THE CANCER THAT DARE NOT SPEAK ITS NAME

The social stigma that anal cancer carries with it prevents the open discussion and awareness needed to battle the disease.

Personal Perspective: THE GOOD PATIENT: FIGHTING ANAL CANCER

Your humble editor maneuvers the system after receiving a diagnosis of anal cancer.

COMPLEMENTARY & ALTERNATIVE MEDICINE AND HEALTHY LIVING

In addition to standard treatment, many people with HIV use CAM to deal with HIV-related symptoms, side effects, pain, and to improve quality of life.

THE ODD COUPLE: HIV AND BACTERIA

“Healthy bacteria” have important roles in the body and are needed to keep people functioning well.

Personal Perspective: STAYING IN THE GAME, DESPITE THE ODDS

It’s hard knowing that some people in the neighborhood call me “homo coach”.

EDITORIAL

Recently, a 55-year-old gay man announced to his dinner companions, “Well, I hear that having HIV is now just about taking one pill a day. I can do that, so I’m going to stop using condoms.”

As anyone living with HIV knows, managing this disease is about far more than taking a pill. First, the once-daily pills will only work if you are infected with a strain of HIV that’s not resistant to any of the medications in the pill (it’s estimated that up to 27% of new infections contain drug-resistant virus). But even if the virus is easily controlled, new research shows that HIV can cause damage even at higher CD4 counts, due to the inflammation caused by HIV’s constant activation of the immune system. That’s one of the reasons the recommendation to start HIV treatment has been bumped up to include anyone with a CD4 count below 500. Some experts and public health authorities (such as the New York City and San Francisco Departments of Health) are recommending that treatment be offered to anyone with HIV, regardless of CD4 count (although preventing new infections is also a factor in this approach).

And living with HIV often means living with other chronic conditions known as comorbidities. Whether these are caused by another virus (such as hepatitis C) or are one of the illnesses so often seen in older adults with HIV (such as osteoporosis), these conditions complicate the care of people with HIV and make their lives anything but simple. This is not to say that life with HIV is miserable, just that it takes a lot of health management and remains something to be avoided – especially if the choice is between using condoms or living with a lifelong infection.

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To the Editor:
I am an inmate at Bayview Correctional Facility. I had to pull teeth, but I finally got the okay to start a health education class. I use your newsletter because it is informative and is where I get my up-to-date statistics. I plead with the public to help me teach the basics of healthy behaviors. But I face all types of young adults and even older people who still label you. It’s sad here in the prison system, because no one wants to be labeled. So they remain in denial.

For one am very open. I’m a woman with HIV and hep C who chooses to speak. I want my voice to be heard. At one time, I used drugs and did all kinds of things to feed my addiction. I’m certainly not proud of that, but now I choose to remain clean once this incarceration is over. I plan to advocate on different issues. I want to be the woman/person I was put on this earth to be. We all have a purpose in life and if I can help one person out of hundreds, I’ve done a good job.

Caridad

Achieve would love to hear from you! Please send your comments to: Letters to the Editor, Achieve, 230 W. 38th St., 17th floor, New York, NY 10018, or email them to: achieve@acria.org
The good news is that people with HIV may live as long as someone who is HIV-negative if treatment is started early enough. But while advances in HIV treatment have saved many lives, the medications used can have side effects that affect different people in different ways. This article will look at some conditions that people with HIV should be aware of, whether they have been on meds for years or are new to them. We’ll also examine how people can improve their quality of life without taking more meds.

**Lipodystrophy**

This condition is defined as the abnormal loss of fat from one area of the body—usually the face, arms, and legs—and an increase of fat in the stomach or at the back of the neck (“buffalo hump”). In women, breast size may increase due to fat buildup. Lipodystrophy became well known in people with HIV in the mid-1990s when combination HIV treatment was first used. Over the years, it has decreased, since the newer meds are less toxic. With the earlier onset of aging associated with HIV and one’s own genetics, however, there is still a risk for lipodystrophy later in life. While there are meds that can be used to treat lipodystrophy, they are often very expensive and may not be covered by insurance.

Managing lipodystrophy can be approached in different ways. First, if one is taking meds that have been shown to cause fat loss, switching may help restore some body fat or stop further loss. A few studies have already shown this approach to be effective. If one is not able to switch because of drug resistance or other reasons, non-medicine treatment options include weight-bearing exercise and nutritional supplements. Weight-bearing exercises include things like bench presses, squats, lat pull-downs, etc., and has been shown to increase lean body mass. Aerobic exercises like running and cycling are not helpful in building lean body mass because they break down muscle even further. If total body weight and lean body mass are stable, however, people can alternate aerobic with weight-bearing exercise. People should talk to their health care provider and an educated trainer before starting any exercise program.

Research also shows a relationship between the fat buildup in the stomach and insulin resistance. This is a condition in which the body’s natural insulin becomes less able to lower blood sugars. Fat and muscle cells need insulin to absorb sugar. When these cells don’t work properly, blood sugar levels rise beyond the normal range and cause negative health effects like high cholesterol. Supplements such as milk thistle, N-Acetyl Cysteine (NAC), and Alpha Lipoic Acid have all been shown to help the body absorb sugar. Omega-3 fatty acids and carnitine can help lower high cholesterol caused by lipodystrophy. These supplements may also have other benefits, such as reducing fatigue, muscle weakness, and neuropathy (pain from nerve damage).

**Wasting**

Wasting can also occur in people on HIV meds. Wasting is generally defined as an involuntary loss of 10% or more of total body weight. Changes in metabolism, lack of appetite, low testosterone, gastrointestinal disorders, and changes in the immune system can all cause wasting. It can be due to any one of these conditions or a combination of them.

When the body is under attack from infection, lean body mass and muscle are usually the sources of energy. The body uses these to fight back, which can result in wasting. When meds are able to control HIV, the weight does return, but usually in the form of fat and water weight. This means that lean body mass and muscle are lost and treatment to address this may be needed.

Treatments for wasting vary. They may include nutritional supplements...
Bone Problems
Many studies have shown a reduction of bone mineral density (BMD) in people with HIV. This can result from continuous use of HIV meds in addition to HIV itself, plus other risk factors such as older age, smoking, alcohol use, steroids, low vitamin D levels, low estrogen in women, and low testosterone in men. Low BMD may be linked to an increased risk of bone fractures. While some studies found no difference between HIV meds, other studies have shown some HIV meds can cause BMD loss. Researchers don’t fully understand why. Of the meds that contributed to the loss of BMD, the greatest loss occurred during the first two years of treatment. After this period of time there may be a partial to full rebound in BMD. Treatment for individuals should be based on their risk factors.

Most people will benefit from calcium supplements. The type of calcium supplement, however, depends on the medications they are taking. Weight-bearing exercise has also been effective in preventing BMD loss. Most younger people with low BMD will not require treatment, and the need for bone-protective therapy should be guided by the risk of developing a bone fracture. Vitamin D levels should be measured in people with an increased risk of fractures, and vitamin D supplements should be taken by those with low vitamin D.

