Challenging HIV Stigma

Peer support is more important than ever.

March 30, 2020 By Sean Strub

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Biomedical advances against HIV since the dawn of the epidemic have been nothing short of astonishing. An almost always fatal disease is now, for those with the privilege of access to treatment, a manageable chronic illness, treated with a single daily pill. A person who acquires HIV today has every reason to expect to live a normal life span.

Yet with such astonishing success in treatment, why is HIV stigma worse today than ever before? Why do so many long-term survivors, including many who were exceptionally open about their HIV-positive status for years, find they must now keep it a secret, sometimes going deeply into closets they thought they had left for good years ago?

Many people—especially those who do not have HIV—find these questions startling. That's because they remember the days when one had to wear a spacesuit to visit a person with AIDS in a hospital or was afraid to eat in a restaurant with gay waiters or refused to touch a person they thought might have the virus.

Those are all stigmatizing reactions—born of combinations of fear, ignorance and bias—but they are ultimately about fear of casual contagion. Today we know so much more about the real routes and risks of HIV transmission, as evidenced by surveys showing the number of people who believe they can get HIV from a drinking glass or sitting on a toilet seat has dropped dramatically.

To stigmatized people—people living with HIV (PLHIV)—the stigma is far more nuanced and complex than simple fear of casual contagion. The stigma is about our moral worth being judged when others find out we have the virus. It is about our words being discounted before they leave our mouths, marginalization, "othering" and, very importantly, self-stigmatization and the internalized stigma we absorb from the broader society.

By those measures, many long-term survivors agree that the stigma has worsened. Unfortunately, there is no pill to cure stigma, but it can be lessened with a better understanding of where it comes from and how best to address it.

In the early years of the epidemic, most people who had moral or religious concerns with homosexuality, promiscuity, sex work or drug use saw PLHIV through a "hate the sin, love the sinner" type of pseudosympathetic lens. We were in pain, suffering, at times looked grotesque, and were expected to die, probably very soon and possibly in a horrific manner.

In the mid-1990s, combination therapy was introduced, and the broader society began to understand that we were no longer dying, but, in fact, we were going to live. Instead of being seen through the lens of our likely demise, we were seen through the lens of our potential survival. If we were living longer, it meant we would be around longer to potentially transmit HIV to others.

The public health and criminal justice systems began to consider us as an inherently dangerous population and a threat to society. We became seen as people who needed to be tracked down, identified, tested, listed, reported, regulated, and, increasingly, criminalized. Those with deep-

seated bias against the populations at greatest risk of acquiring HIV felt like they had a renewed license to demonize us.

The media played a role as well. In those early years, there was a steady flow of feature coverage in the media, inspiring stories about the triumph of the human spirit. The woman working two jobs and raising children, even while managing a serious life-threatening illness.

The child born with HIV who valiantly struggles to go to school and be like the other kids. The two men with AIDS who took care of each other, bringing joy to their final months, weeks, and days.

That kind of media coverage has largely disappeared. Today, when a person with HIV is mentioned by name in a media context, it is frequently in a criminal context: an “HIV predator,” “AIDS monster,” or burdened with similarly pejorative labels in sensationalized, if not hysterical, coverage.

Beyond the public health and criminal justice systems and the media, another factor is how the importance of connecting people living with HIV with each other, once considered absolutely critical, has been downgraded, ignored, and with many service providers is no longer seen as a priority.

In the early years, unless a person was in an acute medical crisis at the time of their diagnosis, the most important post-diagnosis priority was to get the person together with others living with HIV, through a support group, PLHIV network, or other mechanism.

Connecting with others enabled us to ask questions, educate ourselves, and build a network of support to enable us to deal with the consequences of HIV, including disclosing that we have it to our sexual partners, friends, family, and coworkers. It was through these support groups and networks that PLHIV became empowered advocates, for ourselves, each other, and our community.

Hundreds of HIV service providers, including major agencies such as Gay Men’s Health Crisis (GMHC), San Francisco AIDS Foundation, AIDS Project Los Angeles, and others, were founded by people with AIDS, our partners, and our closest friends, including many who didn’t know at the time if they had the virus or not.

The existing health care service delivery structure couldn’t serve us, didn’t want to serve us, which necessitated our creation of a parallel network on a peer-to-peer service delivery model. There were no meetings of boards of directors where members of those boards referred to the agency’s clients as “them,” because clients were in the room, sitting on the board, and serving on the staff. We were not just at the table, we helped decide who else would be at the table.

Over time, as the epidemic grew and service providers “professionalized,” they also began to incrementally move away from the peer-to-peer service delivery model we pioneered, toward the more dominant “benefactor-victim” model, where self-empowerment ideals are not as important.

Those boards of directors that were once all or nearly all people living with HIV transformed into boards where there was no, little, or only token PLHIV representation on them. Funding for support groups and networks was reduced or eliminated. The concept of connecting the newly diagnosed with other PLHIV became a quaint relic from the past, in favor of a mistaken belief that we would treat our way out of the epidemic.

