Trimming Treatment

An HIV-positive writer asks: Can you cut your HIV pill intake in half?

November 5, 2014 By Tim Murphy

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Not long ago, I was preparing for an extended trip and, for the life of me, I could not access those extra 10 days of my longtime HIV cocktail, Viramune (nevirapine) and Truvada (tenofovir / emtricitabine), that I needed to tide me over until I got back.

My insurance only covers the two drugs in 30-day increments. I could not afford to pay for 10 days of pills out of pocket (it would've cost me roughly $650). And my doctor couldn't give me a free tide-me-over, as he has sometimes done in the past.

However, I knew that both drugs had very long half-lives, meaning that effective levels of both stay in your system for a very long time. After consulting with my doctor, I decided to take my combo every other night instead of nightly over 10 days. That got me through my trip. I came back anxious to see if I was still undetectable; turns out, I was.

I've always been curious to know if I could build up an emergency supply of HIV meds and cut in half the potential for long-term side effects (particularly given Truvada's link to bone-density loss). So, still in consultation with my doctor, I continued to take my HIV combo every other night for a month. When I had my labs done, I made sure to do so on a morning after I had not taken my HIV meds. I was still undetectable. Months later, I've continued that pattern.

Let me be clear. I've been undetectable on this combo for over a decade. Research suggests that changing to less-than-daily dosing works better for folks who've been undetectable for a long time compared with a shorter time. Since I still get a 30-day supply of meds every month, I've managed to build up a stockpile in case of future trips or other emergencies and I've halved my intake of these drugs and lowered their potential long-term side effects.

If I can't remember if I took my HIV meds the night before, I take them, just to be safe—no biggie. Overall, I feel pretty great about my experiment, like I've gamed the fixed-dose, high-price HIV-med system.

All this got me wondering how many more of us living with HIV could build up a drug reserve and cut down on potential side effects by reducing our HIV drug dosage. I decided to call Charles Flexner, MD, of

Johns Hopkins. He's an expert on pharmacokinetics (PK), which is how long drugs last and how they interact in the body.

Cautiously, and stressing that I make clear that nobody should attempt this without first talking to their health care provider, Flexner told me that, based on his research, he thought that Sustiva (efavirenz), Viread (tenofovir) and Emtriva (emtricitabine) could definitely be dosed every other day versus daily, and that Viramune and Epivir (lamivudine) could probably be dosed every other day as well.

Because most of these drugs are in combo meds, Flexner added, there is a high likelihood that if you take Atripla (Sustiva plus Viread plus Emtriva, those last two meds making up Truvada) or Viramune plus Truvada (like me), you could cut your dosage to every other day.

According to Flexner, other HIV drugs, including those in the newer combos like Complera (emtricitabine / rilpivirine / tenofovir) and Stribild (elvitegravir / cobicistat / emtricitabine / tenofovir), do not have half-lives long enough to assure that you'd be getting enough drug to block virus over a 48-hour period.

I'm certainly not the first to explore different versions of less-than-daily dosing. A few years ago, the small but well-done five-days-on, two-days-off (FOTO) study found that it was possible to take a Sustiva-based combo on that timetable without losing undetectability, at least for the year that FOTO followed its participants.

As far back as 2001, researchers at the National Institutes of Health showed that people with HIV could go off their meds for up to a week before virus started to rebound. However, conventional thinking among pharmaceutical companies and HIV care providers has been that daily dosing (especially in one-pill formulations like Atripla and the newer Complera, Stribild and Triumeq) is just safer and easier.

Still, I was proud of my thus-far successful experiment with drug reduction, so I decided to contact several top HIV doctors nationwide for their feedback. Their responses were wary, to put it mildly.

"I would certainly be an advocate for this if there were data to support this approach," said Jeannine Bookhardt-Murray, MD, chief medical officer at Harlem United, summing up what many other docs said. "The study would need to include a lot of patients followed over several years." Truth be told, most studies of less-than-daily therapy, albeit promising, have been small and short.