Vitamin D replacement has become an important topic over the past few years. Studies show a direct relationship between HIV and vitamin D deficiency. Vitamin D is essential for bone health, calcium balance, and immune function.

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Vitamin D replacement has become an important topic in the past few years, since studies have shown a direct relationship between HIV and vitamin D deficiency. Vitamin D is essential for bone health, calcium balance, and immune function. It is found in fish, milk, and cereal, but not physically active, are overweight, or male. Some studies have shown a 20% increase of death due to cardiovascular disease in people with HIV.

Treatments vary – ideally, lifestyle changes such as healthy diet, quitting smoking, and starting an exercise program should be a first approach. These alone can significantly help in reducing the risk of heart disease or stroke. They may even reduce the amount of meds needed to treat other medical conditions. In certain cases, a mix of lifestyle changes and meds may still be needed. Certain meds can increase cholesterol, so switching to another medication may help.

People with HIV require six to 25 times the recommended daily allowance of certain vitamins and minerals. Thus a multivitamin is often required, either over the counter or by prescription. It’s important to check with a health care provider before starting any supplements.
**High Blood Pressure**

The normal thickening of fibers in the blood vessels that occurs with aging may lead to higher systolic blood pressure (the top number). The target is to have the top number about 130 and the bottom about 70. The level should not be too low in older adults, however, since that can lead to other complications. Although high blood pressure in people with HIV is most likely due to other factors that can be modified—such as obesity, high salt intake, and physical inactivity—medication is recommended for persistent high blood pressure in order to reduce the risk of heart disease. It should be possible to find a regimen that is easy to take with other medications, since these drugs are often taken once a day.

**Diabetes**

The frequency of diabetes has been reported to be about four times higher in people with HIV. It is usually Type 2, which is associated with aging and obesity, but it can be made worse by certain HIV medications, such as protease inhibitors. Screening for diabetes through blood tests should be done regularly. It is now possible to have this done reliably without fasting through a test called "glycosolated hemoglobin". If diabetes is diagnosed, many times high blood sugar can be controlled with weight reduction and dietary changes, or modification of HIV medications. But if necessary, there are a variety of treatments for diabetes that can be used successfully. The target glycosolated hemoglobin level should be set higher in older persons to avoid the possibility of complications from the blood sugar getting too low.

**Kidney Damage**

As we age, our kidneys usually continue to clear waste products from the body effectively. But high blood pressure, diabetes, streptococcus infection, or other factors can cause kidney damage. HIV has been associated with a specific type of kidney disorder called HIV nephropathy, which is more common in African-Americans. People with HIV should have creatinine, glomerular filtration rate, kidney function, and urinary protein checked annually. If kidney function is compromised, it may be necessary to adjust drug dosages to avoid an overdose. Sometimes the kidneys can be so damaged that they begin to fail, requiring dialysis (regular cleansing of body wastes with a machine). A kidney transplant can be done as a last resort, and has been successfully done in persons with HIV.

**Comorbidities in Older Adults**

On World AIDS Day 2011, the American Academy of HIV Medicine, the American Geriatrics Society, and ACRIA released a report entitled *The HIV and Aging Consensus Project: Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV*. It presents the findings of an expert panel of leaders in HIV care and research as well as clinical and research experts in geriatrics.

Having several illnesses at the same time usually occurs only among people in their late 70s and older. But it is now happening in people with HIV who are younger than 65 (on average, 55 years old). We can only speculate that HIV itself, HIV treatment, the aging process, or behaviors that are seen commonly in those with HIV may contribute to the problem.

If providers use disease-specific guidelines for people with multiple conditions, the treatment plan can become quite complex and involve a large number of medications with a demanding dosing pattern. Issues of adherence and drug interactions become serious concerns. Add mental health conditions, cognitive impairment, substance use, and limited health literacy, and consistently following such a complex regimen becomes a challenge.

**Conclusion**

Treating HIV will bring up different concerns for different people. This is why good communication with a health care provider is so important. With proper counseling, education, lifestyle changes, or supplements, many of these concerns are manageable and the overall quality of life can be improved.

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When you tell someone you have cancer, the first question you often hear is, “What kind?” Unfortunately, if it’s anal cancer, the response may be “colorectal cancer,” mumbled ambiguous words, or some other dodge. Discussion—even mere mention—of the anus is still considered taboo in many cultures, and this silence can be life-threatening, especially for people with HIV.

But anal cancer is affecting more people every year. While the rate in the U.S. is not as high as other cancers, it is increasing at a rate of about 2% a year, and the National Cancer Institute expects 5,820 cases—3,680 women and 2,140 men—to be diagnosed in 2011.

Certain groups are more likely to encounter anal HPV infection, which can lead to anal cancer. Though more women than men are diagnosed with anal cancer each year, some groups, such as HIV-positive men who have sex with men (MSM), have a significantly elevated risk of anal cancer. The social stigma that anal cancer carries with it prevents the open discussion and awareness needed to battle the disease, and stagnates funding to support research and care.

Human papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the U.S. Over half the population will get it at some point in their lives. Each year 6 million people in the U.S. become newly infected with HPV, and 20 million people currently have the virus. While most HPV infections are resolved by the body’s defenses, they cause half a million cases of cancer each year around the world.

A big misconception about HPV is that someone must be sexually promiscuous or have “casual sex” to contract the virus. Since HPV is a virus that is easily transferred, all it takes is one sexual partner to become infected. HPV is transmitted through skin-to-skin contact, including sexual intercourse. However, it can be transmitted by activity that does not include vaginal, oral, or anal intercourse. This includes deep kissing, genital skin-to-skin touching, and use of sex toys. Genital warts, which generally do not cause cancer but are caused by certain types of HPV, are transmitted in the same manner. In 90% of cases, the body clears the virus within two years without any treatment. But some patients, especially but not only those with weakened immune systems (such as people with HIV or organ transplant recipients) have difficulty clearing the virus on their own. If the HPV infection is persistent and caused by a high-risk (cancer-causing) strain of HPV, it can lead to cell abnormalities (also called dysplasia). Severe cases of dysplasia can lead to cancer over time.

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While more women than men develop HPV-related cancers, HPV can cause anal, penile, and head and neck cancers in men. It can also cause cervical, vulvar, and vaginal cancer in women. According to the CDC, more than 20,000 HPV-related cancers occur in women and over 11,000 occur in men each year in the U.S. Worldwide, the World Health Organization documented 500,000 cases of cervical cancer alone and 260,000 related deaths in 2005.

There are about 150 types of HPV, with around 40 types transmitted through sex. Approximately 15 sexually transmitted HPV strains have the potential to cause cancer, and a person can be infected with multiple strains. Two strains, 16 and 18, cause around 70% of cervical and 85% of anal cancers. Most oral cancers are caused by type 16. Types 16 and 18 are also highly common in vaginal and penile cancer.

