Aging with HIV
What We Know and What You Can Do

by Stephen Karpiak PhD, Meredith Greene, MD, and Richard Havlik, MD

In the early years of the epidemic, there were few who thought that we would ever focus on HIV and aging. In fact, many providers are still not facing the massive change in the age of people with HIV and the challenges that come with it.

Although we are seeing new HIV infections in people over 50, the main reason for the rising number of older adults with HIV is better HIV medications. In 1985, a 20-year-old with AIDS might expect to live only to age 22. Today, that 20-year-old can look forward to an almost normal lifespan. This year, half of those living with HIV in the U.S. will be over 50. By 2020, that number may rise to 70%.

But HIV is not the only health issue these older adults face. Research shows that people with HIV have an increased risk of many illnesses associated with aging. These conditions, including heart disease, cancers, kidney disease, osteoporosis, and others, are occurring more often and sometimes earlier than expected. Also, mental health conditions like depression are common among those with HIV.

Does HIV Make People Age Faster?
Research to answer this question has skyrocketed, but a scientific consensus has not yet been reached. The reality is complicated. But HIV, together with other risk factors, does seem to be driving an increased frequency and earlier onset of age-related illnesses. What do we know, and what can be done to prevent or reduce the frequency and severity of these illnesses, known as “comorbidities”? How can older adults with HIV manage them?

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Aging is not a Disease

Everyone, regardless of HIV status, ages. There are complex changes in our body that occur as we age. But aging itself is not a disease. We know that the arc of aging can be very different for each person, due to genetic and environmental factors. The focus of much research is how HIV interacts with the complex changes that occur as we age. And that is only beginning to be understood.

One possible explanation for the high number of comorbidities people with HIV face is that HIV not only attacks the immune system, but also activates it. Known as inflammation, this leads the body to release large amounts of substances into the blood that can cause more harm than good. For example, chemicals called cytokines fight infection, but when present in large amounts due to inflammation they can lead to poor health outcomes.

Inflammation is reduced, but not eliminated, by HIV treatment. Chronic inflammation may play a part in many illnesses, including heart disease and osteoporosis (bone thinning). HIV aside, inflammation is magnified by smoking, alcohol, poor diet, excess stress, etc. And inflammation is cumulative, so people infected with HIV in their 20s will have a longer exposure to HIV-related inflammation than those infected in their 40s. For people who delayed HIV treatment, or who do not adhere to HIV treatment, HIV-related inflammation will be greater. This is one of the reasons HIV treatment is now recommended for all people as soon as they are diagnosed with HIV.

Many older adults also have other risk factors that increase the possibility of developing the illnesses associated with aging. Genetics are beyond our control—does longevity run in your family? But we are responsible for other risks, including smoking, poor diet, lack of exercise, high stress, and substance use. Some risk factors can be managed by medications, and others by personal actions. Here are some conditions older adults with HIV face, and suggestions for dealing with them.

Heart Disease

There is no doubt that older adults with HIV have a greater lifetime risk of heart disease. This risk may come from HIV-induced chronic inflammation or other

The Robert Mapplethorpe Clinical Research Program

BMS-663068
People with HIV who are 18 and older will take BMS-663068 (an experimental HIV attachment inhibitor) or Reyataz for up to 96 weeks. Everyone will also take Isentress and Viread.

Ibalizumab
People with HIV will receive infusions of ibalizumab (a monoclonal antibody) to study its safety and effect on the immune system.

Ibalizumab
People who have become resistant to their HIV medications will receive infusions of ibalizumab every two weeks.

Selzentry
People with HIV who are 18 and older and who have not taken HIV meds will take either Selzentry or Truvada for 22 months. Everyone will also take Prezista with Norvir.

Sovaldi
ACRIA will review the charts of people with HIV who took Sovaldi or peg-interferon for HCV to analyze health resource use before and after treatment.

For more information on these studies, contact us at 212-924-3934, ext. 100. Compensation is available for some studies.
factors like smoking, poor diet, and lack of exercise. Reports based on thousands of HIV patients show that older adults with HIV are at a greater lifetime risk for heart attacks and other cardiovascular conditions than younger patients.

What you can do:
• Discuss with your health care provider how to manage risk factors for heart disease such as high blood pressure and diabetes.
• Stop smoking – this is a priority.
• Avoid recreational drugs – if you do use them, be sure to discuss this with your health care provider.
• Keep your weight within the normal range for your age.
• Exercise – this is key. Walk, run, ride a bike, lift weights, play a sport. Talk to your doctor and choose the one that is best for you, but choose one!

Cancer
Certain cancers (Kaposi’s sarcoma and non-Hodgkin's lymphoma) have historically been linked to an AIDS diagnosis. But today, non-AIDS cancers such as anal cancer, liver cancer, and Hodgkin’s lymphoma occur more often in those with HIV than in those who don’t have the virus. Lung cancer is also more common in HIV-positive adults, but this may be due to the fact that at least half of all older adults with HIV smoke – a rate three to four times higher than that of the general population. However, no increased risk for breast and prostate cancer has been seen in people with HIV.

