Rising Above

People living with HIV are also facing cancer as they age.

July 1, 2019 By Liz Highleyman

As a long-term survivor living with HIV, Sean McKenna has faced numerous battles, including two episodes of skin cancer and several bouts of anal precancer. Jill Cadman, another long-timer, is living with HIV and Stage IV colon cancer. And they are not alone.

“Almost every long-term survivor I know is dealing with HPV,” or human papillomavirus, which causes anal, cervical and oral cancer, McKenna says. “Our bodies are beaten down. So many of us in our 50s or 60s are experiencing things that don’t usually happen until the 70s or 80s.”

Like McKenna and Cadman, a growing number of people with HIV are dealing with cancer as they age. But this is more about a shifting landscape than an overall rise or fall. Since the advent of effective antiretroviral therapy in the mid-1990s, the AIDS-defining cancers—Kaposi sarcoma, non–Hodgkin lymphoma and cervical cancer—have dropped dramatically. But as people live longer, they have more time to develop other types of cancer.

McKenna, now 56, was diagnosed with HIV in 1992, although he thinks he acquired the virus a decade earlier. Effective medications came along just in time, and eventually, he found a combination that kept his HIV in check.

But that didn’t stop other problems. Twenty years ago, when he was trying to get his HIV under control, he was diagnosed with melanoma. Luckily, that spot was removed early and never spread. Then, in March 2018, after watching dermatology surgeon Sandra Lee’s TV show, Dr. Pimple Popper, he decided to see a dermatologist about a cyst that had been bothering him. An initial biopsy showed it was benign, but the lump got bigger and eventually was diagnosed as dermatofibrosarcoma protuberans, a rare tumor that develops in deep layers of the skin.

“I got the call at a friend’s place, and it was very similar to the call I’d gotten years ago saying I had to come in to discuss the results of my HIV test,” he recalls. “Both times, I was caught completely off guard. I hung up the phone and asked myself, ‘Did he say what I thought he said?’”

Last December, McKenna saw an oncologist who “cut a 5-inch hole” in his back. He needed a second skin graft to repair the wound, after losing the first graft to an infection. “They didn’t pay attention to the fact that I was a long-term HIV survivor,” he says, and didn’t prescribe him strong enough antibiotics to shore up his battered immune system.

"When I found out I was HIV positive," Sean McKenna says, "I told everyone, and I did the same for cancer."Bill Wadman

McKenna's skin cancer appears to be cured, but things aren't going so well elsewhere. He also deals with recurring anal dysplasia, or abnormal tissue changes caused by HPV, despite the fact that his viral load has been undetectable for years and his CD4 cells are above 1,000. He has had several precancerous lesions removed and has participated in clinical trials, including one that tested a topical chemotherapy drug.

"It was a real pain in the ass, and it didn't do much good," he says. "I don't know why this is so persistent—it's the most uncomfortable thing in the world."

HIV-Related Cancers

Most cancers develop over time as a result of exposure to cancer-causing factors in the environment and an accumulation of genetic mutations. People with HIV—who are twice as likely to smoke and who have more cancer-causing coinfections—are at higher risk.

In addition, effective antiretroviral therapy means more HIV-positive people are living to the age when cancer typically occurs. According to the Centers for Disease Control and Prevention (CDC), just under half of people living with HIV in the United States are age 50 or older, and 16% are over 65. About half of all cancers occur in people 65 and older.

Before combination therapy, AIDS-defining malignancies accounted for around 75% of all cancers among people with HIV; today, that figure is closer to 25%. But HIV-positive people are still more likely to develop these cancers than those in the general population, largely because many remain unaware that they have the virus and aren't on treatment.

"Cancer is a very important cause of mortality in HIV-positive men and women," says Joel Palefsky, MD, of the University of California at San Francisco, who founded the first clinic devoted to anal cancer prevention. "The AIDS-defining cancers have come down with antiretroviral therapy, but they're not gone. And the non–AIDS-defining cancers have gone up."

In San Francisco, for example, HIV-related causes, including AIDS-defining cancers, still accounted for the largest proportion of deaths of HIV-positive people between 2014 and 2017, at 38%. Non-AIDS cancers came next, at 15%, followed by heart disease at 11%.

