POZ™

Stories of Resilience

Two HIV researchers discuss their recent books on gay men and HIV-positive women.

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In each of the two nonfiction books discussed below, the authors interviewed people living with and at risk for HIV in order to offer insight into two different population groups. Perry N. Halkitis, PhD, MPH, the dean of the School of Public Health at Rutgers University, focused on three generations of gay men, while Celeste Watkins-Hayes, PhD, a professor of sociology and African-American studies and a faculty fellow at the Institute for Policy Research at Northwestern University, interviewed over 100 women living with HIV. POZ emailed each author to discuss their findings; their responses are lightly edited.

Courtesy of Oxford University Press

First up is Halkitis. For his latest book, Out in Time: The Public Lives of Gay Men from Stonewall to the Queer Generation, he interviewed 15 gay men spanning three different groups he labels as the Stonewall Generation (those who came out during adolescence and emerging adulthood in the 1950s to 1970s), the AIDS Generation (the 1980s to 1990s) and the Queer Generation (2000s to 2010s).

What is the topline takeaway from your book?

It’s gotten better, but it’s still not great! More than ever, in this political era, we need to be vigilant or else our rights will be slowly eroded.

In what important ways did the three generations differ?

The major difference across generations resides with the manner in which the men understand and live their identities. Members of the millennial generation, which I have come to label the Queer Generation, possess a more nuanced and sophisticated understanding of the multiple intersectional identities that people possess and the fluidity of these identities. Also, each generation is defined by different challenges. For men of the Stonewall Generation, the struggle was to live openly and without the fear of harassment, persecution and criminalization in an era when being gay was diagnosed as a psychopathology. For men of the AIDS Generation, as I wrote in my last book, the goal was to survive and thrive, especially before 1996 [the year effective HIV treatment became available], when AIDS-related complications resulted in the death of so many gay men. For the Queer Generation, there are two main struggles—as mentioned earlier, the challenge to live full intersectional lives where gay identity is celebrated alongside and in connection with race, ethnicity, culture and gender; the other challenge is coming of age in the post–financial crisis world. Like so many millennials, the economic conditions of these young men are unlikely to be as prosperous as those who came of age before them. It is important to note that these burdens are cumulative across time. The younger men continue to face harassment, AIDS and the other challenges that defined the lives of the Stonewall and AIDS generations.

How do the generations differ in terms of their relationship with HIV?

Three-plus generations of gay men’s lives have now been shaped by AIDS. The differences that have emerged across time are due to the biomedical advances of the last two decades in the form of ART [antiretroviral therapy], U=U [undetectable equals untransmittable] and PrEP [pre-exposure prophylaxis], which empower us as a population with more powerful tools to manage this despicable disease.

But in some ways, the relationship of gay men to HIV is still the same as it was decades ago, including the experience of stigma that so many HIV-positive people face in our society. I often say that for those who do not work in the arena, reactions to HIV nowadays are not remarkably different than they were in the 1980s—ones of fear and shaming. Quite frankly, HIV and gay-related stigma add to the burdens that compromise the lives of gay men even in 2019—conditions that fuel HIV. The one glimmer of hope for younger and, in fact, all gay men is that they witness that biomedical advances empower HIV-positive individuals to live full lives to enjoy a normal life expectancy—although the physical challenges caused by HIV cannot be underestimated. This hope certainly was not the experience for those of us who came of age in the 1980s and 1990s and saw too many of our loved ones succumb to the complications of AIDS.

What narratives or themes recurred across all three generations?

There are consistencies across time and generations imparted by the aggressions that continue to exist in our society despite the sociopolitical advances that have occurred since the Stonewall Riots in 1969. These aggressions—some state-sanctioned, such as the efforts to deny us services including health care, masked under the false premise of religious freedom—perpetuate the deeply felt burdens experienced by gay men. These burdens undermine the psychological health of gay men, leading to heightened levels of depression and substance use among other health disparities as well as catalyzing other risk behaviors. Homophobia also fuels conceptions of hypermasculinity that are evident in the gay population, which also counter effective well-being.