What you can do:
• Discuss screening tests recommended for older adults, such as mammography and colonoscopy, with your care provider.
• Discuss screening tests that are specific for people with HIV with your provider – anal pap smears or other anal cancer screens are important for everyone with HIV, and women need cervical pap smears.
• If you do have cancer, learn as much as you can – many cancers are treatable, but require close coordination of care with a cancer specialist.

Bone Health
Many studies show that older adults with HIV have a significantly higher number of bone fractures, due to increased rates of osteoporosis (bone thinning) and its milder form, osteopenia. Osteoporosis often occurs after menopause in women and later in life in men. In people with HIV, it may be caused by HIV or by certain HIV medications, as well as by traditional risk factors such as alcohol use and treatment with steroids. People with osteoporosis have a high risk of fractures when they fall.

Studies suggest that HIV-positive adults aged 50 experience falls at a similar rate as HIV-negative adults over 65, so falls are an important health concern for people with HIV. But falls are rarely caused by one specific thing. Rather, they are often caused by more than one risk factor, including certain medical conditions, medication side effects, or the person’s physical environment. Peripheral neuropathy (nerve damage in the feet and legs), another common condition in people with HIV, can also greatly increase the risk of falls.

What you can do:
• Talk to your medical provider about DEXA scans, especially if you’re a postmenopausal women or a man over 50 (some groups recommended screening for all older adults with HIV).
• Ask your provider if you should take vitamin D or calcium to support bone health – if you have osteoporosis you may need other medications, such as bisphosphonates.

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The best treatment for falls is prevention:
• Look for loose rugs, electrical wires, or other obstacles where you live. Be very careful in the bathroom, where falls are most common because of slippery floors and tubs. When walking outside, scan ahead for uneven sidewalks that might cause a fall.
• Try exercises that improve balance, like yoga and tai chi.
• Work with your health care provider to manage conditions like neuropathy.
• Get regular vision checkups.
• Talk to your care provider about meds that can affect your balance, such as blood pressure, depression, or anxiety meds.
• If you have a fall, even without any fractures, it’s important to tell your health care provider in order to evaluate the possible reasons for the fall and to try to prevent future falls.

No Health Without Mental Health
In ACRIA’s Research on Older Adults with HIV (ROAH) study of almost 1,000 older adults with HIV in New York City, the most often reported illness in addition to HIV was depression. Many studies show that people with HIV have three to five times higher rates of depression than the general population, which is a prime predictor of medication nonadherence. In people with HIV, depression is also linked to high rates of social isolation and the negative effects of AIDS stigma. In one ACRIA study, over 80% of participants said socialization was what they needed most.

What you can do:
• If you are feeling down or blue and are not enjoying life, discuss that with your health care provider, who can do a screening for clinical depression
• Remember that a diagnosis of depression does not automatically mean you need to be taking medication – counseling alone is often effective. Recent reports show that short-term “talk” therapy (especially cognitive behavioral therapy) can be as effective as antidepressants.
• If you feel isolated or lonely, look for a support group – more of these are focusing on the needs of older adults with HIV.
• Help someone else in need -- tutor, mentor, volunteer. Focusing on the needs of others can be empowering and uplifting.
• Do not hesitate to ask for help! Depression can be treated. Do not accept the depression – seek and demand effective treatment.

Other Conditions
Kidney disease, leading to a reduction in kidney function, is more common in older adults with HIV than in those who are negative. This can be caused by HIV itself or by other medical conditions, or it can be a side effect of HIV meds and other meds. Monitor your kidney function on a regular basis, especially if you take Viread (contained in many HIV combo pills). Liver function should also be regularly checked, and you should be screened for hepatitis C and vaccinated for hep A and B. New drugs are available that can cure hep C – if you can get them.

There is less scientific consensus on whether certain conditions like high blood pressure, diabetes, cognitive problems, frailty, and vision and hearing loss are more common in people with HIV. More studies are needed to clarify the relationships between HIV and these conditions. But they should be addressed by the health care team and patient. For example, in 2015 two large studies showed that older adults with HIV were at increased risk for macular degeneration (a leading cause of vision loss) and hearing loss.

These are just some of the conditions that can affect people with HIV, and many people face more than one. Having two or more chronic illnesses in addition to HIV is called “multimorbidity”.

Less Can Be More
Managing multiple conditions often requires more medications. Taking more than five meds is known as “polypharmacy”. Many people with HIV, when asked how many pills they take, simply answer “a lot”.