Today the top priority after a person is diagnosed is, typically, to get that person on antiretroviral treatment so they will not pose a risk of HIV transmission to others. There are vastly fewer support groups and networks, and referrals to them are a rare exception, no longer the rule.

Today when newly diagnosed people are given this life-changing news, they are put on treatment, told to come back in three months, and ejected onto the sidewalk, expected to go about their lives as if it was no big deal. Yet HIV stigma makes many of us reluctant to share this news with our friends and families. We keep it a secret out of shame, fear, or a preference for keeping our personal health information private.

Shame because most everyone knows how not to acquire HIV today, unlike the “innocent” seroconversions of years past, and we live in a culture of blame. When a person is diagnosed, they are subject to harsh judgment, including from many in the communities that a few years ago were the beacons of hope and bastions of support.

Fear also encourages secrecy about one’s HIV-positive status. Years ago, when a diagnosis meant a person was probably going to become ill, we didn’t worry as much about who knew we had HIV or our long-term career prospects. Our survival timeline and focus were much shorter.

Today, a person with HIV may understandably want to avoid becoming defined by their condition, being subject to the gossip of coworkers, or having their HIV status become an impediment to career advancement. They have the choice of keeping their diagnosis a secret, living a normal life span, and are not likely to show evidence of HIV through wasting, visible Kaposi sarcoma lesions, or other indices.

It is, after all, private information, no one else’s business, so keeping one’s HIV-positive diagnosis a secret is an important right that every person with HIV should enjoy, if they choose. But it also can contribute to isolation, self-stigmatization, and rendering the epidemic less present and less visible to others.

The community context associated with disclosure of one’s HIV status is also different. At one time the LGBT community accepted the epidemic as a collective responsibility, wrapping its arms around those newly diagnosed, expressing its love and support, and sending a message, “We’ll get through this together.” Such is no longer the case, as the LGBT movement moved on to marriage equality, military service, and other priorities.

Even within gay men’s social sexual circles it is very different, with the online hookup apps full of guys who assert they are “clean” and running away from those who bravely share their HIV-positive status. Instead of getting love and support, many gay men with HIV are made to feel like

pariahs, as though they don't deserve as satisfying and fulfilling an intimate life as everyone else.

The reality is that the consequences of disclosure are greater today than they were years ago. If we want to encourage PLHIV to disclose, then we must prioritize making it safer to disclose, not wagging fingers at us telling us what we "should" do. Making it safer to disclose means combating stigma.

Anti-stigma efforts have typically focused almost exclusively on settings where stigma occurs (places of employment, in the health care and educational systems) and on trying to "educate" the stigmatizers. The stigmatized—those of us living with HIV—were sitting on the sidelines, waiting to benefit from the enlightenment thus resulting.

Yet a far more effective strategy to reduce stigma is found by focusing on empowering the stigmatized, rather than educating the stigmatizers. The Civil Rights Movement in the 1960s didn't gain traction and make progress because a white supremacist majority woke up one day and got educated and decided not to be racist; it made progress because a Black minority became empowered, outspoken, and demanded equity.

"Empowerment" has become a buzzword to the extent that it is practically like white noise, having lost any real meaning. Years ago, the U.S. Supreme Court Justice Potter Stewart, in a decision defining what was pornographic, noted he had a hard time defining it but said, "I know it when I see it." That's a bit how I feel about the empowerment of PLHIV.

Empowerment isn't something that one individual or agency can give to another; it is something that arises organically when the conditions are right. Those conditions start with creating opportunities for people living with HIV to connect with each other, whether for social or peer support, for recreation, or to pursue advocacy or educational agendas.

Michael Callen, one of the first AIDS activists, used to say that there was "a special magic" when there were only people living with HIV or AIDS in the room. The conversation is different when stigmatized individuals are able to be with each other, free of the judgment and stigma they typically experience in their lives. In those spaces, we are able to discuss and share our concerns and priorities in a more gentle and generous way, free of polarizing interests that want us to fit their agendas.

When people living with HIV are able to get together, they then have the opportunity to create their own agenda, select leadership that can be held accountable to other PLHIV and, importantly, speak with a collective voice. People living with HIV who are connected with other PLHIV, through support groups, PLHIV networks, or other means, report much higher self-empowerment, are better able to handle stigma, and have a better quality of life and improved health outcomes.

Peer support is vital for every person in every phase of their lives, to be sure. But the more disenfranchised, marginalized, or stigmatized the community, the more important it is. For those of us lucky enough to have survived the epidemic so far—in many cases having come to the brink of death before returning, Lazarus-like, to a bonus round of life we never expected to see—finding

support from each other is more important than ever.

This excerpt is from Bodies and Barriers: Queer Activists on Health, which is available in bookstores and online. The book is written by LGBT health care consumers to inform the health care system.

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