Bill Valenti, MD, an infectious disease specialist in Rochester, New York, said he was concerned that the lower drug levels in the blood afforded by every-other-day versus daily dosing would eventually allow HIV mutations to slip through that could ruin those drugs for me. (Flexner allowed that this was a "theoretical" concern, made more likely by how much time elapsed between doses.)

Gerald Pierone, MD, an internist in Vero Beach, Florida, said that he had patients from the aforementioned FOTO study who, years later, were still taking the weekend off Atripla and remaining undetectable, as well as patients who successfully take their Truvada or Viread three times weekly, which they chose to do after having decreased kidney function (a potential side effect of those drugs).

"We pitched an every-other-day study years ago," Pierone said, "but, surprise, none of the pharma companies thought it was a good idea."

Joel Gallant, MD, an infectious disease specialist in Santa Fe, New Mexico, told me, “I have never recommended that any patient do this on purpose. I think it’s somewhat risky, and I would prefer such an approach be tested first in clinical trials. If patients are having side effects, I’d rather get them off the offending agent rather than reducing the dose. However, I’ve certainly had patients who have spaced their meds out on their own for reasons of cost or inability to get a refill in time. Most of the time they get away with it, but not always.”

Interestingly, Doug Ward, MD, an infectious disease specialist in Washington, DC, told me that he has 18 patients who were still undetectable on a dosing system he presented at a conference six years ago—another seven-days-on, seven-days-off approach—with only one case of viral rebound. He said his patients on this system were on all manner of combos, not just those with the drugs Flexner mentioned above. Ward said he thought the key was achieving total viral suppression over seven days, which kept viral activity from starting off meds for another seven days.

Ward said he thought his approach was safer than my way, which creates drug-level floors lower than if I were dosing daily. (Basically, picture a graph with overlapping bell curves showing drug levels over a 24-hour period, then space them out another 24 hours.) He said he worried that, over time, I could develop the dreaded KR65 mutation, which would knock out all my options in the HIV drug category that includes Viread, Emtriva and Epivir.

But Ward definitely felt that less-than-daily dosing was still a conversation worth having, even as HIV meds seemingly become less toxic. “I’ve got 20-year-olds starting therapy,” he said. “They’ll see a cure in their lifetimes, but many patients still have 30 more years of taking these drugs. We know they’re pretty safe for 10 years, but for 40? We need to address the long term.” In other words, if it’s possible, it’s not a bad idea to take fewer drugs over the long haul.

Another word of caution: It’s likely easier to remember to take meds every day—it’s like brushing your teeth!—than every other day. You may need to create some kind of memory-jogging system to do that. Plus, our bodies absorb HIV meds differently based on age, size and possible other factors, so you’d need to head down this road carefully.

That said, not only does my approach have the potential to lessen side effects down the road, but it could also save money for individuals and insurers, both private and public, particularly in states with stressed-out AIDS Drug Assistance Programs (ADAPs).

The way I see it, I could eventually take generic versions of Viramune, Viread and Epivir. This could possibly save on my co-pays over the branded drugs, and because my generics will cost significantly less than their old branded versions, I could even be able to buy supplies out of pocket when and if I need to.

Again, this isn’t for everyone. There’s a reason drug makers developed one-pill-daily formulations. For many if not most folks, they’re probably easier to take. But isn’t it good to know that you may have some wiggle room amid the fixed-dose, 30- or 90-day-supply landscape we all currently exist in?

As for my own treatment, am I thinking outside of the pharma-driven box? Yes. But sadly, it’s unlikely that companies are going to fund testing of current drugs to see if they work effectively in different ways when the money lies in developing new drugs that will have fresh patents and profits.

As for me, I'll admit that a few of the doctors I talked to for this story gave me a mild fright that, eventually, my HIV might break through my every-other-day barrier and develop resistance to my longtime combo of Truvada and Viramune. If I become detectable, I'm back to daily dosing. If I develop resistance to my meds, I know that, thankfully, I now have a lot of other options.

Until then, I'm sticking with my every-other-day plan. I've cut my Truvada intake in half, possibly doing my kidneys and my bones a favor in the long run. Plus, I'm not stressing about how I'm going to come up with that handful of extra pills the next time I travel.

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