Compared with two decades ago, the number of pills a person takes for HIV has been significantly reduced. But that decrease has been accompanied by the need for more pills to treat other illnesses, and pills to manage the side effects of those meds. Many also take over-the-counter drugs like vitamins, herbs, and pain relievers. Polypharmacy can lead to unwanted drug interactions and still more side effects. And, as the number of pills increases, it’s harder to remember to take them, lowering adherence. The increase in
Managing multiple medications:
• Keep a list of all your medications (including over-the-counter meds like Tylenol, antacids, vitamins, and herbs).
• Show that list to all health care providers – especially your primary care provider and pharmacist.
• Discuss possible side effects and the number of pills you’re taking – ask whether a drug is being used only to treat the side effects of another drug.
• Be honest with your provider if you’re having a hard time taking all of your pills.
• Identify one provider who can help you review any new treatments added by specialists or consulting doctors.

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Geriatric Care
HIV specialists have always kept a watchful eye on viral loads and CD4 counts, but with the aging of the HIV population, their focus must now shift.

Geriatric care providers have received additional training in the needs of older adults. They have expertise in dealing with multimorbidity and polypharmacy, since these are more common as people age. Geriatric care emphasizes overall function, such as how well someone can manage tasks like shopping and paying bills, as well as basic tasks like getting dressed and bathing. They include these functional abilities when deciding to add another medication or to screen for other illnesses.

But functional status is just one part of a typical geriatric assessment. Providers also ask about falls, cognitive abilities, mental health, and what social supports are available. New research suggests that falls, functional impairment, and frailty may occur at slightly earlier ages in adults with HIV and suggests that patients and providers should discuss such concerns.

Integrating geriatric principles into the care of older adults with HIV is critical. Managing multimorbidity and polypharmacy, preventing falls, and assessing caregiver support are just a few examples of how geriatric care principles can be used in the care of people with HIV. Integrating social and mental health services is essential. This may be challenging, since some age-related conditions may occur in people with HIV before the traditional “geriatric” cutoff point of 65. We should look at a person’s functional status and the presence of geriatric conditions, rather than just their age, to determine what services are needed.

We do not expect geriatricians to manage all of the care of older adults with HIV. But we do need them to provide guidance to HIV providers who treat older adults. Continuing medical education will be needed, as well as involving nurses trained in geriatric care. Geriatricians know that treatments are added for each illness, the risk associated with polypharmacy, drug interactions, and drug toxicities increases. And all health care must be integrated. Today, that is largely done by the client – it needs to be a team effort.

Who Will Care for You?
Older people with HIV often face another challenge. Those who have been caregivers know the importance of having familiar people around who provide all levels of support. Research by ACRIA and others has shown that over 70% of older adults with HIV live alone. This doesn’t always lead to poor social support, but much research has shown that many older people with HIV have fragile social networks. As they age, they may become isolated from families and friends for many reasons, including health issues, HIV-related stigma, and ageism.

Many people, especially long-term survivors of HIV, may be isolated due to the loss of partners and friends in the early days of the AIDS epidemic. Others may be estranged from family and friends because of their sexual orientation or drug use history. Without social supports (known as informal caregiving), they will need more formal support (in this time of reduced health resources).

Treatment strategies for an older adult with HIV must consider their often poor support networks. The buddy system, including phone support, was used in the first decade of the epidemic as a way to address this gap – perhaps it’s time to bring it back.

Conclusion
Older adults with HIV may face many challenges, but there are many successes and reasons to celebrate. In fact, there are many long-term survivors of HIV who have shown great resilience. And there are many things people with HIV can do to optimize their health as they age. The fear of experiencing multiple diseases and conditions may increase anxiety, but there is enormous clinical experience on how best to manage the health of older adults. People with HIV and their providers must be proactive and address potential problems before they become serious. The website www.hiv-age.org can be helpful in dealing with the management of comorbidities.

Everyone with HIV deserves the highest quality of life, and that’s attainable with the knowledge we now have. It will be even more so as new knowledge is gained.

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Talking with Seniors About Sex

by Karol Tapia, LSW

“It was 19, the first time, and a soldier on leave in France. I paid $5 – my whole week’s salary – and she was worth every penny.”

It’s not uncommon to hear stories like this when you’re talking about sex. I’ll never forget being in front of a particularly quiet group of seniors, when this 90-year-old man started telling this story of his first time. He looked back on this experience fondly, and he greased the wheels for an open conversation by the group about their sex lives.

As in all of my groups about sex over 60, we talked about redefining sex as we age, and of course about HIV and staying safe. One couple in the group had just gotten married. Some had been divorced or were widowed. Others had been married for almost 50 years. I always joke that they were having sex long before I was born, and they appreciate that I accept they have more experience with this topic than I do. They also appreciate that there is someone out there who acknowledges they are sexually active.

LiveOn NY (formerly Council of Senior Centers and Services) is a not-for-profit organization that champions the rights of older adults. Together with ACRIA, we have worked for the last eight years in New York City to provide education to service providers and seniors on HIV, aging, and related health topics. Most of my sessions have been with providers who actively serve seniors or people with HIV. The providers serving the aging may not know the most current information about HIV, and the HIV service providers don’t always have a good grasp on what happens as we get older and how best to work with older adults. We work to bridge the gap between the two groups so they can better serve older adults living with and at risk for HIV.