The book addresses the importance of pride and coming out. How do these affect a person's health, specifically in regard to HIV?

The narratives in the book clearly demonstrate this association. When you are able to live your truth, not subjugating who you are and experiencing pride in who you are, then your physical, social and emotional health simply improves. Pride is embodied in the resilience that many gay men have developed, which is as powerful, if not more powerful, than condoms and PrEP at preventing seroconversion and as important in helping HIV-positive gay men live their own beautiful lives with health and determination and drives as is witnessed in the pages of this magazine.

Do the risks of contracting HIV (or the prevalence of the risks) change from generation to generation?

The epidemiological data indicate that the greatest impact was on those born in 1960 to 1964, members of the AIDS Generation. Yet the disease has highly differential effects shaped by social conditions. These undermine the well-being of Black men more so than other [groups] and make these men even more vulnerable. It is clear from my own research and that of others that Black men do not engage in more risk—quite the contrary. What is true for so many Black men is that they are subjected to homophobia plus racism from society and within the LGBTQ population. Plus, they experience more limited access to the economic and other social privileges due to the inequities that are so much part of our society. For young Black gay men in the South, conditions mimic those of the 1980s, indicating that despite these many biomedical advances, HIV is as much a social disease as a biological one.

Did anything surprise you as you worked on the book?

I went into the project with the notion that there were similarities across time and space in the coming-out experiences. If anything surprised me, it was how remarkably similar so many of these experiences were—that the psychological reality is a constant. That feeling of otherness that so many of us have at young ages is no different in 2010 than it was in 1960. Finally, what became so clear to me is that all sexual and gender minority individuals spend their lives coming out. That in and of itself creates its own burdens.

I want us to understand that there is still a lot more work to be done until we live in a society free from any LGBTQ+ and HIV hate. But that is not now. As we know, according to the latest FBI data, hate crimes against LGBTQ+ people are on the rise. Harassment of people of color continues to be perpetuated by our society. And the haters would gladly strip the rights of anyone who is not like white straight America. These conditions are a call to action for all of us.

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Courtesy of University of California Press

And now for the interview with Celeste Watkins-Hayes. For her latest book, Remaking a Life: How Women Living With HIV/AIDS Confront Inequality, she interviewed over 100 women living with the virus in the Chicago area.

What is the topline takeaway from your book that you'd like to leave with the POZ reader?

The most important takeaway from the book is that we discount the lives and experiences of marginalized populations at our collective peril. When I look at the success of the HIV/AIDS movement and the work that remains, the underlying theme is the way in which people in the minority—those who are systematically marginalized on the basis of sexuality, race, class, gender identity and other statuses—have created a movement and a tangible support structure to save and improve not only their own lives but also the lives of those around them. The HIV movement has led to important medical discoveries, changed the face of patient-physician interactions and generated models for what holistic wraparound care can look like in a variety of settings. In a moment when those on margins are routinely and visibly attacked and discounted, the danger of counting people out and devaluing what they can contribute cannot be more relevant.

You interviewed over 100 women living with HIV. What connective threads and recurring themes unite these stories of transformation?

By interviewing women living with HIV for over a decade, I was able to illustrate how the HIV epidemic helps us pinpoint how women move from what I call "dying from" to "living with" to "thriving despite" personal traumas and systemic injuries of inequality, including but not limited to HIV. I heard many accounts of distress and struggle, perhaps not surprising given the devastation wrought by HIV and the social dynamics that fuel the epidemic. But I also heard stories of transformation as women described thriving despite those obstacles. The connective threads that made these personal transformations possible were women's resilience as well as the collective strength of the HIV community. Perhaps one of the most important but underrecognized outcomes of HIV/AIDS mobilization is the emergence and sustainability of an extensive HIV safety net made up of policies, institutions and people who have proven vital for individuals confronting an HIV diagnosis and other challenges. In its most robust form, the HIV safety net offers access to health care, modest economic assistance, extensive social support and a path to political and civic engagement. For women who were able to gain access to those resources and truly leverage them, it proved to be transformative.