The Vaccines
There are currently two FDA-approved vaccines: Gardasil and Cervarix. Both protect against the two most common cancer-causing strains, HPV-16 and HPV-18. Gardasil also protects against HPV-6 and HPV-11, which are linked to 90% of genital warts. Both use virus-like particles to enable the body to develop immunity to these strains of the virus. If a person is infected by HPV but has not been exposed to all four strains covered by the vaccine, it can still protect against the other strains.

The HPV vaccine is not mandatory in the U.S., but the CDC recommends that both men and women, and the parents of boys and girls, discuss the vaccine with their medical providers. In November 2011, the CDC amended its policies to recommend that both boys and girls be routinely vaccinated against HPV. Vaccination allows both sexes to take a proactive step toward protecting themselves and their partners from the virus and its potential consequences. Since HPV is easily transmitted, vaccinating against the virus before a person becomes sexually active offers the most protection. Even after sexual activity has started, however, a person may still get protection from the vaccine.

The FDA has approved Gardasil to prevent vulvar, vaginal, and cervical cancer in women, and anal cancer and genital warts in men and women. It is approved for use in males and females ages 9-26. It is routinely recommended for girls and boys, with a target age of 11-12. "Catch-up" vaccination is routinely recommended for women in the 13-26 year age range and in men aged 13 to 21 years. The vaccine is also recommended for men aged 22 to 26 years, but the recommendation in this group is "permissive" and not "routine", meaning that men may not have it covered by their insurance. The FDA has also approved Cervarix to prevent cervical cancer. It is approved for girls ages 9-25. Recent studies suggest it may also protect against anal HPV infection, which can lead to anal cancer.

To date, HPV vaccination rates in the U.S. have been very low: a 2010 CDC report showed that only 32% of females aged 13 to 17 received the full three-shot course of the vaccine. By comparison, countries such as Australia and the United Kingdom have rates that are double or more than the U.S. (partially due to school vaccination programs). While all countries with access to the vaccine will see a decrease in HPV-related cancers, those with more people vaccinated will see a sharper reduction in these cancer rates. Mistaken concerns that vaccinating adolescents against a common STI will encourage early sexual activity may be partly to blame for the slow ramp-up of vaccinations in the U.S. Others have cited concerns about possible side effects as a reason to delay vaccination, but the FDA and the CDC continuously evaluate the vaccines' safety and have determined that both vaccines are safe.
Vaccination is by far the best way to prevent HPV infection. But further steps should be taken to prevent HPV-related diseases, even in vaccinated persons. Some people may already be infected with HPV before getting vaccinated, while others may contract an HPV type not covered by the vaccine.

While having just one sexual partner can expose you to HPV, fewer partners can reduce your risk of being infected with the virus. Of course, one can still contract the virus with just one partner. Although condoms can reduce the risk of HPV infection, they are not entirely effective because HPV can be transmitted through skin surfaces not covered by the condom or during sexual activity that occurs before the condom is used.

Risk Factors
It’s important to talk to your doctor about your risk factors for HPV and ask about testing options. Anal cancer does not affect all groups equally. In general, more women than men are diagnosed with anal cancer.

HIV-negative MSM are seventeen times more likely to develop anal cancer than non-MSM, and HIV-positive MSM are twice as likely as HIV-negative MSM to develop it. Rates of anal cancer are especially on the rise in older MSM with HIV. While HIV treatment has been successful at prolonging the lives of people with HIV, a weakened immune system over a long period of time can allow for an infection like HPV to develop into cancer. Sexual experiences that occurred years or even decades earlier may have resulted in an HPV infection that can lead to a malignancy years later.

A woman who has persistently tested positive on a cervical HPV test may be at higher risk for having an HPV infection in the anus that can lead to anal cancer. Women with a history of cervical cancer or vulvar cancer may also be at higher risk. Anal sex is not a requirement for anal HPV infection or anal cancer in women (or men), as studies have shown HPV infection to be present in the anal canal of heterosexual men and women without a history of anal sex, including adolescent females. This is why women should request anorectal exams as part of a routine check-up, and women with persistent high-risk HPV cervical infection should speak with their doctor about annual anal Pap smears. Current New York State recommendations are that all men and women with HIV should get an annual anal Pap smear.

A study published in 2010 concluded that anal cancer rates are rising among people with HIV and that HIV treatment does not appear to reduce the risk of developing it. However, there has been speculation by scientists that since HIV treatment improves immune function, it may prevent the progression of HPV to anal cancer. Still, it is clear that people with HIV have a significantly higher risk for anal cancer than those who are HIV negative. On its HPV information website, the CDC states “some experts recommend yearly anal Pap tests to screen for anal cancer in gay and bisexual men and in HIV-positive persons. This is because anal cancer is more common in those populations.”

Certain other factors such as smoking and a higher number of sexual partners may also be linked to an increased risk of anal cancer.

HPV and Anal Cancer Screening
In order to monitor potential HPV disease, everyone should have regular checkups after the onset of sexual activity. The cervical Pap smear and regular gynecological checkups have dramatically reduced the numbers of cases of cervical cancer in the U.S. in the last 40 years. But neither gender is regularly screened for HPV risk in other parts of the body, such as the anus or the mouth.

Women are routinely screened for cervical cancer when they receive their annual Pap smear at the gynecologist. But men often fall through the cracks when it comes to routine screening because anal HPV tests and anal Pap smears are not commonly offered to them by physicians. There are currently no routine anal cancer screening protocols. Certain anal specialists suggest the best way to check for anal cancer is through a digital anorectal exam. The name may be confusing, since there is no digital equipment used in the examination – in this case the “digit” is simply a finger. In
Unfortunately, anal cancer is often misdiagnosed and its treatment delayed. If you are diagnosed with what is believed to be a hemorrhoid and it has not resolved for several weeks, have it formally re-evaluated. MSM in particular should be very aware of changes in the anus. Any abnormal bleeding or new bumps should lead to an immediate examination – by a specialist, if needed.

Unfortunately, when diagnosed in late stage, anal cancer can have devastating effects. One of the authors of this article lost her mother to anal cancer in 2010. Farrah Fawcett, the actress and model, lost her life to it the year before.

Regular check-ups and testing have been credited with reducing cervical cancer rates in the U.S. over the last half century. With increased awareness, vaccination programs, improved screening practices, and proactive questions from patients, the HPV cancer burden for anal cancer and other HPV-associated diseases can be reduced in the U.S. in the coming years.

Our Mission

The HPV and Anal Cancer Foundation is a 501(c)(3) not-for-profit organization established in 2010. The mission is to provide support for patients and families, improve preventive care measures and fund therapeutic research.

Justine, Tristan, and Camille Almada started the nonprofit after their mother died from anal cancer. The organization aims to spread awareness and knowledge about the disease, breaking the stigma of a cancer that is often misdiagnosed and misunderstood. The organization also seeks to empower people living with anal cancer to feel unashamed about having HPV or anal cancer.

We encourage you to reach out to us with any questions, concerns, or to share your story with us at www.analcancerfoundation.org.