It’s critical to educate providers about aging, sexuality, and HIV. They are on the front lines with seniors and people with HIV and are key to busting stigma and stereotypes. While many of them are excellent at what they do, even they may not be free of society’s negative beliefs about sex and aging. By promoting a sex-positive atmosphere in both senior and HIV services, and by avoiding the stereotype of nonsexual old folks, we promote happy and healthy sex lives for all ages. And that’s important! When we can talk more openly about sexuality, we’re able to have more empowering conversations about safer sex. But more on that later.

The Realities of Sex and Aging

All too frequently we relegate older adults into a nonsexual role. Some seniors may even agree with that, saying things like, “I’m too old for that nonsense,” or “My husband is gone and I’ve closed that chapter in my life”, or even, “I’ve had a hip replacement and I’m afraid I won’t be physically able to have sex.” At one center, a staff member said, “Oh, there’s only one married couple here, so no one else is having sex.” I could go on.

While I won’t deny that celibacy is an option for older adults, we know that only a minority of them make that choice. We also know that sex is about intimacy and partnership – not necessarily about the sex act itself. I’ve had seniors say, “I just like the feeling of someone in my bed” or “It’s his touch that I miss the most.” They are talking about the relationship, the intimacy, and the feeling of having someone close to them, not just about having sex.

But it’s also important to acknowledge that sex for seniors doesn’t always occur within a serious relationship. We know they engage in casual sex – which could be about just the sex itself, or about a need for intimacy.

At one senior housing center, we were talking with the staff about HIV and older adults. They were not at all surprised that they were at risk, since they had seen it firsthand. “Every month, when they get their Social Security checks, we see it. We have to remove a mattress from behind the building where they put it at night. And we clean up condoms. Not only are they having sex, they’re hiring prostitutes.” I was shocked, but I found that other agencies had similar stories. They knew it was happening, and did what they could to make sure the seniors were safe. But there was only so much they could do.
Sex is a challenging topic to discuss, especially with the amount of stereotyping and stigma associated with both older adult sexuality and HIV. We have a natural discomfort with broaching the topic. Many people don't want to think that their grandmother – or any older person, for that matter – could be having sex. And we don't like to think that older people are getting HIV. When I tell providers that one out of every six new HIV infections is in a person over 50, their minds are blown.

HIV is not just a concern for young people. And sex is not just the domain of the young, either!

“Every month, when they get their Social Security checks, we have to remove a mattress from behind the building. And we clean up condoms. Not only are they having sex, they’re hiring prostitutes.”

Change Is Good

One reality about sex is that, just as every part of us changes as we age – vision, hearing, health, career, social life – sex, too, must change. Another reality is that many older adults experience profound loss. Losing a partner either through death, severe illness, or divorce changes your life. That loss can have a huge impact on your sexuality – whether you have a partner who is alive and capable of sex, both physically and mentally, is the biggest factor in having a sex life.

If we do have a partner, we must admit that our expectations of performance, frequency, need, desire, etc., must change as we age. Let’s try a little exercise: Stop reading and think about your most recent sexual experience. Get a nice picture in your head. Now compare it to your first sexual experience. They weren’t the same, right? And they shouldn’t be! Sexually, we don’t want the same things today that we did in our teens and twenties. This is what I mean by changing expectations. At some point, we’ll all find ourselves saying something like, “I don’t like this position anymore, it makes my sciatica act up”, or “My tummy gets in the way”, and so on.

But change is not a bad thing. Accommodating a new disability or desire may lead you down a path you never thought you’d enjoy, but discover you do. In fact, I spoke with one older woman who said sex for her was better now than ever: “I’m free from worry about pregnancy, from my Catholic guilt, from body image issues. It’s just me and him in bed – or anywhere else! And it’s amazing.”

Just like the rest of us, seniors want to know what is normal when it comes to sex. Some of the questions I’ve run into bubbling under the surface are:

- Should I expect that my partner won’t be able to get an erection after a certain age?
- Will I become a frigid old woman when I hit 70?
- What if I have pain when I have sex?
- What if I’m just not interested anymore?
- Will I find another partner who will want me?

Many people won’t say these questions out loud, so we have to tell them what is normal to expect as we get older. For older men, erectile dysfunction is not inevitable, but is often a sign of other health issues. I always make a point to tell all the men in my trainings, young or old:

- Most common dysfunction, erectile dysfunction.
- Challenges associated with chronic illnesses and physical disabilities.
- Erections requiring more intense or prolonged physical stimulation.
- Longer time for erectile response.
- Less rigid erection with some softening during sexual activity.
- Decreased intensity of ejaculation.
- Decreased amount of semen.
- Delay in ejaculation.
- Increased time between erections.

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Many women are concerned with changes that come with menopause. Increased vaginal dryness is the chief complaint, and it can cause pain or decreased sex drive. I always tell them – lube is your friend! I’ve had several women come to me after a workshop, asking me about my favorite lubes and the stores where they can get them. I’ve also had ladies share rousing endorsements like, “Now I use a lot of lube and it’s changed my sex life.”

