Time for A HAART-to-HEART

By Rob Quinn

Along with Valentine’s Day and Black History month, February marks American Heart Month, a great time to open up the conversation around HIV and cardiovascular health. When someone fashioned the handy acronym HAART (Highly active antiretroviral therapy) in 1996, very little was known about long-term side effects, if any, and the connection between heart disease and HIV medications that we know today. Who knew HAART would put some people living with HIV/AIDS (PLWHA), especially long-term survivors, at a higher risk for HEART disease. One long-term PLWHA being me. This is my story.

At age 56, it has been 22 years since I was diagnosed HIV-positive, and 16 years since I was diagnosed with AIDS. I currently take fifteen medications daily even having downsized over the years to only two pills for HIV. The rest of my prescriptions, a crowd of white-topped orange plastic bottles, are to treat the many ailments and conditions that are a result of aging with the virus, along with years of taking the sometimes toxic medications to treat it. Being a long-term survivor I face a myriad of challenges rooted in HIV. My highest hurdle to clear right now is a recent diagnosis of HIV-associated cardiomyopathy and coronary artery disease. My cardiac cocktail consists of five medications daily—a flashback to my early days of HAART. My recent relocation back to Boston last fall was due in large part due to my own need for the more intensive medical care and the support services to PLWHA, the latter including a peer-led long-term survivor support group.

In 1986, my Dad, at age 53, passed away suddenly and unexpectedly from congestive heart failure. My recent diagnosis of HIV-associated cardiomyopathy and coronary artery disease brought me back to 1999, a dark place in my life and when I was diagnosed with Kaposi’s sarcoma (KS), a strain of skin cancer common to AIDS patients. That year I suffered a heart attack related to chemotherapy treatment for KS. Just like back in 1999, I recently saw HIV as a death sentence again. What if I wasn’t HIV-positive? If I wasn’t a long-term survivor who took countless older generation HIV medications which we are now just seeing the side effects of? What if I were diagnosed HIV-positive today with access to the newer generation medications? My thoughts, although cognitive distortions and not rational, were real to me.

My cardiology team at the Institute for Heart, Vascular and Stroke Care at Massachusetts General Hospital in Boston recently recommended that I consider the strong possibility that I will need an implantable cardioverter defibrillator (ICD), a small device that’s placed in the chest or abdomen, in the very near future. Doctors use the device to help treat irregular heartbeats called arrhythmias. As a gay, HIV-positive man already dealing with body-image issues resulting from lipodystrophy and lipoatrophy, the thought of an ICD protruding from my chest was just too much for me to cope with.
Initially I wanted nothing to do with this potentially life-saving medical intervention. I was done! Many times on this journey I have asked myself. “when is enough enough?” After much trusted support from family, my healthcare team, friends and peers living with HIV/AIDS, I came to the realization and made an informed decision that it is in my best interest to proceed with the recommended ICD. If this technology was available to my Dad 29 years ago, I believe he would still be alive. I believe if my heart disease was found to be genetic that I would have coped with this experience differently. I have known since losing my Dad that I was genetically at a higher risk for developing heart disease. However, it wasn’t until after genetic testing, thyroid testing and a second angioplasty to rule out additional blockages (all of which came back negative) that I was diagnosed with HIV-associated cardiomyopathy and coronary artery disease.

Heart disease remains the leading cause of death in the United States, regardless of HIV status. The good news? Heart disease can often be prevented when we make healthy choices and manage our health conditions. Prevention is the best medicine. So, regular monitoring by our provider of our overall and cardiovascular health should be part of our plan for living longer and living well. Getting on treatment for HIV is one of the best things we can do to stay healthy. Scientists say that newer antiretroviral drugs may be easier on our heart. If you are HIV-positive, check with your healthcare provider to find the best HIV medications for you. While we cannot control all of our risk factors for heart disease, there is a lot we can do to reduce our risk such as quitting smoking, improving our diet, exercising regularly and stress management. By setting small, achievable goals and tracking those goals, we can make a big and lasting difference in our health.

In closing, I again no longer see HIV/AIDS as a death sentence and believe that I can still live a long, healthy life if I commit to making a few changes and respect my heart condition. I have always been a non-smoker. Already having successfully overcome multiple high risk factors, including an alcohol addiction and morbid obesity, along with being virally suppressed for years, I am in a good position to reach my full potential and thrive in a meaningful, productive and connected life.

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