Camille Almada and Nicoletta Bumbac are members of the Board of Directors of the HPV and Anal Cancer Foundation.
The Good Patient: Fighting Anal Cancer

Five years ago, at age 50, my doctor suggested I get an anal Pap smear. “What’s that?” I asked. She told me it was a test for precancerous lesions caused by HPV (human papillomavirus), and that any gay man with HIV should have one done on a regular basis. I agreed and was surprised that she was able to give me the results in about ten minutes: abnormal cells had been found.

There were a few options to deal with them, and she told me there was a rectal specialist on site who could treat them with something called Infrared Photocoagulation. Since I’ve always been aggressive in treating any health problems, I made an appointment immediately. The inpatient procedure was relatively easy, and a few lesions were taken care of. Or so I thought.

In August 2007, I found blood in my underwear after sex. And not just a little blood – enough to scare me. I made an emergency appointment with the rectal specialist, who assured me it was just a hemorrhoid, cauterized it, and sent me on my way. I didn’t think about it until November, when the bleeding returned. This time, he looked at it and seemed concerned. “I’m going to send you to a rectal surgeon.”

What followed was the most callous diagnosis I have ever received. The surgeon examined me and said, “Well, it’s cancer” without the slightest hint of empathy in his voice or any recognition of the impact of his words.

“Cancer? What does that mean?”

“That means chemotherapy and radiation. I’ll give you a referral.”

And that was that – no more info, no hand-holding, no hope-building, just a phone number and a goodbye.

I was devastated. I went to the nearest pay phone and called my boyfriend. “It’s cancer.”

“Yeah, right. Stop joking.”

“I’m not joking – it’s cancer and I have to start chemo and radiation right away.”

The moment of a cancer diagnosis is just about the same as an HIV diagnosis: The world seems to slow down, everything is in a haze, and it’s hard to know what to do next. I called the rectal specialist who had misdiagnosed me and he agreed to see me immediately. I was furious that someone whose specialty is rectal exams of gay men was unable to identify anal cancer when he saw it, but I had to talk to someone. “Well, if you have to have cancer, this is the one to get, since the cure rates are so high – almost 90% if caught early, like yours was.” That was little consolation to me, but at least it was some more info.

The surgeon said, “Well, it’s cancer” without the slightest hint of empathy in his voice or any recognition of the impact of his words. And that was that – no more info, no hand-holding, no hope-building, just a phone number and a goodbye.

Now I was thrown into the world of cancer care – very different from the world of HIV I had lived in for 25 years. I began getting referrals to anal cancer specialists, but when I called, they wanted me to wait a month for an appointment! What? Let this thing spread for a month before even seeing someone? No way. Luckily, my HIV doc intervened and got me into the NYU Cancer Center in a few days. I liked the oncologist and started to move forward with treatment.
But the responsibility on me was enormous. All along the way, I was expected to manage my care myself – making all the appointments, checking on my insurance coverage, learning about treatment options. Once again, virtually no hand-holding. I wondered how people with less experience as a self-advocate – people who aren’t able to be as much of a “squeaky wheel” as me – would fare in this system.

Luckily, I had years of experience advocating for myself, because of having HIV. The day I was diagnosed, I joined the Yahoo anal cancer support group (groups.yahoo.com/group/anal-cancer) and found incredibly well-informed, caring people who did everything they could to help me out. What a godsend. It was here that I learned much of what I needed to know about how to get through treatment. Many of the radiation side effects (impotence, infertility, hair loss, etc.) were never discussed by my doctors. I brought them up with my doctors after learning about them from the support group. Numerous tips and tricks for dealing with the side effects once again came from the group and not my doctors – to this day, I’m shocked by how my care providers minimized or ignored the potential side effects.

But perhaps the toughest thing was my family’s denial. Having known about my HIV for 20 years and seeing me thrive in spite of it, they seemed to be not very concerned about the cancer. So unconcerned, in fact, that after giving them the news shortly before Thanksgiving, I didn’t get a single call to check on how I was doing. My answering machine was filled each night with messages of support from my friends and fellow activists, but nothing from my family. You can guess how much that hurt, and when I later asked why, they said they felt that I was so strong no calls were needed. I guess I gave them the wrong impression!

In reality, I was petrified. For me, cancer is far scarier than HIV ever was, and hearing about the potential for lifelong side effects from radiation therapy only made things worse. (I should pause here and say that my reaction to treatment was my reaction – not everyone will go through what I went through, and it appears my side effects were more extreme than most.)

I began chemo and radiation in mid-December, and ended up in the ICU on Christmas Eve. My neutrophil count was so low that any simple infection could have killed me. (I later learned this was because my chemo continued on next page
I recall my oncologist walking in the exam room and the first words out of his mouth were, “Well, the first thing is: no cure.” And not even an explanation of what he meant!

I proceeded to confide in her, with tears in my eyes: “No one in my family has called me since my diagnosis. So I cancelled Christmas with them, and I just couldn’t bear to spend it here.” She looked at me without the slightest hint of sympathy in her voice and said, “I understand, Mr. Milano, but it’s necessary for you to stay in the ICU.” I checked out against medical advice, and had the most emotional and wonderful Christmas with my boyfriend that I’ve ever experienced. And I didn’t die.

Treatment continued, and the side effects piled on, with the worst being nausea. Nausea is something that many doctors don’t take very seriously. “So you’re nauseous? So what, it ain’t gonna kill you.” I recall lying in the ER for 24 hours with horrible nausea, but not having a single doctor check on me. It got so bad I ended up in the hospital for three weeks and lost 25 pounds in a month. At one point, I told one of the many nameless doctors who stopped in that the nausea was so bad I’d rather die. But rather than prescribe more aggressive nausea treatment (which I now know was not being given to me), he put me on 24-hour suicide watch!

I finished treatment and set about the process of healing my body. I gained the weight back quickly – too quickly, in fact. No one informed me that losing and gaining that much weight quickly can lead to an altered body composition, and now I’m saddled with permanent gynecomastia (fat in the chest) unless I can find $5,000 to have it surgically removed. But I was better, tests found no cancer in my anus, and I was ready to move on.

Until one year later. My first post-treatment MRI found a suspicious lesion in my left lung. Further scans confirmed my worst fears: It was metastasized cancer (the anal cancer moving to my lung). I recall my new oncologist walking in the exam room and the first words out of his mouth were, “Well, the first thing is: no cure.” Gee, that’s hopeful. And not even an explanation of what he meant! You see, in cancer, the word “cure” has a very specific definition: If you survive five years without a recurrence, you’re considered cured. Since I had a recurrence, even if I survived five years I would not be pronounced cured.

We surgically removed the tumor and did six more months of chemo (with Erbitux, the drug Martha Stewart went to jail for) and I once again hoped I was okay. No such luck. A non-cancerous lesion we had seen in the left lung at the same time we saw the one in the right lung turned out also to be cancerous, and I had to have that removed. This time I passed on more chemo.

I had a slight respite for about a year, until a scan last May found a lesion on my left kidney. A biopsy came back negative, and I breathed a sigh of relief. But my HIV doc wasn’t convinced. “They missed it, Mark. You have to let them try again.” I did, and it was metastasized anal cancer – which I’m told never happens in the kidneys.