Normal Changes for Women
- Most common dysfunction, lack of desire and lack of arousal.
- Challenges associated with chronic illnesses and physical disabilities.
- Decreased clitoral engorgement.
- Decreased vaginal lubrication.
- Decreased breast swelling.
- Diminished pre-orgasmic sweating.
- Diminished orgasm intensity.

The women I was talking to – all in their 60s and 70s – hadn’t learned that they can say “no” if their partner won’t wear a condom.

Condoms
The biggest take-away for seniors is the discussion of safer sex and the fact that your age won’t protect you from STDs or HIV.

I once spoke with a group of older women in the Bronx. We had a great time talking about sex and aging, but things got more serious when we discussed safer sex. One of the women opened up: “My boyfriend is in his 70s, and he is a very traditional Hispanic man. He won’t wear a condom. And I don’t know what to say to him.”

This was an “Aha!” moment for me. I can remember being in high school learning “no glove, no love” and other silly sayings, all encouraging us to send the same message: “If you don’t wear a condom, we’re not having sex.” I learned how to have “that talk” with a potential partner. But the women I was talking to – all in their 60s and 70s – never got that message. They hadn’t learned that they can say “no” if their partner won’t wear a condom. Or that they can demand an HIV test before they get into bed. Why wouldn’t we teach all women (and men for that matter) that this is the new normal? Many of them are dating for the first time in 30, 40, or even 50 years, but they haven’t realized that the rules have changed. That woman inspired me to always include condom negotiation skills in my trainings.

Conclusion
Through eight years of working with seniors and providers to make their world a little sexier, I’ve learned a great deal. I’ve heard things like, “I’m a sexy lady over eighty!” I’ve talked to providers who never imagined they would need to know where in the neighborhood they could send their seniors to buy condoms or lube. Or centers that embraced safer sex and offered bowls of condoms and lube onsite.

The most important lessons I’ve learned from all the conversations I’ve had are the following tips for talking with seniors about sex:

- Be comfortable – if you aren’t comfortable addressing the issue, don’t!
- Agree on rules for group discussions:
  - Feel free to speak your mind – this is a safe space.
  - Like sex, this will be interactive – please don’t just sit there.
  - Laughter is healthy and sex is silly – don’t be afraid to laugh out loud.
- If you are younger than the participants, acknowledge the age difference – they will appreciate it.
- Learn from them – be an expert, not a know-it-all.
- Treat it as a conversation, not a one-sided lecture.
- Use words that you and your audience are comfortable with – when in doubt ask them (make a game of it).
- A little respect goes a long way.
- Small groups work best – some people may want to talk about sex but not with a lot of people listening.
- Have fun and be creative!

I hope that everyone reading this will take the opportunity to grab an older person that you love and admire and talk about sex. And stay sexy, seniors!

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It has been ten years since ACRIA collected the data for its Research on Older Adults with HIV (ROAH) study. Including 1,000 New York City older adults with HIV, ROAH’s data became a catalyst for bringing the HIV and aging issue onto radar screens locally, nationally, and globally. ROAH focused on psychosocial characteristics that better defined the characteristics of people aging with HIV.

ROAH continues to be the source for research papers, abstracts, and presentations, including three Satellite meetings at International AIDS Conferences, and three HIV and Aging conferences. It provided the evidence base for eight years of funding for older adult HIV prevention efforts from the New York City Council. ROAH positioned ACRIA to advance HIV and aging policies, leading to a White House Conference on HIV & Aging, two U.S. Congressional hearings, and ongoing advocacy with the CDC and UNAIDS. The White House Conference provided the impetus for the NIH Working Group on HIV and Aging. ROAH has been a model for other research efforts in San Francisco, Canada, the U.K., Brazil, Uganda, and South Africa.

ROAH 2.0
On the tenth anniversary of ROAH, ACRIA is launching an extension, ROAH 2.0. Its goal is to inform the care and support services provided to older adults with HIV. As they age, their burden of disease increases. They, and their care providers, must confront the challenges of managing multiple chronic conditions. ROAH 2.0 will use its evidence base to confirm that psychosocial factors significantly affect care utilization and health outcomes. Those factors must be addressed and integrated into any care plan for older adults with HIV if they are to achieve optimal health and aging.

ROAH 2.0 will be a quantitative and qualitative research effort that will begin in NYC, with 1,000 participants completing a one-hour survey. We plan to expand it to other sites as funding is obtained. We are actively seeking additional support and welcome any other collaborators and funders. We are targeting Chicago, New Orleans, Baton Rouge, Atlanta, Washington, D.C., San Juan, Los Angeles, and San Francisco. Why? Because the level of medical and social support varies significantly by city and region in the U.S.

Many states that have not embraced the ACA’s expansion of Medicaid are unable to provide the level of care provided by states that have expanded Medicaid. Also, people with HIV confront varying levels of stigma when they seek medical care, depending on their location in the U.S. These local factors affect health outcomes.