The non-AIDS cancers with the greatest disparities between people with and people without HIV are caused by viruses, including HPV; hepatitis B and C viruses (HBV and HCV), which can cause liver cancer; and Epstein-Barr virus (EBV), which causes some types of lymphoma, throat cancer and other malignancies.

Researchers often classify cancers as AIDS-defining or non–AIDS-defining, but a more useful distinction may be whether or not they're HIV-related. In fact, HPV cancers demonstrate how classification can be more about politics than science. In the late 1980s, some activists felt it was important to have a woman-specific condition included in the CDC's definition of AIDS. As a result

of their efforts, invasive cervical cancer was added, but anal cancer—essentially the same disease with the same cause—was not, which has had ongoing ramifications for screening and care.

Studies show that people with HIV have more types of HPV on average—including types 16 and 18, which cause a majority of cervical and anal cancers—and are less likely to clear the virus naturally. In addition, they may experience more rapid progression of HPV-related disease, from low-grade cell changes to advanced dysplasia (known as high-grade squamous intraepithelial lesions, or HSIL) to invasive cancer.

A leading cause of cancer death in lower-income countries, invasive cervical cancer is relatively uncommon in the United States because regular screening can catch HPV-related cell changes early enough to be treated before they progress to cancer. In one of the greatest achievements in public health, cervical cancer rates plummeted by around 75% after the adoption of routine Pap testing in the 1950s.

But anal cancer is a different story. The incidence of anal dysplasia and cancer has risen since the advent of effective HIV treatment. About half of HIV-positive men who have sex with men have HSIL, according to Palefsky, and they have an 80- to 100-fold greater risk of developing anal cancer compared with the general population. Women with HIV are at increased risk too. And, as McKenna learned, undetectable HIV and CD4 cell recovery don't eliminate that risk.

Anal screening is neither routinely done nor included in federal HIV guidelines, although it is part of New York's state guidelines and has been adopted by some providers who see many gay men living with HIV.

Some doctors are hesitant to provide anal screening—and insurers are reluctant to cover it—because of the lack of gold-standard evidence showing that early detection and treatment of HSIL actually prevent anal cancer. "We know screening works in cervical cancer, and we adopted that system before we had proof that it worked," Palefsky says. But the balance of benefits and harms is different for the two cancers. "If a woman has [cervical] HSIL, you can remove a large portion of the cervix. But you can't do that in the anal canal, obviously."

Palefsky's ANCHOR (Anal Cancer HSIL Outcomes Research) trial aims to supply the needed evidence. In this study, men and women diagnosed with HSIL will be randomly assigned to receive either immediate treatment or active monitoring. The study is currently recruiting participants in more than a dozen cities (visit AnchorStudy.org or call 844-HIV-BUTT).

For younger individuals, a vaccine can prevent nine types of HPV. Although it works best before people become sexually active, the CDC recommends the vaccine for HIV-positive men and women through age 26, and the Food and Drug Administration (FDA) has approved it for those up to age 45.

Liver cancer—caused by heavy alcohol consumption and fatty liver disease, as well as by chronic hepatitis B or C—is among the few cancers that are rising in the United States. According to the CDC, about a quarter of people with HIV have HCV coinfection. HIV-positive people have about a

fourfold higher risk of liver cancer—and they may develop cancer at a lower stage of liver damage. Fortunately, hepatitis B can be prevented with a vaccine, and new antiviral medications can now cure almost everyone with hepatitis C.

Beyond these viral cancers, people with HIV also have about twice the rate of lung cancer—the leading cause of cancer-related death for HIV-positive and HIV-negative people alike, says Michael Silverberg, PhD, MPH, of the Kaiser Permanente Division of Research. HIV-positive people are more likely to smoke, but their risk remains disproportionately high even after controlling for smoking. A history of respiratory infections may be part of the reason for this, according to Silverberg. The link with immune deficiency might even hint that an unidentified virus plays a role in lung cancer. But, he says, “Smoking is such a strong risk factor that it probably explains most of the excess risk.”