You write that these women face "injuries of inequality." Can you expand on that phrase and its context in your book? What are the most common injuries of inequality?

We often hear the term "social determinants of health" when we talk about health inequality, but in my view, that term can downplay the injustices and harms directly and indirectly committed against marginalized populations. I prefer "injuries of inequality" because it foregrounds inequity as the primary driver of health disparities and calls upon us to reflect on how people are wounded by the differences in resources and power that we too often see as an acceptable status quo. Injuries of inequality—big and small wounds to personal, family and community well-being—result from interpersonal, institutional or systemic violence or trauma rooted in the exploitation of unequal power dynamics. Injuries of inequality produce, and are produced by, a comprised ability to protect oneself from harm.

The HIV/AIDS epidemic is both an example of and fueled by injuries of inequality. The virus is transmitted through social and sexual networks; and our networks tend to be segregated by race and class and have unequal access to protective resources such as information, prevention and treatment resources. In addition, some of the biggest drivers of the epidemic—such as homophobia, racism, transphobia, sexism and poverty—shape the historical and present-day disparities in health care access and quality as well as our political and policy responses to these issues in ways that leave marginalized groups more vulnerable to HIV than more privileged sectors of society.

Finally, we must recognize how individual behaviors can be tied not only to structural violence but also to interpersonal violence. During the interviews we conducted with women living with HIV from diverse racial, ethnic and economic backgrounds, one in four revealed that she had been raped or molested before age 25, and two thirds of the women with histories of drug addiction reported experiences of early sexual abuse. Those issues are intertwined. The interaction between the epidemics of sexual violence and drug addiction has produced a landscape that draws in highly vulnerable people, situates them in a structure that further reduces their power and increases their risk of contracting HIV. All of these dynamics are, or produce, injuries of inequality because they are more likely to happen to people with less power.

What were the most common elements that helped these women transition from “dying from HIV/AIDS” to “thriving despite” the virus?

The complex lives of the women I interviewed demand that we see them not as victims but as survivors who have agency. Once these women received access to health care, economic assistance and robust social support through the HIV safety net, they were not only able to live with the disease but also to tap into their reservoirs of resolve to thrive despite it. Women’s agency met up with stabilizing institutional supports and responsive public policies to help them come to a place of health, economic and social stability. This then enables them to not simply cope but eventually confront and resist injuries of inequality and the forces that generate them by helping others in similar circumstances or by becoming politically active in their communities.

I also talked with more economically and socially privileged women, for whom the HIV diagnosis was a stunning setback, an experience that contradicted the relatively smooth trajectory they believed they were following. For them, “thriving despite” the virus was less about getting access to services but about finding ways to confront the stigma and shame. I found that middle-class women of various racial backgrounds tended to use the HIV safety net through highly individualized services. Rather than attending support groups, they often relied on private therapists, their physicians and small networks of friends and family members for most of their HIV-related support. In the book, I discuss some of the class-based issues that shape how women engage with the HIV community and how their needs differ. Nevertheless, what women had in common, regardless of background, was a moment in which they accepted HIV as a chronic illness that could be managed rather than a death sentence.

What role do AIDS service organizations and the HIV community play in these women's lives?

Looking at the HIV/AIDS community reveals how public policies and institutions—by implementing programs, distributing resources, and facilitating everyday social encounters—can play important roles in helping people move from "dying from" to "living with" to "thriving despite." The Ryan White CARE Act, Housing Opportunities for People with AIDS (HOPWA), the AIDS Drug Assistance Program (ADAP) and the Affordable Care Act [the ACA, or Obamacare] have been important policy interventions. And the culture of the HIV safety net is equally important. Service delivery that is non-stigmatizing, trauma-informed and sex-positive and gives space for women to tell their stories for the purpose of creating positive change is one of the things that I observed that was the most beneficial and productive.