Unfortunately, every surgeon I’ve seen refuses to remove it. They all say the risk outweighs the benefit. Finally I found an alternative: radio frequency ablation, in which a probe is inserted to burn the tumor away. I was excited and hopeful the day of the procedure, only to be told at the last minute that it couldn’t be done, since a new CT scan taken from a different angle showed that the tumor was in a place that made it too risky to do the procedure.

I continued the chemo, which has shrunk the tumor nicely, but everyone says it will return when I stop. I have found some alternatives, but once again it feels like I’m on my own. So I face my mortality with the hope that somewhere I’ll find a doc who is willing to fight for my life as strongly as I will. There must be one out there somewhere.

And what have I learned? That cancer care, like much medicine, may still be more art than science. So I don’t trust doctors blindly. You want to live, you do it for yourself. You find the support you need. You do your own research, become your own expert. I’ve had to accept that I might not live to see 60. So I treasure each day, spend as much time with dear friends as I can, and try to avoid wasting my energy on petty problems. It’s hard to change lifelong negative coping mechanisms, but I do what I can. Thank god for my incredibly caring and strong boyfriend. I can’t imagine going through this alone.
Most of us take steps to improve and maintain our health. Our beliefs about health can lead to far-reaching behaviors that may create a more holistic health lifestyle, but sometimes we choose individual health practices that make us feel better now or that we think will help us feel better down the road. Sometimes, these behaviors are guided by conventional health care providers, such as physicians, pharmacists, and chiropractors. Sometimes providers recommend these approaches based on medical knowledge or research we don’t know about. Often, such practices become accepted as common sense and are largely taken for granted as the things everyone should do.

But sometimes we seek care from practitioners of complementary and alternative medicine (CAM) who are not part of the conventional health care system. And sometimes we take care of ourselves with limited or no input from any type of health care provider at all. Such self-care might come from folk or family remedies, or from something we heard on the news, from a friend, or on the internet. Taking action to improve our health feels right, even when we don’t have evidence that what we are doing will work. Belief and science don’t always align, but when it comes to our own health and well-being, who said they had to?

People with HIV need to be vigilant about maintaining their health. In addition to standard HIV treatment, many use CAM to deal with HIV-related symptoms, treatment side effects, pain, and to improve their quality of life. Although estimates vary, two reviews of a range of studies concluded that 60% of people with HIV use CAM. Given that large number, it is useful to ask what CAM is, who uses it and why, how well its use is integrated into conventional medical care, and if there are risks we need to be concerned about?

What is CAM?
The National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as a group of diverse medical and health care systems, practices, and products that are not considered part of conventional medicine. It defines complementary care as CAM use in conjunction with conventional medical care, while alternative care is defined as CAM use in place of conventional care. Generally, complementary care is much more common than alternative care, which studies suggest is now quite rare. Integrative care refers to the combined use of conventional medical care and CAM for which there is evidence of safety and effectiveness.

Although estimates vary, two reviews of a range of studies concluded that 60% of people with HIV use CAM.
A broad range of activities and practices may be considered CAM. The NCCAM distinguishes four distinct domains of CAM:

• Biologically-based practices
• Manipulative and body-based practices
• Mind-body practices
• Alternative medical systems

Biologically-based practices, which are the most commonly used, include the use of herbal products and dietary supplements, such as high doses of vitamin C or other vitamins, herbal or mineral supplements, probiotics, teas, and supplements like garlic. For persons living with some chronic diseases, including people with HIV, marijuana use to manage weight loss, nausea, and pain is relatively common. Manipulative and body-based practices that often have stress-reducing effects include massage therapy, manipulation, and other bodywork. Mind-body practices that reduce stress and enhance feelings of well-being include meditation, prayer, hypnosis, and yoga. Alternative medical systems include naturopathy, acupuncture, and homeopathy. Some types of CAM are more likely to be provided by a CAM practitioner, while others are more likely to be used as a form of self-care.

Who Uses CAM?

CAM is widespread among Americans in general, and people with HIV in particular. One recent national study estimated that 38% of Americans had used CAM within the past year, and many more had used CAM at some point in their lives. Rates of use were highest among those aged 50-59 (44%). CAM use among people with HIV is higher than it is among Americans overall – about 60%.

Among people with HIV, CAM use is particularly high among men who have sex with men, non-minorities, those with higher education, and those with higher incomes. People with AIDS, those living with HIV longer, and those with more HIV-related symptoms are also more likely to use CAM.

Some evidence indicates that people who seek social support, engage in problem-focused coping, and use positive reinterpretation (finding the best in a bad situation), are more likely to use CAM. Such coping strategies might promote well-being and contribute to the often-observed beneficial association between higher levels of CAM use and lower levels of depression, psychological distress, and mental health problems.

Self-Care vs. Integration

In the early years of the HIV epidemic in the U.S., when there were few effective therapies and people were literally fighting for the lives, there was a widespread belief that “you have to be your own doctor.” In those years, building on social, cultural, and family practices that were in place before the HIV epidemic, many people advocated for HIV self-care that often involved the use of CAM. As better HIV treatments have become available, many people have continued using CAM in conjunction with conventional treatment. Most of the evidence shows that only a very small minority use CAM as an alternative to standard HIV therapy, so it is important to consider how often and how well conventional care and CAM are integrated.

It has been suggested that the response of the medical profession to CAM has shifted from condemnation to reevaluation, integration, and, perhaps, cooperation. But evidence from the 2007 National Health Interview Survey (NHIS) suggests that we might not have traveled as far down the path of integration as needed. That study found that only 42% of all Americans disclosed their CAM use to their physician.

In studies of people with HIV, disclosure of CAM use ranges from 38% to 90%. We do not know, however, what people with HIV discuss with their health care providers or the extent to which holistic, coordinated care is accessible. Based on how often Americans generally discuss their CAM use with their physicians, we can presume that such coordination is not generally available. Integrative care, as defined by the NCCAM, is limited by the fact that people often do not discuss CAM with their health care providers for a variety of reasons. Also, conventional and CAM practitioners often do not coordinate care, and there is limited research on the safety and effectiveness of commonly used CAM therapies.
Adverse Effects
In a chronic disease like HIV, health practitioners often consider a broad range of behaviors to be CAM. Conventional providers are likely to pay more attention to some forms of CAM than to others because some have the potential to undermine other treatments. Concern about whether particular forms of biologically-based CAM undermine HIV treatment echoes throughout the research literature, even though limited evidence on adverse effects currently exists.

In one national study from 1997, approximately 26% of persons in conventional care for HIV were using CAM that had the potential for adverse effects. The NCCAM includes some warnings on its website that are relevant to HIV care. For example, they report that garlic supplements sharply reduced blood levels of Invirase, and that St. John’s wort could significantly lower the effectiveness of Crixivan. St. John’s wort probably also changes the blood levels of other drugs that are broken down by the liver, such as Sustiva, Reyataz, and Kaletra. Many people with HIV may be using CAM treatments that interact with the medications they are taking. It’s very important that people discuss their CAM use with their doctors, and providers need to make greater efforts to integrate conventional care and CAM.

