Time for a Little Healthy Perspective

A long-term HIV survivor reflects on the gaps and challenges that remain to end the epidemic.

July 11, 2018 By Matt Sharp

The AIDS epidemic is almost 40 years old. This anniversary should be an opportunity for a collective and individual reflection upon the enormity of the last 38 years. It's time to take stock of our multiple losses, assess trauma, acknowledge our mistakes and our successes from the past and then identify and plan for the challenges that lie ahead. Pause, take a deep breath and with wide eyes, open ears, clear minds, and full hearts allow for a little healthy perspective to unfold for the road ahead.

Despite untold tragedy that has inflicted so much pain, suffering and loss, the big miracle of AIDS are the survivors who live to tell their own stories, coveting a legacy of community mobilization, advocacy and activism the world has never seen. Realization of long-term survival has become a new movement no doubt motivated by the difficulties associated with earlier aging caused by a controlled but persistent virus. Also, the after effect of complex trauma, loss of support networks, fear of the future in a world and community that has simply moved on from AIDS has led to isolation, depression and suicide.

Yet in many arenas survivors are starting to find purpose and meaning in a new quest for survival as they come together to tell their stories from the early years before effective antiretroviral therapy was in widespread use. With that healing, they are mobilizing, building new networks and reinforcing community, supporting each other locally and nationally. More recently they are joining together with a diverse rainbow of people living with HIV who may have been diagnosed later in the epidemic, yet are survivors in their own right. Over time people with HIV/AIDS are destined to coalesce into a larger "coalition of survivorship," built on a rich legacy of advocacy, support and community building.

There is no doubt that survival is due to remarkable scientific achievements in HIV treatment and prevention powered by an engaged advocacy and empowerment force from people living with HIV/AIDS. Today, effective antiretroviral treatment options are potent, safe — at least in the short term — and easy to take. Some are combined in fixed-combination daily dosing. Effective antiretroviral prevention with pre-exposure prophylaxis (PrEP), a daily pill that is taken by HIV-negative individuals at risk, is slowly rolling out. In addition, there is solid evidence that treatment is prevention. If HIV-treated individuals remain undetectable on their antiretroviral regimens they cannot transmit HIV to an uninfected partner. Undetectable truly equals Untransmittable (U=U).

As we remember our successes, there remain gaps and significant challenges where we must keep a little healthy perspective, if we are ever going to end new infections and bring the epidemic to a close.

In particular, I want to highlight an unrecognized and often forgotten segment of the epidemic: multi-drug resistant (MDR) survivors. Out of 1.2 million estimated to be living with HIV in the United States, 460,000 to 660,000 are on antiretroviral treatment, 20,000 to 25,000 are MDR, and 10,000 to 12,000 are in dire need of new treatment options. This represents about 1 percent of the U.S. HIV population who are still in urgent need of a new treatment option because their latest combination treatment is failing. Most have been treated sequentially adding one new drug to an older drug. Over the years of trial-and-error the mutations add up, and now there is less pressure to stop HIV replication. The immune system is further weakened, health is jeopardized, symptoms increase and a there is a risk of transmission.

Since I began HIV treatment I was informed and motivated to try the newest antiretroviral drugs, often only accessible in clinical trials and expanded access programs. My consistent strategy throughout my 30-year survival has always been to “buy time” until better drugs, and preferably an HIV cure were available. But in reality my only mistake was an intense will to survive in an era when so many were sick and dying, and most researchers and doctors misunderstood they were prescribing a recipe for disaster. Eventually, I was able to add two new drugs that finally controlled my HIV, yet I remain MDR.

The good news is that finally, after years of build up of viral mutations rendering a segment of the epidemic virtually without options, the Food and Drug Administration (FDA) has approved Trogarzo, a new monoclonal antibody for people with untreatable MDR. Today, if the community becomes more aware of this MDR segmented population, the word will spread to physicians and advocates. They can become treated, and no longer live on the precipice of fear that they will ever beat HIV.

Whenever reflection of the HIV epidemic is proposed, in broad policy-making or in a POZ guest editorial, it is incumbent upon every advocate, every decision maker, prescriber, researcher and politician to address social determinants of health. With the interrelated epidemics of HIV, viral hepatitis, sexually transmitted infections and tuberculosis in the United States and globally increasing disease burden and worsening health disparities — including stigma and discrimination — all need to be prioritized if we are ever going to succeed in ending the HIV epidemic.

Finally, an end to the global HIV pandemic can only be achieved with a vaccine or ultimate cure. Most likely either of these panaceas are imminent, yet promising research continues, and the hope to see them one day is a little perspective we all need.

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