Linking Heath Data
Due to our collaborative work with colleagues at Weill Cornell Medical College, a unique feature of ROAH 2.0 will be the opportunity to link clinical health records with psychosocial survey data for a subsample of participants. We also plan to develop ROAH 2.0 as an ongoing study where participants will be followed and assessed in the years ahead.

Including clinical data in ROAH 2.0 reflects the single most significant challenge that older adults with HIV and their care providers face: how to manage the health of a person who has multiple illnesses, known as multimorbidity. We know that treating each disorder individually does not result in the best health outcomes, and in fact can cause serious harm. Multimorbidity is fast becoming the norm rather than the exception in older adults with HIV, so understanding how best to manage it, along with its psychological and emotional effects, is a primary goal of ROAH 2.0.

Research Advisory Committee
ROAH 2.0 will be led by ACRIA researchers Mark Brennan-Ing, PhD and Stephen Karpiak, PhD. They will be advised by a national Research Advisory Committee of consumers and researchers. The Committee will be chaired by ACRIA consultant and collaborator Richard Havlik, MD, a retired Laboratory Chief at NIH National Institute on Aging. The Research Advisory Committee will be used to develop our survey instrument and research protocols, and will provide insight and expertise to inform data analysis and reporting. As in the past, we will make ROAH 2.0 data available to any qualified researcher who requests access.
Three Women

by Joel Goldman

I was eight years old when I decided I wanted to work on social issues when I grew up. My “aha!” moment came when my parents asked me to pack a box of my toys, and we drove to a migrant worker camp. My Dad, a rabbi, had worked with the great activist Bella Abzug, so he knew many of the people at the camp. He left me alone there for the day to play with children who had no toys, slept on dirt floors, and had little to eat, but who seemed so happy. From that day forward, my career path was clear in my mind.

Twenty years later, I was living my dream. My partner and I had built a home and were leading a full life with our careers, volunteerism, lots of friends, and a loving, supportive family. Then, I was diagnosed with HIV – and told that I had about two to three years to live. Though it was the early ’90s and I was living in Indiana, I decided to tell all my friends and family. I believed then, and still do, that the only way to fight stigma is for those of us who are positive to be open about it.

I started attending weekly support groups, but I left feeling depressed and guilty. I just whined about the side effects of AZT, while the others spoke of being fired, disowned, or losing friends. I saw how much I was blessed, and had another “aha!” moment. I realized that all of us with HIV share a common bond, even though our stories are often very different.

In the support group, we talked about the lack of political leadership on AIDS support and research. Our hero was Elizabeth Taylor, who seven years earlier had announced she was committing her life to fighting AIDS. She convinced President Reagan to make his first and only public speech on AIDS before he left office. Protesting the U.S. immigration ban on people with HIV, she held up her British passport and said “I am an immigrant, President Bush – would you deny me entrance if I had AIDS?”

I asked my friends who were on the college lecture circuit for advice, and they told me to find common ground. My response was, “How? I’m a Jewish guy with HIV from the North.” Another friend, T.J. Sullivan, told me it didn’t matter where I came from, or what religion I was. “They’ll relate to your drinking and sex stories, and then get a punch in the stomach when you reveal your diagnosis.” The truth was that I had always used condoms, except when I was drunk. Alcohol played a big role in my college life and in my HIV diagnosis.

So on the eve of the 1992 presidential election, I nervously stepped up to a podium to tell my story in George Bush’s home state. It was amazing. They laughed at my tales of drinking parties and moaned when I said I woke up and didn’t know who was in my bed. And you could hear a pin drop when I disclosed my HIV status. I could see tears in their eyes as I shared how I told my parents that I only had two or three years left to live. When the speech came to an end, there was a long and thunderous standing ovation. The students lined up for over an hour to hug me, ask questions, or quietly disclose that a loved one had HIV or had passed away from AIDS.
But people left that evening somber – too somber. So T.J. and I created a program that was funny, yet moving. We thought it would only last a few years because of my health (we even talked about collecting a T-shirt from each school to use in my eventual AIDS Quilt panel). Then along came the HIV drug “cocktail” that saved many of us who are now over 50. T.J and I spoke together for eight years at more than 1,000 campuses and student conferences.

When the program finished, I went to work with The Elizabeth Glaser Pediatric AIDS Foundation, organizing college students to do grassroots fundraising and educational programs. One important learning moment for me was when Scott Wolf and Brooke Shields signed on as co-chairs for a fundraising event. Other celebrities soon joined: Lucy Liu, Kimberly Williams, Tia & Tamera Mowry, Jaime Pressly, and “Survivor” and “Real World” cast members, to name a few. It showed me the importance of celebrity in getting media attention for a cause.

It was hard to leave EGPAF after 14 years, but I continued to get attention for health-related causes by working with the entertainment industry and pop culture. I was a Director for St. Jude Children’s Hospital, Feeding America, and Malaria No More. I loved supporting these causes, but I missed working for the cause that touched me personally. Then a friend introduced me to the Trustees of Elizabeth Taylor’s estate. My resume was on their desk later that day.