But I would offer two caveats to my points about the strength of the HIV safety net. First, the most comprehensive approaches to confronting injuries of inequality demand systemic solutions: overturning existing economic, social and political dynamics that drive the contours of the epidemic. What the HIV community has created is valuable, but it does not upend existing power structures. It helps people to cope with personal traumas and systemic injustices that have shaped their lives. But ideally, those traumas and injustices would not exist in the first place.

Second, we must acknowledge that the AIDS safety net does not work equally for all populations and that gaps in services exist. We must repair the safety net where it is tattered and establish it where it is nonexistent. Geographic variations in the efficacy of the HIV safety net are particularly troubling. Women's access to resources in my book was largely predicated on living in urban centers in the United States with robust HIV/AIDS infrastructures that had historical roots in a politically mobilized LGBTQ community. The patchwork of support that many women weave together through AIDS services organizations is much more difficult to construct in the South and likely impossible to create in some rural areas. And increasingly, dollars are moving away from some community-driven services such as peer support, advocacy training, support groups and case management in favor of an emphasis on biomedical approaches to treatment that do not address the social and economic challenges facing large numbers of people living with HIV.

I would also be remiss if I did not also point out one of the deep and disturbing ironies of my book. Access to a safety net that allowed women to transform their lives was granted not based on need but an HIV diagnosis. It took a diagnosis that was seen as a threat to public health for these women to gain access to the help they always needed. That is a striking commentary on our now-tattered social safety net that leaves so many to fend for themselves as they navigate growing economic and social inequality and its resultant injuries to individuals, families and communities.

Did any of your findings surprise you?

Something that may be surprising to some are the ways in which cisgender and transgender women of color have been unsung leaders and foot soldiers in HIV/AIDS activist and advocacy work. For the most part, their platforms have been smaller, their organizations have enjoyed fewer resources, they have not been at the center of stirring portrayals in our news and popular culture that tug at a nation's conscience, nor have they always had broad and visible support from their various communities. But they have long been in the fight and have contributed a great deal. They have partnered with others to build coalitions. They have taken risks and fought for women's whole selves to be seen and heard as beings with political, economic, social and even sexual rights. They have been change agents within hospitals, community organizations and governments to affect policies and programs, partnering with women across racial and class lines to challenge the case definition of AIDS, to create women- and family-centered HIV/AIDS services and to build powerful networks of women working in the field of HIV/AIDS. And many have partnered with gay and bisexual men of color to lead efforts within minority communities and to push for racial justice frameworks to be adopted by the HIV community. By pushing for increased access to culturally sensitive services, shared decision-making power and attention to the unique needs of all the populations deeply affected by HIV/AIDS, those operating in this tradition continually push the AIDS community to stay true to the mission of moving people from death to life and have demanded that that be defined in the broadest sense of those terms.

Finally, can you summarize a few steps—calls to action, if you will—that will help other people with HIV transform their lives surviving with HIV into "thriving despite" the virus?

We are at an important moment in the history of the epidemic. We now have medications that are scientifically demonstrated to be very effective at preventing HIV transmission (PrEP) and lowering viral loads to levels in which the virus cannot be detected in the bloodstream. That means that there are now biomedical tools to end the epidemic. But the people who are best positioned to take advantage of these medical advances and virtually eliminate HIV in their sexual and social networks are people who are already privileged. If significant inequities hamper access to medications, health care and other necessary resources, we will see a growing "undetectable divide" between groups. We cannot let that stand. It is critically important to have honest conversations about how homophobia, racism, transphobia, sexism, classism and other forms of intersectional marginalization continue to shape the epidemic and to fight back against this. People look to the HIV/AIDS community for models on how to move the needle on intractable social problems, and we must continue to do the difficult work and lead by example.