakis recently published a study of gay men in New York City sex venues, which found that, out of the 80 percent who were solid Truvada candidates, more than three-quarters didn't think they were at enough risk to use PrEP.

But perhaps the strongest case for PrEP isn't necessarily made from within the context of an anonymous encounter. Critically overlooked research suggests that gays are much more likely to use a condom for a hook-up, and that between one-third and just over two-thirds of HIV transmissions between men occur within their primary partnerships. In other words: A lot of guys are getting HIV from boyfriends, not booty calls.

The window of transmission appears to open oftentimes when the desire to show trust and to experience intimacy in a new relationship brushes condoms aside—before the men have tested for HIV and discussed monogamy.

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Unfortunately, a not-yet-published study led by New York University psychology and public health professor Perry Halkitis, PhD, MPH, found that young MSM in romantic relationships were less likely to see the use in taking PrEP, despite not using condoms.

On the flip side are findings from a recently published paper coauthored by Brown University's Kristi Gamarel, PhD, and Hunter College's Sarit Golub that studied adult New York City MSM—an older set, with an average age of 32—who were in steady relationships in which both partners were HIV negative. When the men cited intimacy as a reason why they sometimes had condomless sex with their partner, the odds that they'd express interest in PrEP rose by 55 percent. Those who said they'd recently had condomless sex with someone other than their main partner were also more likely to say they'd use PrEP.

Consider as well that HIV hits black MSM most disproportionately: They make up about a fifth of all yearly infections in the United States. Young black MSM are at particularly high risk. A staggering 12 percent of young black MSM in Atlanta contract the virus each year.

The key to engaging this demographic, says Black AIDS Institute founder and chief executive officer Phill Wilson, is using peer-driven efforts.

"Someone comes out with a tennis shoe or a rap song or a T-shirt and it is popular in the Bronx," Wilson says. "Four days later it is off the charts in Watts and Compton. So there are mechanisms in place that are used every single day to reach young black men."

Unfortunately, trying to obtain Truvada often means battling with primary care physicians who refuse to write a prescription they are unfamiliar with, which they believe will lead to risk compensation, and which they wrongly consider highly complex to monitor for safety.

Part of the problem stems from Gilead's decision not to market Truvada as PrEP. Instead, the company gives modest grants to community groups, universities and public health agencies, which pick up some slack in educating both the public and physicians. This stands in stark contrast to birth control's rollout in the 1960s, when G.D. Searle & Company sent an army of "detail men" into doctors' offices to plug the contraceptive Enovid.

"In some instances, because gay sex is so stigmatized, it is leading clinicians to make judgment calls that are inappropriate," says José Zuniga, PhD, MPH, the president of the International Association of Providers of AIDS Care.

Until recently, Kaiser Permanente's San Diego clinic required those seeking PrEP to sign a form that warned, "At any time, Provider may consider stopping PrEP if there is ongoing evidence of unsafe sex or positive STDs." Never mind that both having sex without a condom and contracting sexually transmitted diseases are on the CDC's list of what makes someone a PrEP candidate in the first place.

Lisa, a 34-year-old living in a major East Coast city who is looking to get pregnant with her HIV-positive boyfriend, first asked her gynecologist about PrEP.

"As soon as I told her my partner was positive, the look that woman gave me was of such disgust," Lisa recalls. "She talked to me like I was an irresponsible person, and the scum of the earth."

As is apparently highly common, Lisa's doctor told her to see an infectious disease physician, who then told her that he didn't see HIV-negative people and to go see her primary doctor, subjecting her to months of bouncing back and forth as she searched for a PrEP-friendly MD. "It was so humiliating," Lisa says.

Daskalakis, for one, fears that experiences like Lisa's mean that specialist clinicians will largely be the ones writing Truvada prescriptions and that regular physicians aren't going to be screening for potential PrEP candidates.

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Promising efficacy data aside, troubling findings emerged in iPrEx's open-label phase: Participants took four or more pills per week just 33 percent of the time and adhered daily 12 percent of the time. Fortunately, it appears that MSM taking Truvada can miss up to three doses a week and probably remain fully protected. Even two days a week is estimated to reduce HIV risk by 76 percent.

