I Want To Be Heard in My Healthcare

An HIV activist shares his journey to become heard as an individual instead of a risk pool statistic.

September 21, 2017 By Josh Robbins

“I want to be heard.”

It is really as simple as that. I just want to be heard.

More specifically, I want to be heard in my healthcare. I want my healthcare delivered to me to be personal, derived specifically for me, and the exact opposite of community-wide healthcare. I don’t want to be a statistic anymore and I could care less what risk pool in which I’ve previously been placed or grouped. Sometimes the labels and words like ’MSM’ (men who have sex with men) and ’high risk’ (sexually) completely veil my identity within my own health. And it isn’t okay, anymore.

I am an individual first, and my healthcare needs to be mine. I want to be heard.

As a cisgender white male, I have substantial privilege, obviously. I completely accept that, as neither my fault nor my reward. I cannot affect it. But as an HIV-positive queer trying to navigate healthcare, at times, I feel I am losing. I have yet to find health equity--and I’m putting in the work.

Since the Affordable Care Act was implemented, I have been dropped by insurance companies four times--each followed by brief interruptions of me seeing my doctor and once completely stopping my adherence to antiretroviral meds. I consider myself to be pretty savvy at navigating the system. If I am having trouble with the system, I suspect others may have already just stopped trying to figure it out altogether. But I am not giving up on healthcare. I am fighting to stay engaged.

When I finally make it to the doctor’s office, I also want to be heard. In 2012, my first appointment with my HIV specialist focused on community wide recommendations to begin antiretroviral therapy immediately. Sure, there are benefits to starting treatment early, but at that time, arguments could be made for waiting -- especially because I was showing signs of being an HIV controller.

Since being diagnosed with HIV in 2012, almost every time I have a minor illness or issue arise, I sometimes cringe when telling any non-HIV specialized doctor or nurse practitioner that I am positive because it immediately changes how they treat me both literally and medically. Usually the moment that I disclose that I am positive, everything is attributed to the virus. I understand, accept, and believe that HIV treatment works -- but not every minor issue is related to living with

HIV.

I joke sometimes that I could run into a glass door and break my nose, and when I hit the emergency room instead of helping me with my sideways nose, they would be attempting to study how HIV is starting to affect my cognition. “My nose is broken because I ran into a glass door. HIV isn’t to blame,” I would say.

I just want to be heard.

When I describe some of the health problems that I experience to my physician, like the embarrassing issue of HIV-related diarrhea, I wasn’t met with recommendations for FDA-approved diarrhea treatment. Instead, I was told on more than one occasion that my doctor “does not see diarrhea anymore” because of the improved HIV meds that we now have.

Honestly, I do not care what they see or don’t see among patients living with HIV, because I am experiencing that side effect. And I wanted to be heard -- to be treated individually and not ignored.

This year I have learned that my healthcare requires my active participation, my active engagement, and my resolve to fight battles for myself like I could never imagine I would be fighting.

When an insurance company dropped my coverage in my state -- I fought to get new coverage. I will fight at the end of this year again. I will be heard.

When I was told that I had to order my medicine from a specific pharmacy -- I fought to keep my pharmacist because I believe they are important in my patient journey because they know all my allergies. I will be heard.

When my doctor made treatment plans based off of statistics instead of recommending what would be best for me as an individual, I fired that doctor and found a new one who now listens to me and takes what I have to say into consideration before making a plan. I will be heard.

As much as we are told to stand up and fight for social issues, to rise up and speak against inequalities, and to do the important work to bring justice and equity to all people -- I realize that each of us has the right and needs to be heard as an individual in our own personal healthcare.

I will be heard. You should be heard, as well.

Let’s fight to make it happen.

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