What’s more, several studies suggest that people with HIV may develop various cancers at earlier ages, may be diagnosed at more advanced stages of disease and may have poorer survival than HIV-negative people.

Because of the strong association between HIV infection and the development of cancer, starting and staying on antiretroviral therapy is one of the best ways to prevent and control cancer among people living with HIV. The large START trial showed that people who started HIV treatment immediately rather than waiting until their CD4 count fell below 350 reduced their cancer risk by 64%. Effective treatment both limits damage to cancer-fighting immune cells and helps reduce cancer-causing inflammation.

Regular screening is also important to catch cancer early, when it’s easier to treat. “There’s no strong evidence that any of the routine cancer screenings should be different for HIV-positive and HIV-negative people,” Silverberg says. (See screening recommendations below.)

Living With Cancer

Studies looking at the links between HIV and other nonviral cancer types have yielded mixed results. For example, rates of melanoma, kidney cancer, oral cancer and stomach cancer were found to be higher among people with HIV in some studies but not in others. And some cancers consistently appear to have no association with HIV—or may even occur less often in HIV-positive people—including breast cancer, prostate cancer and colon cancer.

“Breast and prostate cancer are interesting stories,” Silverberg says. “HIV patients have an increasing burden as they age, but when you compare them to people without HIV of a similar age, we’re actually seeing a lower risk than you would expect.”

But that doesn’t mean people with HIV are out of the woods, as these are among the most common cancers in the population at large.

Jill Cadman, a longtime HIV treatment advocate and former editor for GMHC and The Well Project, was diagnosed with HIV in 1992. She started on sequential monotherapy, and when new drugs were approved, she put together an effective three-drug regimen. Her viral load has been

undetectable for 20 years, her CD4 count is high, she has never been sick with opportunistic infections and she has had few side effects.

Jill Cadman and her dog, CarlyCourtesy of Jill Cadman

“I was lucky there was always another drug available when I needed it,” she says. “In those early days, I would do bitter melon enemas and mistletoe from the buyers club. I don’t know how much that helped, but I stayed well until whatever drug I was taking stopped working, and then there would be something else. As the standard of care evolved, my treatment evolved along with it.”

But Cadman’s experience with cancer treatment has been more frustrating.

Cadman was diagnosed with Stage IV colon cancer in November 2017, at age 54. Her HIV doctor had noticed a decrease in her hemoglobin but couldn’t figure out why. She developed constipation and back pain and began losing weight. She’d previously had a colonoscopy at age 51, but the results were normal, and her gastroenterologist didn’t think she needed another so soon. Eventually, another doctor agreed to do a second one, which revealed a tumor in her colon. Scans showed that cancer had spread to her lungs.

“I finally got an answer, and it was the worst possible thing,” she says. “Nobody, from the GI doc to the hematologist, seemed to be concerned enough about what was going on with me, even though I probably had a higher risk of cancer being long-term HIV-positive. I was too accepting when I was told that the second colonoscopy wasn’t necessary. If I had pushed harder and gotten it sooner, the cancer might have been found before it spread.”

Cadman started on standard combination chemotherapy known as FOLFOX and had surgery to remove the colon tumor in December 2017. She continued the chemo regimen longer than expected—she says acupuncture kept neuropathy at bay, and homeopathy helped manage her nausea—but she finally had to stop taking one of the drugs because of side effects. Genetic testing showed that her cancer probably wouldn’t respond to any of the newer targeted therapies.

“It’s been frustrating, because that wasn’t how it was with HIV—if a new drug came out, the only thing that would prevent you from taking it would be resistance,” she says.

As indicated by Cadman’s experience, recommended cancer therapy for HIV-positive people on antiretroviral therapy is generally the same as for HIV-negative people. Yet according to the National Comprehensive Cancer Network (NCCN), people living with HIV are much more likely to receive no cancer treatment—a legacy of a time when they were sicker and HIV therapy was more complex.