CAM in Older Adults
It is estimated that by 2015, 50% of people with HIV in the U.S. will be over 50. As more people are aging with HIV, they are encountering the chronic health conditions that become more common at older ages. As a result, they are experiencing more complicated medication regimens. With increasing numbers of medications, the potential for interactions among conventional and CAM treatments increases.

Recognizing this potential, the American Association of Retired Persons (AARP) and the NCCAM teamed up in 2010 to examine CAM use among adults over 50. They found that 53% of older adults had used CAM and 47% had used it in the past year. Use of herbal and dietary products, which are most concerning from the standpoint of adverse effects, was the most common type of CAM reported (37%). Among those who had ever used CAM, 78% were using at least one prescription medication at the time of the survey, while 37% were using four or more medications. Among all older adults, 33% had talked with any health care provider about CAM. Among CAM users, that rate almost doubled to 58%. People who discussed CAM with a health care provider were more likely to talk about it with their physician than with any other type of provider, and they were much more likely than the health care provider to bring up the topic.

Among those who talked about CAM with a health care provider, the conversation focused on:
- Interactions between CAM and other medications (44%)
- Whether to start CAM (41%)
- The effectiveness of CAM (41%)
- What to use (40%)
- The safety of CAM (38%)
- Where to get more information about CAM (28%)
- Referrals to CAM providers (21%)

Among individuals who did not talk with their health care provider about CAM, a variety of reasons were cited:
- Health care provider never asked (42%)
- Didn’t know they should (30%)
- Not enough time during the doctor visit (17%)
- Didn’t think the health care provider knew about CAM (16%)
- Thought the provider would be dismissive or tell them not to use CAM (12%)
- Didn’t feel comfortable talking with the provider about CAM (11%)

It’s very important that people discuss their CAM use with their doctors, and providers need to make greater efforts to integrate conventional care and CAM.

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Researchers from Syracuse University and ACRIA used data from ACRIA’s Research on Older Adults with HIV (ROAH) study to examine CAM use among people with HIV who were over 50. ROAH found that 28.8% of the sample reported CAM use, including:

- 13.9% using body-based CAM (such as massage or Reiki)
- 16.0% using mind/body-based CAM (such as acupuncture, yoga, or prayer)
- 11.7% using biologically-based CAM (such as herbs, supplements, or vitamins)

Consistent with prior research, whites and people with higher education, higher incomes, higher levels of pain, and lower levels of depressive symptoms were more likely to use CAM.

Among those who used CAM:

- 55.3% used some body-based CAM
- 63.2% used mind/body-based CAM
- 45.6% used biologically-based CAM

High levels of CAM use among people with HIV are likely to continue, and many CAM health behaviors most likely pose no risks. They are practices that can reduce stress, build fitness, and promote well-being.

Among CAM users, use of body-based CAM was higher among women, LGBT people, and those taking HIV medications. Use of mind/body-based CAM was higher among LGBT people, those who felt they were in worse health, and those who were not taking HIV medications. Finally, use of biologically-based CAM was higher among non-LGBT people, whites, Hispanics, employed persons, people on Medicare, and people not taking HIV medications. These complex patterns reflect the diverse social and cultural influences on CAM use, as well as the fact that some individuals use CAM to enhance existing health and well-being while others use CAM to manage pain, symptoms, and the side effects of treatment.

However, some forms of biologically-based CAM may pose risks of drug interactions that could undermine health. More research is needed to determine which of these are safe and effective and which are not. More efforts need to be made to make sure that state-of-the-science information about the safety and efficacy of CAM is available to people with HIV. Health care providers must start conversations about CAM and be able to answer questions about it.

The NCCAM defines integrative care as the combined use of conventional medical care and CAM for which there is evidence of safety and effectiveness. This is a worthy goal to pursue for the sake of holistic health and well-being.

Andrew S. London is Chair and Professor of Sociology, and Co-Director of LGBT Studies, at Syracuse University.
There are more than a thousand types of bacteria that live in our bodies – on our skin, in our mouths, and in our gut. Of those bacteria, only 50 are known to be harmful. The rest, what we will call “healthy bacteria”, have important roles in the body and are needed to keep people functioning well. This may be particularly true for people with HIV.

HIV affects the immune system, and a large part of the body’s immune system is located in the intestines and gut. During the early stages of HIV infection, the virus can upset the balance of healthy bacteria in the gut, leading to health issues. This article will look into some of these complications and the ways people can change their diet to reduce their occurrence.

History of Healthy Bacteria
The idea that bacteria can be helpful dates back to 1907, when the Russian scientist Elie Metchnikoff postulated that bacteria might provide health benefits. He observed that regularly eating certain dairy products, such as yogurt, was associated with better health and longer life. Because of this, he drank sour milk every day until he passed away at age 71. Though he didn’t have the ability to prove his theory, today scientists are discovering that healthy bacteria can positively affect health, both in the gut and beyond.

Scientists think the human diet once contained several thousand times more bacteria than it does today. With the advent of cleaner water, better sewage systems, antibacterial soaps and anti-biotic drugs, the amount of bacteria that people are exposed to has decreased. High standards of hygiene kill bad bacteria but also kill healthy bacteria. Some experts think that reduced exposure may have a negative effect on our health and may disrupt the immune system’s ability to function at its best. This is called the "hygiene hypothesis".

Certain healthy bacteria that help the immune system are less frequent or in some cases completely absent in both our environment and in our diets. This is particularly harmful for people with HIV.

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In addition to helping the immune system, healthy bacteria help digest food into nutrients that our bodies can absorb, and are useful in the body’s defense against other infections in the intestine. Recent data further suggest that there may be a specific bacterium that helps with T-cell development.
Healthy bacteria and other microscopic organisms like yeast are called probiotics because when eaten in the right amount, they help people stay healthy. These probiotics have also been associated with better immune function in people with HIV. Several studies from different countries suggest that probiotics may be able to delay damage to, or help preserve, the immune function of people with HIV. They may do this by stimulating natural killer cell activity, lowering the rate of infection from other harmful bacteria, and possibly lowering inflammation, but different studies have found different results when looking at this.

Good sources of healthy bacteria include foods such as yogurt, sauerkraut, miso, tempeh, Kombucha tea, and fermented vegetables. These are all "fermented foods", meaning they have undergone a chemical process in which the bacteria change the original food into a simpler and more easily digestible form. For example, yogurt is basically fermented milk. The process of fermentation actually helps preserve the food as well, so it takes longer to spoil. When these healthy bacteria-rich foods are included in one's diet, health benefits may occur in the gut, and possibly in the immune system.

One study examined 24 HIV-positive women with CD4 counts over 200 and diarrhea. Half of the women took probiotic yogurt every day for 15 days and the other half did not. The women who did not eat the yogurt saw their CD4 counts drop, while those who did eat it had an increase in their CD4 counts, and also experienced improvement in their diarrhea. But the study was so small and short it’s hard to say whether the results were real or due to chance.