At the end of August, I will celebrate my two-year anniversary as the Managing Director of The Elizabeth Taylor AIDS Foundation. I feel like two of the greatest Elizabeths – Taylor and Glaser – hover over me like angels every day. And Mary Fisher has become a friend and an ETAF Ambassador. It’s ironic that three of the women I had watched on TV and read about have become part of my life.

Even before I took this position, I said that if not for Elizabeth Taylor making people pay attention to HIV, co-founding amfAR, and doing advocacy work, many of us would not be here today. I certainly never thought I would reach age 51. Yes, all of us over 50 have a lot of aches and pains. But those of us who have been living with HIV for decades have things happening to our bodies at a faster pace. I’m not complaining, since I’ve had 20 bonus years added to my original prognosis.

After arriving at ETAF, I learned about our grant to ACRIAd about HIV and aging. I was surprised to meet seniors in the room who were newly infected, and who were heartened to learn from the long-term survivors in the room. It was a moment of hope.

I recently traveled to Malawi to see the Elizabeth Taylor Mobile Health Clinic program in action. It was a full circle for me, as many of the homes we visited reminded me of the dirt floors in the migrant worker camps I saw as a child. And, like the kids I played with then, these children couldn’t have been happier, despite living in one of the poorest villages in the world.

The Elizabeth Taylor mobile clinics are helping break down the stigma of getting tested for HIV, and helping 900,000 people receive treatment and care. The first day I arrived, I was greeted by a hundred people who were waiting to get tested. Asked to say a few words, I decided to disclose my own status as a long-term survivor of HIV. As the translator repeated what I said, I heard a gasp, and then applause. I went on to tell them that because I take my medication every day, I am still here nearly 25 years after my diagnosis. HIV meds had only recently been introduced to that area of Malawi, and access to health care prior to our mobile clinics was sparse, which meant that there were not many long-term survivors in the crowd. I was shocked at how many wanted to hug me and even take a photo with me. While my story was once a cautionary tale to young people in Texas, in Malawi it had become a symbol of hope.
When have you felt like the only one? The only artist, the only person of color, the only Democrat?

I recently asked this of a class of graduate social work students at NYU. Their eyes were closed as I took them through this exercise, asking them to recall as much as they could about the experience emotionally and physically.

Where were you? What was happening? Who were you with? How did it feel to be the only one? What was going on in your body – your stomach, back, shoulders?

Then I asked them to take a mental photo of the expression on their face, to save the picture, and to slowly come back to the room. What followed was a discussion of the effects of stigma on our physical health, the way we interact with others, and our feelings about ourselves.

“I felt alone and scared,” one student stated. Another was close to tears: “I felt insecure and thought I was going to throw up.” Another jumped in, “Not me. I was angry.”

“What if a social worker approached you at that moment?” I asked. She replied quickly, “I would have bitten her head off. I didn’t want to talk to anyone.”

For social work students, the exercise is especially important because they must be able to empathize with their clients, to understand not only the way stigma can spoil one’s positive identity but also how stigma and the acceptance of being stigmatized can serve as obstacles to the very help these students want to provide. Only when they remember what it’s like to feel like “the only one” can they bridge the gap of mistrust and begin to build the alliance that can help heal the wounds of social stigma.

I learned this exercise when I was a social work intern at SAGE doing sensitivity training on LGBT aging with Arlene Kochman in 1992. And, despite the gains the community has made over the past 23 years confronting homophobia, the lesson is still relevant.

The Triple Threat

Gay men often refer to aging with HIV as a “triple threat”: the homophobia they’ve always encountered, the stigma of HIV, and now ageism as they live into middle age and beyond.

Homophobia is a continuing reality in the lives of gay men. Over 75% of LGBT adults aged 60 to 91 have experienced some form of victimization due to their sexual orientation (D’Augelli & Grossman, 2001). An HIV diagnosis can reopen the old wounds of homophobia, and older adults continue to experience the consequences of HIV stigma in their daily lives. Additionally, for many HIV-positive gay men, who never thought they would live to middle age, growing older involves confronting the unanticipated realities of ageism. Here’s what three gay men over 50 say about the triple stigmas they’ve experienced (names have been changed for privacy):

Luis, 51: You couldn’t walk the streets together. They would beat you up.

Mario, 53: The trauma of feeling like I was the only gay person in the world.... It was always a waiting game of finding out that people really didn’t want you around because you were gay. When I was diagnosed with HIV, it happened again – I literally walked around shell-shocked for about two or three weeks after that.

Mark, 54: I felt alone and scared. I was angry. What if a social worker approached you at that moment?

