

HIV: Still Epidemic After 30 Years

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December 1st is World AIDS Day. This article, from June 2012, was inspired by a conversation I had with a friend who was pursuing her Masters in Public Health. For a group project in epidemiology, she had tested a survey mechanism among college undergrads—a disturbing number of whom responded that they did not understand what “HIV” meant. We began ruminating on how “young people” (not substantially younger than ourselves) could be so clueless about a disease that had had such a devastating impact within recent memory. My question: Would this lack of awareness eventually result in a resurgence of a disease that, in truth, has never really gone away? —AMH

In the 30 years since the first cases of HIV were diagnosed in the United States, almost 620,000 people have died of AIDS in this country. In a very short period in the early 1980s, HIV morphed from completely unknown to epidemic in its scope; at one point, an estimated 130,000 new infections occurred each year in the US.

Today, that number has decreased substantially, to about 50,000 new infections per year. (Data from 2000 indicated the annual rate of new infections was 56,300, while CDC surveillance data from 46 reporting states in 2010 put the number at around 47,000.) In addition, the development and use of highly effective antiretroviral therapy has meant that people with HIV can live longer, healthier lives—provided, of course, that they have access to and comply with treatment.

Despite these improvements, however, is it acceptable that 1.2 million people in the US are living with HIV (20% of whom don't even know it)? “No, that number is certainly not satisfactory,” says Folusho E. Ogunfeditimi, MPH, PA-C, Director of Advanced Practice Providers at Henry Ford Health System in Detroit and a member of the American Academy of Physician Assistants Clinical and Health Affairs Commission. “We cannot take our foot off the pedal regarding education, prevention, looking at outcomes, and also looking at the impact of disparities and trying to eliminate those disparities.”

OMG, WHAT'S HIV?

It is possible that American success at reducing (though hardly eliminating) the spread of HIV has actually undermined awareness. It sometimes seems to be a national characteristic that if we don't see people dying in droves before our very eyes, we don't think there's a problem. A Kaiser Family Foundation survey conducted in 2009 revealed that just 6% of Americans considered HIV/AIDS to be “the most urgent health problem facing the nation,” down from a high of 44% in 1995.

In the 1980s and early 1990s, HIV and AIDS were hot topics in the news; it was impossible not to hear tales of horror or fear on a daily basis. While the reduction in misinformation dissemination is probably a positive, the Kaiser survey indicated that only 45% of Americans reported hearing, seeing, or reading “a lot” or “some” about the domestic problem of HIV/AIDS in the previous year. This might not be deeply concerning—there are, after all, plenty of other issues to discuss—until you realize that 62% of Americans consider the media to be their prime source of information about HIV/AIDS (compared with just 13% who say their health care provider is).

While awareness is an issue across demographic groups, the most potentially concerning is younger adults. This is a generation who most likely cannot tell you who Ryan White was and whose members were not alive during (or were far too young to re-

member) the major crisis of the HIV/AIDS epidemic.

“Sexually, they’ve grown up in an era where we have really good treatments,” says Susan LeLacheur, DrPH, PA-C, Associate Professor of Physician Assistant Studies at the George Washington University in Washington, DC, and a national lecturer on infectious disease and HIV infection. “When they meet people with HIV, those people are healthy.”

“Because we have, for lack of a better term, taken our foot off the pedal regarding HIV/AIDS awareness,” says Ogunfiditimi, “we run the risk of having people coming out of high school and into college not being as aware as we might have been in that age-group in the ’80s and early ’90s.”

In the Kaiser survey, 45% of respondents ages 18 to 29 indicated they had never been tested for HIV. Of those, 70% gave as a reason “you don’t think you’re at risk” and 33%, “your doctor never recommended it.”