In this light, there's hope in the early findings of an ongoing study of real-world use of PrEP among MSM and trans women in San Francisco, Washington, DC, and Miami. A month into the study, the participants were adhering four or more days a week at rates of 92 percent, 90 percent and 73 percent, by respective city. Daily adherence, however, was only a respective 66 percent, 45 percent and 19 percent. And should this study follow the iPrEx open-label phase trends, adherence rates may decline over time.

AIDS Healthcare Foundation (AHF) president Michael Weinstein, the media's go-to guy for oppositional quotes about PrEP, insists, "There's no proof in scientific literature that PrEP is a successful public health approach." He points to the fact that poor adherence has dragged down population-level efficacy, and then he paints those average risk reduction figures as failures. The AHF "PrEP Facts" media campaign opposes PrEP as a public health intervention for those reasons.

But another way of looking at a 44 percent average efficacy (see sidebar below) is to say that if you give PrEP to a good number of high-risk gay men, HIV rates will lower.

Those figures are also close to the approximate 60 percent reduction in risk of female-to-male transmission that male circumcision confers. Research is starting to show that the massive push to circumcise African men is not only linked to reduced HIV among the circumcised men, but among women as well. Which returns to Daskalakis's point that PrEP can effectively prevent people from passing HIV on to others, by keeping people who are having risky sex from getting HIV in the first place.

Weinstein's ultimate argument is that the predominant prevention approach should focus on promoting condoms along with diagnosing and treating HIV-positive people, and that PrEP should be reserved for "special cases."

Indeed, recent research suggests having an undetectable viral load makes it virtually impossible for positive people to transmit HIV. But poor adherence to antiretrovirals drags down the population-level efficacy of "treatment as prevention" (TasP) as well: An estimated 75 percent of Americans treated for HIV actually have a fully suppressed virus.

Another way of looking at it is that only 40 percent of all HIV-diagnosed Americans are on treatment and just 30 percent are virally suppressed. Granted, giving meds to individuals with HIV is a much more targeted way of curbing transmissions than providing Truvada to HIV-negative people in hopes of thwarting any HIV they might encounter. But all things considered, PrEP is still being held to a much higher standard: Adherence is always factored into the debate about its worthiness while that element is largely ignored when discussing TasP. Furthermore, only a minority of MSM apparently adhere consistently to condoms.

"There is not a single person I know who thinks that PrEP is perfect or that adherence isn't a critical issue," says Mitchell Warren, executive director of the global HIV prevention advocacy group AVAC, who added that adherence is critical to all forms of HIV risk reduction.

"If there were a perfect intervention, we would want it instead," he says. "But in 2014 the best approach is a patchwork of good but not perfect approaches. Why we'd want to give up on any one of them makes no sense to me."

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By the Numbers
Understanding the efficacy of PrEP

44 percent
In the iPrEx trial of MSM and transgender women that first proved PrEP's efficacy in 2010, the group given Truvada had a 44 percent reduced rate of HIV infection when compared with the placebo group.

92 percent
Only 51 percent of the participants assigned to take Truvada in iPrEx had detectable drug in their systems, but they had a 92 percent reduced HIV rate when compared with those with no detectable drug. The U.S. Centers for Disease Control and Prevention (CDC) incorrectly states that consistent Truvada use reduces HIV risk by "up to 92 percent." The figure is not an upper limit of Truvada's risk reduction with perfect adherence; it represents an average reduced risk among those taking any drug at all.

99 percent
Statistical modeling (called a regression analysis) based on the iPrEx data projected that taking Truvada seven days a week reduces HIV risk by 99 percent. The true figure, the researchers estimated, could be between 96 percent and greater than 99 percent.

100 percent

In iPrEx's placebo-free phase, researchers parsed the data with what's called a stratified analysis, which allowed their estimate to more directly reflect the fact that, as in iPrEx's initial phase, no one in the trial contracted HIV while taking Truvada four or more days a week: They projected that adhering to the regimen that well offers 100 percent efficacy. A drawback of using this different form of statistical analysis was a larger estimate range: They could only speculate with confidence that the efficacy was no less than 86 percent.

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