Five Things My Heart Surgery Taught Me About HIV

I'd like to tell you about a life-changing experience that altered the course of my HIV advocacy.

August 4, 2021 By Bob Leahy

I've just spent eight days in hospital undergoing open-heart surgery. I had an aortic valve replacement and a by-pass. It was one of the most challenging life events I've ever had to navigate. Four weeks later, I'm well on the way to recovery, but the scars, real and emotional, remain.

It's been a life-changing experience, a series of revelations that showed both my strengths and my vulnerabilities. It also influenced how I view my own HIV and that of others and where I go next. Here is what I learned:

Glimpses of a previous era; the '80s revisited

While I was in the hospital, my HIV was not really an issue. All medical professionals I encountered were respectful and unconcerned that I was HIV-positive, from the operating room down. Despite that, I had a highly triggering experience. Due to a potential infection unrelated to HIV I was designated "no contact" for a while, pending investigation. My food was left outside my room. Extra protective gear appeared. I was devastated; the circumstances just seemed too reminiscent of something horrible in our collective past. I cried. I remembered all the while the song "Will I Lose My Dignity." (And yes, I did feel I lost just that, at least for the duration of my stay.) Clearly the impact of our history lies just under the surface for many of us.

Our resilience is real and ready for its close-up

I learned of my HIV status in the era before effective treatment existed, when HIV was fatal. I remember thinking at that time that HIV was all I could handle. To be diagnosed with a subsequent illness was beyond my comprehension, well beyond my ability to manage. This was before "comorbidities" became a buzzword within our community. Fast forward to 2021, and here I am not only managing my HIV but also saddled with heart disease, not to mention diabetes. I'm coping (kind of) well. The truth is, though, that serious comorbidities are virtually inevitable as one ages. Listen up: Your resilience is about to be tested. It may be mightier than you think

My HIV is no big deal (your experience may vary)

While in hospital recovering from surgery I couldn't help reflecting on the difference between the treatment of my HIV – one pill a day for many – and heart disease, the latter often requiring majorly intrusive surgery with a prolonged recovery period. HIV is typically less dangerous. HIV/AIDS, in fact, ranks nowhere in the top 20 causes of death in Canada. (Heart disease is number one.) Sure, there is HIV-related stigma out there, but for many of us, the times have been right to "rise up to HIV," as the T-shirts say. I certainly did, but then I'm privileged. All in all, I've come to believe that the response to HIV hasn't changed enough since it was a majorly life-threatening condition. Instead, we face the growing danger of HIV being overblown in relation to other diseases. That opinion won't win me many friends, I know, but it's the truth as I see it, born of lived experience that extends beyond HIV. Don't knock lived experience.

Heart disease recovery focusses on wellness; we can learn from that

I found the approach to heart disease recovery to be fresh, engaging and people-centered, not number-centric. In contrast, our focus on HIV treatment has become maybe too centered around clinical numbers. We have become highly focused, for example, on the ability of people living with HIV to become undetectable and as a community, to meet 90-90-90 objectives. True, that focus has come with tremendous benefit to people living with HIV, particularly with the advent of Undetectable Equal Untransmittable (U=U). We can't abandon that—but we can add other objectives. I can't help thinking that as important as attaining an undetectable viral load is achieving wellness. Recovery from heart surgery involves a holistic combination of exercise, rest, nutrition, breathing and mindfulness. Very little of that approach is seen in HIV circles. It's a significant gap that is only just receiving some attention.

I need to quit

At 74, I've been working independently in and out of the HIV sector for almost 30 years. I'm proud of what I've achieved, particularly around bringing U=U to Canada. But surgery has changed me. I need some time to myself now, to enjoy retirement free of the frustrations of a sector, at least in Canada, that has been spinning its wheels, achieving poor results where it matters most. New HIV diagnoses in particular are trending the wrong way. The industry, in truth, needs a shake-up. I'd love to see a new generation of activists approach that task, to help fashion a response to HIV entirely differently from the current one, in fact. In any event, today I'm retiring; it's the turn of others to have a crack at it.

Thank you to all my readers and my colleagues everywhere. Adios! It's truly been an honor to share my musings on POZ.com and elsewhere with you!

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