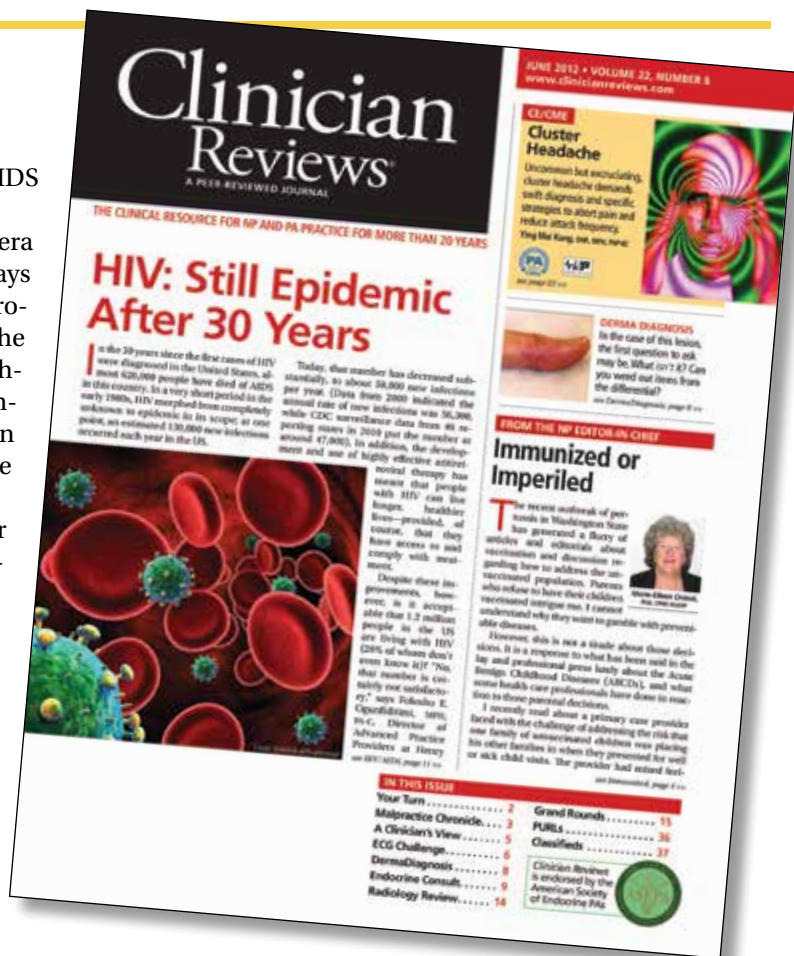
In 2008, the CDC estimated that 25% of new HIV infections occur among adolescents and young adults (ie, those ages 13 to 29). This is part of the reason Ogunfiditimi says a renewed focus on education is essential; he also thinks PAs and NPs are well suited to provide that information, given their reputation as patient educators and their frequent work at the community level.

“We need to take this message back to those [age-] groups, back to those communities and schools,” he says, “and conduct health education seminars and HIV/AIDS awareness programs in the schools so that we can start to educate our younger ones.”

TARGETED OR UNIVERSAL SCREENING?

Under the direction of President Obama, who has said the US “is at a crossroads” in terms of HIV/AIDS, facing “a domestic epidemic that demands a renewed commitment, increased public attention, and leadership,” the White House Office of National AIDS Policy (ONAP) has set ambitious goals for HIV prevention. Outlined in the National HIV/AIDS Strategy for the United States, those goals—with a deadline of 2015—include:

- Decrease the annual new HIV infection rate by 25%.
- Decrease the HIV transmission rate (currently



5 persons infected per year per 100 people living with HIV) by 30%.

- Increase the number of people living with HIV who know of their infection from 79% to 90%.
- Increase the number of people with newly diagnosed HIV who have regular health care within three months from 65% to 85%.

The strategy (available at www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf) was commissioned and developed in response to concern that without bold action, “we face a new era of rising infections, greater challenges in serving people living with HIV, and higher health care costs,” as stated in the executive summary of the report.

It may not help the cause that health care providers receive seemingly mixed messages about how to approach HIV screening. Since 2006, the CDC has recommended routine screening for HIV, stating that “HIV screening is recommended for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines (opt-out screening).”

The CDC expressly recommended that separate written consent and prevention counseling should not be required, in part as an acknowledgement that

busy practicing clinicians who have to screen for a multitude of conditions and often provide acute care during an office visit are under time constraints.

“That doesn’t mean you don’t do any counseling at all,” says Julie G. Stewart, DNP, MPH, MSN, FNP, Assistant Professor and Coordinator of the FNP Program at Sacred Heart University and an HIV NP at Southwest Community Health Center in Bridgeport, Connecticut, “but having discussions with your patients about their life and their health and their risk factors in every facet should include HIV testing.”

At the same time, both the CDC and ONAP em-

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phasize that certain populations are at higher risk for HIV infection and therefore need to be targeted. These include:

- Gay, bisexual, and other men who have sex with men: 2% of the US population but 61% of new infections (2009 data)
- Black men and women: 14% of the population but 44% of new HIV infections
- Hispanic and Latino persons: 16% of the population but 20% of new HIV infections
- Injection-drug users: 9% of new HIV infections

The CDC also reports that heterosexual persons account for 27% of new HIV infections.

In a tough economic climate, when the US investment in response to the domestic HIV epidemic has risen to more than \$19 billion per year, it makes sense to strategize how to most effectively utilize available resources to reduce disease burden. But do we run the risk of missing cases because we make too many assumptions about who is or is not likely to have this infection?

