State of Stigma 2020

It’s 2020 and people still want us to prove AIDS-related stigma exists. I’m tired.

January 22, 2020 By Andrew Spieldenner, PhD

My friend was just diagnosed with HIV. The conversations we’ve been having feel familiar. He’s worried about meds. He is searching for a doctor. He does not know what to tell his friends and past dates. He wants to live around family. He doesn’t believe the result is true.

He’s lonely.

He feels dirty.

We text fairly often but I have not seen him in over a year. He lives in Peru as a refugee and he is waiting on papers.

Most of us living with HIV understand his loneliness, and that feeling of being dirty. In the US, we do not necessarily have a sense of his feeling of precarity - waiting on papers.

I am on a plenary panel at a stigma conference at my alma mater. Thrilled to be speaking on the same stage I graduated from at Howard University, I am less excited when the Q & A turns into a researcher needs vs. community needs conversation. My friend and colleague, Dr. David Malebranche responds to a researcher’s question, “you don’t need a P-value for everything; stigma exists – find ways to improve it, work with people living with HIV to make things better. Listen to us.”

So we know stigma exists, but what can we do?

Education alone does not stop stigma.

People can know that U=U (Undetectable = Untransmittable) – that is, an undetectable viral load indicates zero chance of transmission- and still tell people to not have sex or use drugs with people living with HIV. There are people with doctorate degrees who will not tell people who are undetectable that we do not have to use condoms. I was at a statewide stigma meeting where the health department and elected officials had signed onto U=U and yet they said that local medical doctors probably would not spread that message.

We need to demand more of our supposed allies. What can they do to interrupt this kind of stigma?

In our own community, we still have work to do.

There are still gay men who put up profiles on sex and dating apps to "out" people living with HIV. While I'm sure that these particular gay men think they are helping the community, they are using their position of safety to put others at risk – of assault, of interference from law enforcement, of rejection and social alienation. Just so these particular gay men can feel like they are "doing good."

If you know people doing this, tell them to stop and publicize who they are.

HIV Foundation Queensland conducted this intervention to raise awareness about stigma in the gay community. In it, people read the vile things that people will dump on you if put HIV on your profile. Watching their emotions as they read it, how upsetting it is for them to see what it's like being us – even for just a moment – is moving.

But what happens next?

Recently, I was talking to an HIV planning body about stigma. One person complained loudly that we need to recognize that gay men and particularly Black gay men are not using condoms and there is an "epidemic of STDs out there." He seemed to be asking a return to fear-based messaging to scare gay men into using condoms. While I acknowledge that STI rates are way up in the US, I also recognize that most of these are treatable. With a functioning and free health care system, the STIs can be managed.

At the same meeting, another man pulls me aside. He works with a group of young African American male sex workers and he has been instructed to provide PrEP referrals. He worries that this would be encouraging them to stay in sex work. "Can you provide them a job that they want and can do?" I ask. "No," he admits, "so I guess I need to provide what I can, right? The system sucks."

We agree.

The Global Network of People with HIV/AIDS (GNP+) is rolling out the second version of the HIV Stigma Index. It offers a community-based participatory research model to intervene in stigma at multiple levels. It is an intervention designed and implemented by people living with HIV, for people living with HIV, and with people living with HIV.

I am working on the HIV Stigma Index in the US. It is unseemly data, difficult to see across locations and regions due to the differences in sampling and coding. Because of these factors, some researchers and funders have a hard time with grasping how important it is to center our voices as people living with HIV, that this research and these interventions must benefit us first. We are still working off the first version of the Stigma Index. We have collected data in Louisiana, New Jersey and Michigan. Articles have started to come out in books and academic, peer-review journals.

And we are still being asked to prove AIDS-related stigma exists.

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