In 2018, NCCN issued new guidelines recommending that clinicians should offer cancer treatment to most people with HIV just as they would for those who are HIV negative. However, some cancer medications can interact with certain antiretrovirals—integrase inhibitors are less likely to cause problems—and some drugs can lower white blood cell counts, including CD4 cells. For these reasons, the guidelines stress the importance of collaborative care managed jointly by oncologists and HIV specialists.

Drawing on her HIV expertise, Cadman sought out clinical trials, including a study of the immunotherapy drug Opdivo (nivolumab), but learned that most cancer trials are closed to people living with HIV.

“People always say, ‘Oh, something new is going to come out—maybe there’s a trial you can enroll in,’” she says. “It never occurred to me that HIV would be an issue. It took away something that really gives you hope—that maybe you could enter a trial and help yourself and help others.”

But that’s changing. Last November, at the urging of the American Society of Clinical Oncology and Friends of Cancer Research, the National Cancer Institute and the FDA expanded trial eligibility criteria to allow people with certain coexisting conditions, including HIV, impaired kidney or liver function and cancer that has spread to the brain.

Cadman’s doctor urged her to stick with her chemotherapy regimen for the time being because it was still working. But a couple of months ago, facing low white blood cell and platelet counts, she and her doctor decided to stop the chemo. “They took all the cancer out of my colon, and it hasn’t come back. The nodules are just in my lungs, and my scans have been stable,” she says. “I may be overtreating. So now I’m not doing anything for three months and giving my bone marrow a break.”

Still, when she hears about new drugs, Cadman checks her genetic test results to see whether she might be eligible for any of them.

“I’m hoping that one day, just like with HIV, there will come a drug for me that, if it doesn’t cure me, will make the cancer chronic.”

Looking to the Future

In some ways, cancer today looks like HIV in the mid-1990s: on the brink of a breakthrough. The field is moving away from the traditional “slash, burn and poison” approach and toward precision therapies that target cancer with specific genetic mutations and immunotherapies that help the immune system fight cancer. These new treatments have already led to durable responses and longer survival for many patients.

These treatments don’t yet work for everyone or for all types of cancer. But early research suggests that people living with HIV can benefit as much as HIV-negative people—and that they don’t experience worse side effects or setbacks like viral load rebound. Some research suggests that checkpoint inhibitors, a type of immunotherapy that unleashes cancer-fighting T cells, may help suppress HIV and even reduce the viral reservoir. Now that advocates have opened up more oncology trials to HIV-positive people, we have new opportunities to learn about optimal cancer treatment for this population.

Palefsky urges people with HIV to join studies of cancer prevention and treatment for the sake of both their own health and the larger community. “Cancer is one of the next frontiers after antiretroviral therapy, and cancer control is one of the next big steps in keeping HIV-positive people healthy,” he says.

Going beyond better treatment, people living with HIV and cancer have much to contribute in terms of lessons learned from advocating for themselves, fighting stigma and building support

systems.

“When I found out I was HIV positive, I told everyone, and I did the same for cancer. I’ve already had three people thank me because I scared them into getting checked, and they found something that needed to be removed,” says McKenna, who convinced GMHC to restart its Buddy Program with a focus on long-term survivors. “It does seem like there’s less support for people with cancer than for people with HIV,” he adds. “I want people who are long-term survivors—who are now facing other health issues—to have the same sort of support people had when they were dying from AIDS.”

Cancer Prevention Tips

- Stay on effective HIV treatment.
- Stop smoking.
- Limit alcohol consumption.
- Eat a low-fat, high-fiber diet.
- Maintain a healthy weight.
- Exercise regularly.
- Protect yourself from the sun.
- Get vaccinated against hepatitis B and HPV.
- Get treated for hepatitis B or C.
- Get recommended cancer screenings.

Courtesy of METUP

Calling All Advocates

The cancer world hasn’t seen much of the in-your-face activism that helped turn the tide for people with HIV, but METUP—the Metastatic Breast Cancer Exchange to Unleash Power—is changing that.

After countless fund-a-thons and pink-ribbon promotions, metastatic breast cancer remains invariably fatal, despite advances in prevention and curing early cancer.