Similarly, another study examined 68 HIV-positive women in Tanzania over a three-year period. This study saw an increase in CD4 counts and concluded that the introduction of probiotic yogurt was significantly associated with an increase in CD4 counts.

Yet another study looked at 77 HIV-positive children and found that healthy bacteria may have improved the immune systems of children who ate fermented foods. Children who ate yogurt regularly saw a small increase in their T-cells. And those with diarrhea saw a slight improvement in their symptoms. Once again, the study was small as were the benefits – so this type of study just proves that we need more research.

A major barrier to building up healthy bacteria in people with HIV is heavy use of antibiotics, which kill bacterial infections. Antibiotics are over-prescribed and overused in American culture. They are frequently given to people with HIV, either to prevent or treat an infection. Since healthy bacteria are vital for the immune system, it is worth questioning whether or not liberal use of antibiotics is bad for one’s health. For example, it’s critical that people with HIV and a CD4 count below 200 take meds like Bactrim to prevent PCP. But one study showed that it can take the healthy bacteria in the gut four years to recover from one round of antibiotics. Of course, people at risk for PCP need antibiotics to prevent this deadly disease. But as more research emerges on how healthy bacteria help the immune system, we should study how to minimize the effect antibiotics have on them.

**One Man’s Story**

Sandor Katz has been fermenting foods for the past 17 years. He says his goal is to promote fermented foods in our culture and “spread the word about the glorious nutritional and healing powers of live fermented foods.” As a self-proclaimed “fermentation fetishist”, he eats fermented foods regularly. He has also been living with HIV for over 20 years. He takes his meds and knows that he wouldn’t be alive without them, but he also claims much of his good health is due to regularly eating fermented foods.
At his sickest, Sandor weighed less than 100 pounds. He experimented with veganism (not eating meat or dairy products). When that didn’t help, he switched gears and began eating fermented foods. He thinks these foods have been an essential part of his healing, and have strengthened his ability to tolerate the side effects of the HIV meds.

Sandor has published a book, *Wild Fermentation*, and travels around the country giving lectures and fermentation demonstrations. He praises the benefits of healthy bacteria, and believes that they may prevent other diseases, such as cancer. But he is clear to say “that doesn’t mean sauerkraut cured my AIDS.” Fermented foods certainly aren’t miracle foods in the sense that they can cure disease. But they may help improve health and better manage illnesses.

**Species and Strains**

Not all healthy bacteria are created equal. There are several different kinds that work in different ways to improve health. Studies show that some strains are particularly helpful for the immune system, while others are more helpful for treating intestinal problems, such as bloating, constipation, or diarrhea. Most fermented foods will say on their labels which specific species or strains of healthy bacteria are present.

**Safety**

Some question the safety of eating healthy bacteria or taking a food supplement if HIV-positive. Though people with HIV are at greater risk of opportunistic infections, there is no published evidence that eating foods that contain healthy bacteria increases that risk. Two studies have been conducted to assess the safety of healthy bacteria in patients with HIV, and the findings support their safety.

At the moment, our understanding of how best to use healthy bacteria to enhance or maintain immunity is at an early stage. There is still much to learn, and researchers are looking into the reasons why certain bacteria are helpful. This may lead to a better, more personalized way of eating healthy bacteria and lead to better health outcomes.

Food supplements containing healthy bacteria are not FDA regulated, and one study found that many commercial products did not contain the amount or type of probiotics their labels claimed. For this reason, they should be purchased with caution. A sensible recommendation would be for people with HIV to include more fermented foods in their diets, to boost healthy bacteria intake naturally.

Many fermented foods are “pre-digested”, making them better tolerated. For example, some people are lactose intolerant, which means they can’t digest dairy products. But often those who are lactose intolerant can tolerate yogurt. This is because the lactose in yogurt is fermented, making it more digestible.

**Conclusion**

There is still a lot to learn about the relationship between the human body and healthy bacteria. Though the role, safety, and effectiveness of healthy bacteria in people with HIV needs more research, much of what has been discovered is promising. Currently, registered dietitians recommend that people with HIV eat a variety of fruits, vegetables, whole grains, protein, and healthy fats. Fermented foods are not officially on that list, but they should be. Sandor Katz serves not only as an inspiration, but as evidence of the positive effects that these foods can have on people with HIV. As he says in his book, “the [real] health benefits have only encouraged my devotion to fermentation.”

Sarah Robertson is the Coordinator of Nutrition and Meals at GMHC and is the treasurer of the Infectious Diseases Nutrition Dietetic Practice Group of the American Dietetic Association.
thought you got HIV because of living a bad lifestyle like using cocaine or crystal meth or heavy drinking. I didn’t live like that so I thought it couldn’t happen to me.

When I found out I was HIV positive I called my mother and I cried so hard she didn’t know who I was. I told her I was HIV positive and she said, “Hold on, I’m coming.” She flew out to Cleveland all the way from L.A. When she got there she prayed with me and hugged me and said, “Everything is going to be okay.” But it wasn’t.

My mother has such a flip-flop personality. Since then she’s told me, “Because of your lifestyle, you deserve what you have.” She keeps telling me to get saved. I keep telling her, “God doesn’t make mistakes.”

The negativity of my family weighs me down. I’ve had to fight it and deal with my own fears of what HIV could do to my body. I used to be afraid to go to sleep because I thought I’d wake up and be sick and skinny and ugly. So I would try to stay awake all the time. I was so tired, but I would only sleep in little spurts until I would pass out because I was exhausted. I could never keep a job because I couldn’t focus.

I’ve been afraid of people rejecting me because I’m HIV positive and of all the horrible names they would call me like “AIDS infested mo’ fo’” and “monster”. I’ve even been afraid of HIV meds because I thought they would stop my heart from beating. I thought those meds would do my body more harm than good and I would swell up and die. I used to think to myself, “When is it going to be my turn?”

In the ’90s, I started a basketball league at a YMCA. It was good to be active and part of a team. I recruited drug dealers and gang-bangers, to get them off the street. It’s been really good and I’m proud of myself. It’s been hard sometimes being a basketball coach because of my HIV status and being gay. It shouldn’t make a difference, but it does. It’s hard knowing that some people in the neighborhood call me “homo coach”. It’s terrible, but I keep going year after year. I have never been ashamed of who I am and I always try to keep a professional image.
I still coach today and I’m still afraid of the stigma from the players and their parents. But sometimes I have conversations with the players about HIV. I tell them they should go get tested because you don’t have to look sick to be sick. I tell them to take care of themselves and make good decisions. Maybe that can help them stay healthy, too.

Today I’m not afraid to tell people I’m HIV positive, and I’m trying to make new relationships. I just told a friend that I have HIV. When I told him, he took a deep breath and swallowed hard. But he said he was okay with it and didn’t think less of me. Things are different now than they used to be – I feel more comfortable with myself.

