Loud and Clear: Undetectable = Uninfectious

Here’s why we need the Prevention Access Campaign.

July 25, 2016 By Bruce Richman

Undetectable = Uninfectious.

People living with HIV have the right to know it. And, the HIV field must start saying it to end the dual epidemics of HIV and HIV stigma.

In 2003 I was diagnosed with HIV. Like so many of us living with HIV, I was burdened with fear, shame and anxiety from carrying the deadliest sexually transmitted infection (STI) in the world. I couldn’t imagine a life with someone who would feel safe with me. I didn’t feel safe with myself.

My most important question has always been "Am I a danger to my partner?"

Back then, conventional wisdom was a deafening “Of course you are.” I know now that answer is a miraculous “NO.”

I knew it was critical for my health when I became undetectable in 2010. But it wasn’t until 2012 after a condom broke that my doctor told me not to worry that because I’m undetectable, I’m uninfectious (U=U). Having sex with a broken condom was perfectly safe? I had severe cognitive dissonance! I’d spent the last three months in fear waiting for the post-PEP test results for someone I’d been dating, who was now terrified of me. While my doctor wouldn’t put U=U in writing (I’m a lawyer, of course I asked!), he said he’d assure anyone I was dating that, while other STIs could still be transmitted and were an escalating problem, I could not transmit HIV.

“Safe” is not something I thought I’d ever equate with sex. While I fully trusted my doctor, it was a huge leap to internalize this incredible news after nine fairly isolating years of feeling toxic and dangerous. I started collecting research to prove U=U to myself and others, often coming up against serious resistance and being treated like a liar. I was called a “danger to gay men’s holistic health” by one doctor who felt I was encouraging condomless sex. Actually, I was helping people with HIV have healthy sexual and reproductive lives free of fear and shame. While that was frustrating and often hurtful to be judged and shamed, science was and continues to be on my side.

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It’s a deep mental, cultural and social shift to acknowledge that people with HIV can have sex with or without condoms with HIV-negative people without transmitting the virus. Getting to that point means rewiring thirty-five years of deeply entrenched fears of HIV and the people who have HIV, and challenging the longstanding unproven assumption that condoms are always necessary to prevent HIV transmission.

HIV stigma is a major public health crisis and the greatest challenge to ending the epidemic. Stigmatizing attitudes and assumptions influence many agencies in the HIV prevention field which continue to communicate exaggerated risk, often based on outdated research and influenced by agency and funding restraints and politics.

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I used to be enraged and take it personally when I found information online or saw a social marketing campaign communicating that people with HIV with an undetectable viral load are still a risk. Even saying “less risk” or “small risk” means we’re still a risk to take into serious consideration. Essentially, we’re a smaller bomb, but we’re still a bomb! My gut reaction was “why are they still lying about us?” Now, I recognize change takes time and many organizations are beginning to acknowledge the science. We’re helping them change the narrative.

I’m working with a coalition of community partners, HIV activists and the leading researchers on this issue. We’re called the Prevention Access Campaign (PAC), and one of the goals is to help agencies catch up with and communicate the science.

I’ve met too many people with HIV from all over the world who are suffering and struggling to find meaningful information to answer that basic question “Am I a danger to my partner?” Since realizing that I cannot transmit the virus, I’ve experienced a new sense of freedom and the lifting of many years of shame and fear of being a danger to others. PAC fights stigma by ensuring that other people with HIV, their partners, their providers and the public realize it too.

For more about PAC, visit PreventionAccess.org, where you can also find research and resources including a consensus statement on the risk of HIV transmission from someone with an undetectable viral load and our Undetectable = Uninfectious campaign (U=U).

[UPDATE: After I wrote this blog, we changed the name of the campaign to “Undetectable = Untransmittable” because the use of the term “Uninfectious” may be stigmatizing to folks who are not undetectable due to choice or circumstances outside of their control.]

My Twitter: @BR999

Prevention Access Campaign’s Twitter: @PreventionAC Facebook: PreventionAC

Check out my Q&A with POZ on the PARTNER Study: “Does Undetectable Mean Uninfectious? The Challenge of Explaining HIV Study Results.” (July 26, 2016)

Check out my Blog on POZ "Big UNDETECTABLE Mistake! Why a 96% reduction in risk doesn’t mean you still have a 4% chance of getting HIV. And why it isn’t about being undetectable." (August 2, 2016)

Check out Mark S. King’s brilliant and inpsiring “Will HIV Ever be Safe Enough for You?” which fueled my passion to start this work. (March 11, 2014)

Get the No Shame About Being HIV+ t-shirt here