“In the last 30 years, the needle wasn’t moving,” says METUP president Susan Rahn, who was diagnosed with metastatic breast cancer at age 43. “The same number of people are dying. We need to start making more noise.”

Founded by cancer patients Beth Caldwell and Jennie Grimes, METUP held its first action in April 2015—a die-in at the Living Beyond Breast Cancer conference in Philadelphia. An early member was part of the LGBT community and made connections with people from ACT UP.

“It was like a funeral, as person after person lay down and Jennie read a eulogy about 108 people a day dying—similar to the number of AIDS deaths at the height of the epidemic,” Rahn recalls. “All of us on the ground were in tears because we all knew we would be in that position.”

METUP wants researchers to focus more on people with advanced cancer and demands that the FDA work faster to approve new treatments.

“In the emergency room, they’re not going to take someone with a broken bone before someone with a gunshot wound,” Rahn says. “Forget about a cure—if we can figure out how to make cancer chronic and have a decent quality of life, I’m good with that.”

Advocates for people with cancer and people with HIV have often worked side by side—such as opposing Medicare changes that would limit access to treatments for both diseases—but they’re increasingly working hand in hand as well.

Longtime AIDS activist and Treatment Action Group executive director Mark Harrington recently gave a talk on treatment activism at the National Breast Cancer Coalition’s annual summit.

“It was wonderful to meet these fierce, determined, scientifically grounded and politically focused activists and survivors,” Harrington says. “In the current political environment, it is critical for disease-specific research advocates to work together to ensure the protection and expansion of federal funding streams for all research.”

Rahn concurs: “The more voices we have together making noise, the better heard we’re going to be. There’s more power in numbers.”

Cancer Screening

Routine screening is the best way to prevent the development of cancer or catch it at its early stages when it’s easier to treat. For most cancers, screening guidelines don’t differ for HIV-positive people, but it’s especially important that those living with the virus follow these recommendations.

Anal cancer: There’s no consensus about routine anal cancer screening, but some doctors offer anal Pap tests and blood tests for cancer-causing human papillomavirus (HPV) for those at risk, including HIV-positive gay men. Some experts think anal cancer screening recommendations should be similar to those for cervical cancer—the ongoing ANCHOR study will shed more light on the potential benefits. Get checked out if you have symptoms like anal pain or bleeding.

Breast cancer: The American Cancer Society (ACS) recommends that women at average risk should receive annual mammograms starting at age 45, switching to every other year at age 55. Some women may benefit from earlier screening based on individual risk factors and personal preference.

Cervical cancer: ACS recommends that women get Pap tests every three years starting at age 21. Those over 30 have the option of Pap tests combined with HPV “co-testing.” Abnormal results should be followed up with colposcopy, which uses a magnifying instrument to examine cervical tissue. Guidelines recommend that HIV-positive women have a Pap test after being diagnosed with HIV and another one six months to a year later; after three normal tests, they can switch to

every three years.

Colon cancer: ACS recommends that adults at average risk should undergo regular screening starting at age 45. Colonoscopies, which are more accurate but can be uncomfortable and carry a small risk of complications, and fecal blood tests are both acceptable—the best test is the one that gets done!

Liver cancer: Experts recommend that people at risk for liver cancer—including those with hepatitis B or C, especially if they have developed cirrhosis—should be screened every six months with alpha-fetoprotein (AFP) blood tests and ultrasound scans.

Lung cancer: ACS recommends annual screening with low-dose CT scans for people ages 55 to 74 who have at least 30-pack-year smoking history (for example, one pack a day for 30 years or two packs a day for 15 years) and who currently smoke or have quit within the past 15 years. However, a recent study suggests people living with HIV may develop lung cancer at a younger age and may benefit from earlier screening.

Prostate cancer: ACS recommends that men at average risk should talk to their health care provider about the pros and cons of blood tests for prostate-specific antigen (PSA), a biomarker of prostate cancer, starting at age 50. Black men and those who have a father or brother with early prostate cancer should have this conversation sooner.

Skin cancer: The American Academy of Dermatology encourages everyone to perform regular visual skin self-exams. A dermatologist can help you decide how often to receive skin exams from a doctor based on individual risk factors.

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