I’m also not afraid of HIV meds anymore. A year ago my doctor told me he wanted to take precautions so I wouldn’t get sick now that I’m older. He told me the new meds weren’t like the meds back in the ’90s that were really hard on a person’s body. So I thought I’d give them a try. When I first started, I vomited because I wasn’t used to them. But now I don’t have any side effects and I feel stronger and healthier – I’m even gaining back the weight I lost.

I just told a friend that I have HIV. When I told him, he took a deep breath and swallowed hard. But he said he was okay with it and didn’t think less of me.

My life has been a roller coaster, and coaching is what gets me through it. I still love my family, despite how they feel about me and how they’ve treated me. But it’s a cold love because they have given me so much stress. Some of the bad things from my past stay with me, but I have to ignore the haters and keep doing what’s right for me. I have God in my life, and I know it’s because of him that I’m still here today and that my viral load is undetectable. His plan for me on earth isn’t over yet. It’s like one my favorite inspirational songs says, “We fall down, but we get up!”
ACRIA Low Mood / Depression Study

Are you a person living with HIV 45 years or older and feel you have Low Mood or Energy or feel Sad or Blue?

ACRIA is conducting a telephone research study on assessing and supporting treatment for low mood, sometimes called depression.

Call 860-951-1104 for a free 10 to 15 minute assessment.

Your call will be completely confidential.
You will receive a roundtrip MetroCard for completing the initial screening.

If eligible, you may be offered up to six months of support and treatment at no cost to you, except for medication co-payments. If you qualify and enroll in the study you will receive $25 and an additional incentive when you complete the study.

If you have any questions about this study, please call:

(Spanish) Elizabeth Figueroa 860-951-1104 (English) Dr. Mark Brennan-Ing (212) 924-3934 x131
EDITORIAL

Health Homes: Keeping Clients Front and Center

Today, people with HIV are living longer, but many experience additional chronic conditions such as asthma, diabetes, and cardiac problems. They also often need housing, food assistance, substance use services, job training, support groups, and treatment education. Since no single agency can meet all of these needs, some people visit dozens of organizations. As part of the Affordable Care Act, the health care legislation passed in 2010, the U.S. Department of Health and Human Services is promoting “coordinated care”.

Coordinated care means collaboration among primary care doctors, medical specialists, and nonmedical providers. The National HIV/AIDS Strategy also endorses coordinated care as a promising new direction. Ideally, it means taking all of a person's needs into account instead of just treating for symptoms as they arise. In order to be successful, it must prioritize the client's own voice in all health care decisions.

The rapid rise in U.S. health care costs has resulted less from higher quality care than from higher profits and administrative costs. Clients receive better care when they develop a plan with a single provider who anticipates long-term needs and oversees the delivery of all services. Better coordination can prevent unnecessary duplication of services and readmission to hospitals and ERs, where care is costly and rarely includes adequate follow-up. Additionally, the coordinating provider is better equipped to spot problems early and intervene before they become dangerous and expensive.

This approach seems logical, but health care in this country remains remarkably disorganized, and according to a 2008 report in the New England Journal of Medicine, little consultation occurs between providers, even in dire situations. When a recently hospitalized client returns to a primary care doctor, it is unlikely that doctor will have received any information about the discharge plan. The report also estimates that 33% of physicians do not consistently notify their patients about abnormal test results.

Our health care system still functions on a profit-driven model that prioritizes short-term payment over the long-term well-being of patients. How are people supposed to manage their care if no one sees the full picture of their health?

People with HIV who have other conditions are far more likely to report undergoing unnecessary procedures and, worse, having serious ailments overlooked. Faulty referrals and incomplete background information make them more likely to be unnecessarily hospitalized, which can raise costs, stress, and stigma. These negative experiences, combined with a feeling of alienation from uninformed providers, can lead them to forgo care altogether. This lack of coordination can perpetuate health disparities, leaving the most vulnerable populations without adequate health support.

Many people with HIV manage their care and services through COBRA, a case management program that connects Medicaid clients with comprehensive services. But COBRA is underfunded and does little to encourage communication among providers. The Affordable Care Act gives states the option of providing “Health Homes” services for Medicaid enrollees, and they are encouraged to do so, with the federal government covering 90% of the cost in the first two years.

According to guidelines released by the Centers for Medicare and Medicaid Services (CMS), a designated Health Homes provider will oversee all care, linking clients to a team of specialists, nurses, pharmacists, dieticians, social workers, behavioral health providers, chiropractors, and even alternative medicine providers. The guidelines include important factors like transitional and culturally appropriate care, aimed at maintaining people with chronic conditions in care for the long term.

So far, providers and clients alike have been frustrated by the lack of available information regarding Health Homes, and many worry that the transition into coordinated care could disrupt current client-provider relationships, particularly for those in Medicaid-paid COBRA case management.

Care coordination is an essential step in the fight to end AIDS, but only if clients have control. They must feel a sense of ownership over their own health, and personally commit to adhering to care. CMS has recommended that states treat the “whole person” by incorporating the voice of clients, and it is our responsibility as health care advocates to ensure this. Coordinated care can save Medicaid dollars, but only if quality health care remains the first priority.

Health Homes has potential for building trusting relationships that will take precedence over profit. Its success or failure depends on a collective effort to monitor and critique the program. We must build alliances among clients, providers, public and private insurers, health delivery systems, and community and labor organizations. And we must pay close attention to the implementation of the Health Homes program to ensure that it adequately addresses health disparities and bring new opportunities to people with HIV.
National Capacity Building and Technical Assistance in 2012

ACRIA’s National HIV and Older Adults program, funded by the MAC AIDS Fund, will conduct an HIV capacity-building session in Puerto Rico. Topics include:

• Immune System and Immunosenesence
• Speaking to Older Adults about Sex and Risk
• Preventing HIV in Older Adults
• HIV Multi-morbidities and Aging

For more information, contact Hanna Tessema (HTessema@acria.org) 212-924-3934 x135 or Cesar Angel (cangel@acria.org) 212-924-3934 x137.

ACRIA’s National HIV Health Literacy Capacity Building and Technical Assistance Program will present in Mobile, Alabama; Biloxi, Mississippi; and Baton Rouge, Louisiana. Topics include:

• HIV Prevention,
• Treatment and Care Integration
• Cultural Competency
• HIV Treatment Update
• HIV Health Literacy

For more information, contact Lisa Frederick (LFrederick@acria.org) 212-924-3934 x119.

Tell Congress You Care about HIV Prevention!

A CALL TO ACTION

In December 2011, Congress reinstated a ban on federal funding for syringe-exchange programs, despite overwhelming scientific evidence that these programs work.

This inexcusable policy change, along with the decision to wastefully spend scarce tax payer dollars on failed abstinence-only education programs, shows that we still have much work to do. As we move into another budget cycle, we need to let our policy makers know that they must focus their attention on proven HIV prevention methods.

Call your U.S. Representative at 202-224-3121 and tell them to fulfill their commitment to an “AIDS-free generation” by using our tax dollars wisely to improve access to HIV prevention and treatment tools.