“The information that has been pushed out there has really tried to focus on these high-risk groups—and yes, we understand that those groups need to be identified,” says Ogunfidity. “But when you’re trying to increase the amount of testing, then the message needs to be more general so that practitioners who have natural biases won’t implement those biases into their decision as to whether to test someone.”

“What worries me is that the recommendation has been to test everyone at least once, and then again as indicated,” says LeLacheur. “As indicated’ means

you have to ask. In parts of the country where HIV is not as prevalent as it is in DC, I can understand how it falls off the radar. But there are still a few [cases]—maybe not one in 20, maybe more like one or two in a clinician’s lifetime—and there is just no telling from the outside.”

“Perception of risk is huge,” adds Stewart. Her state was one of the first to mandate prenatal HIV testing, and she recalls instances in which a woman tested positive and the clinician was shocked because, Stewart says, “the perception was that ‘She is not at any risk at all,’ based on where she lives and her background. But the clinician didn’t really know.”

LeLacheur also points out that assumptions work both ways: “Oh, he’s a nice boy” and “Oh, he’s not a nice boy.” In one of her classes, a gay male student shared his experience seeking a diagnosis for what turned out to be Crohn’s disease. “The minute he told his clinician he was gay, all of a sudden he had AIDS and the clinician wouldn’t look anywhere else,” LeLacheur reports. “And that just wasn’t an issue; this was a kid who had been raised in an era of safer sex and had been very careful.”

Advocates say that implementing universal screening, per the CDC’s recommendation, would not only capture more cases but would also reduce the stigma associated with targeted screening.

TRUTHS AND CONSEQUENCES

So perceptions and assumptions play important roles in how the US addresses HIV testing—both the perceptions of some patients that they are not at risk or that having HIV isn’t a big deal anymore, and the assumptions by health care providers that they don’t need to screen all patients for HIV. That faulty logic can have dire consequences, even if HIV is no longer an automatic death sentence.

“I think there’s a lot of passive testing, a lot of disease-induced or behavior-induced testing,” Ogunfidity says. “A patient comes in with complaints of what sounds like a sexually transmitted infection and that may spur a provider to initiate the discussion around HIV and subsequently do testing to back that up. But I don’t get the sense that HIV testing is promoted significantly.”

“They get sick” is how Stewart says many people learn their HIV status. “That is still frequently the way people become aware of their illness—they are sick in the hospital with an opportunistic infection.... If

we can identify people who are HIV-infected earlier, we can capture them at higher CD4 counts, and then they have an improved life expectancy. We can start treatment, and that also impacts transmission.”

Echoing Stewart’s comments, LeLacheur also notes that the major pneumonia or other infection that leads to hospitalization and diagnosis of HIV can cause permanent damage. “I have a couple of patients who appear to be poststroke because of a viral infection in their brains that people get very late in HIV,” she says. “Now, their viral loads are undetectable and their CD4s are very high. Their immune systems are in good shape, and in every other way they’re healthy. But they can’t walk.”

For those misguided patients who think HIV isn’t such a big deal these days, LeLacheur has some hard facts clinicians can share. “You don’t realize until after you have HIV and someone explains it to you that the minute you get it, it essentially knocks out the entire immune system in your intestinal tract—which is more than half of your immune system—and that’s never coming back,” she says. “That infection in the gut is never going away; the medicines don’t touch it. So your digestion will never be right. There are things we can’t fix about HIV.”

And heaven help the patient who tries to rationalize that “you just take one pill a day.” First of all, that one pill ties up your liver, as LeLacheur points out, and second of all, HIV medications cost about \$16,000 a year. Not many people can afford that on their own, and some states have 700-person-long

waiting lists for assistance programs.

The consensus among clinicians who treat HIV-infected patients is that, yes, the US is much better off than it was at the height of the crisis. But there is still enough disease, still enough devastation, to warrant continued vigilance. And that starts with talking to all patients about HIV.

Ask the questions, they advise, do the test, and be prepared to refer patients to a specialist who can help them manage their illness. But don’t drop the ball on those patients even when they have specialty care; study up on drug interactions and know what you are prescribing to patients taking antiretroviral therapy.

“As PAs and NPs, we absolutely have to be the ones carrying that banner up front,” Ogunfeditimi says. “We’re the ones who have that opportunity to spend time with those patients and make sure we walk them through the urgency and the importance of being aware that this disease is still very rampant in our communities. I don’t want to say that we have taken it for granted, but we have definitely not paid as much attention as we used to in the ’80s and the ’90s, and we need to get back to that.”

“We can never forget,” Stewart concludes. “We spend a lot of time learning about and testing for breast cancer, prostate cancer, diabetes, and hypertension, all in an effort to take care of our patients the best we can. Screening for HIV should be in that same category.”

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