Mark, 54, feels sideswiped by the ageism he experiences from other gay men. He feels invisible in the gay community, where he once received support: “It’s all about young, pretty boys, blah blah blah, whatever.”
Stigma takes a toll on our mental and physical health. It can lead to depression, a lack of social support, and can affect whether people seek medical and mental health care (Emlet, 2013). These conditions can manifest in physical symptoms and create a negative feedback loop of illness and isolation. Joe, 63, knows the pain of living with stigma: “My muscles turn to stone”, he says, from the depression of living an isolated life.

Managing the triple threat of homophobia, HIV stigma, and ageism is essential to gay men’s health and well-being.

**Fight or Flight**

Humans have an innate physical reaction to danger. Our bodies flood with hormones that propel us into action. We are compelled to act quickly, either to confront an aggressor or to flee to safety. This instinct, referred to as the fight/flight response, can also kick in when we react to stigma. We respond to the threat of a homophobic assault just as we would respond to an attack from a predator in the wild. Gay men who have been victims of repeated homophobic abuse can experience a fight/flight reaction even when the threat of danger is not immediate. Just the anticipation of stigma can be alarming enough to trigger the fight/flight response.

Anger is the emotional response that compels us to fight. Just as a flood of anger propels us to fend off an attacker, so too can rage surge in our bodies when we experience the assault of stigma. But anger is not a dangerous emotion in itself. Where would the LGBT community be today if an angry mob hadn’t fought back against a police raid at the Stonewall Inn in 1969? In fact, activism is a form of channeled anger.

Tim, 50, can still get worked up when he hears about someone being discriminated against for being gay or reads about federal cuts to AIDS funding. But he’s not getting into fights with the police anymore – instead, he focuses his anger into writing letters, joining protests, and speaking out as an openly gay man with HIV. When we are aware of our anger, we can find productive outlets for that feeling, like Tim does. Unfortunately, when we are unaware of our anger we can turn it against ourselves and the people close to us in destructive ways.

Fear is the emotional response that compels us to take flight. Just as we might run from an attacker, we can flee from situations that trigger the fear of stigma. Many middle-aged and older gay men remember when the threat of imprisonment, unemployment, homelessness, and violence compelled them to hide their sexuality.

Joe lived through the pre-Stonewall years and learned to be a “private guy” who kept his sexuality to himself and his closest friends. When he developed facial wasting caused by HIV (which he referred to as “the look of AIDS”), he started isolating. As his family reunion approached, he was torn. He wanted to see family members he hadn’t seen in years, but the fear that his HIV diagnosis would be revealed by his face made him hesitate. He weighed the risks of disclosure against the advantages of reconnecting with family members.

When Joe developed facial wasting, he started isolating. As his family reunion approached, he was torn. He wanted to see family members, but the fear that his HIV diagnosis would be revealed by his face made him hesitate. He weighed the risks of disclosure with the advantages of reconnecting with family members.

At 51, Peter can look back on his life and see the damage stigma has caused. He realizes that his low self-esteem has held him back from getting the most out of his career and personal relationships. But he is committed to changing his attitudes and behaviors.

*I’ve learned that I must fight off those internalizations. I must keep who I am here, free from those internalizations somehow. Because that’s who I really am. And that’s a challenge for me.*

For many of us, the gay community provided a refuge from homophobia, and positive interactions with other admirable gay people reversed our negative self-view. The gay pride movement told us that homosexuality was not something to be ashamed of, but an aspect of our identities of which we should be proud.

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Managing The Triple Threat  continued from previous page

Ronald, 58, found that getting reconnected to the gay community helped empower him as he faced the stigma of aging with HIV:

Being around gay men who are successful gay men, who are out and have been for years, it has somewhat blunted my fear of being discovered.

Research suggests that successful management of homophobia serves a protective function that can help us face the challenges of aging (Kimmel, 1977). Coming out gives us a sense of crisis competence and provides us with tools we can use to combat the challenges of aging. Mario knows that learning to deal with the homophobia of his youth has made him stronger today. As he puts it, “If you go through that without throwing yourself in front of a bus…” then you can handle anything.

Enhancing Resilience
How can we combat the negative realities of stigma while enhancing the positive strategies we developed to cope with it? We must foster the qualities that enhance our resilience. Resilience can be thought of as “strength plus flexibility”. It allows a person to adjust to life’s challenges by using coping strategies adaptively, rather than rigidly. When we are resilient, we integrate our past experience with the strengths and support of others to develop new approaches to our problems. Here are four practices you can start right now to help you to build your resilience as you face the triple threat of homophobia, HIV stigma, and ageism.

Affirm Yourself
Many gay men say that a lifetime of stigma has left them with an “old tape” playing negative messages inside their minds. The recording, which can turn on at any time, might tell them they’re “too effeminate”, “not handsome enough”, or “too dull”. The tape is different for each person, but the overall message is the internalized expression of stigma: “Something is wrong with you.”

The first action you can take to develop resilience is to stop the tape. When you are aware of the “stinking thinking” that stigma generates, redirect your thoughts. Come up with a phrase you can use whenever you catch yourself falling into negative self-talk (like “There’s that tape again, sweetie.”) or make up a word that stops the tape (such as “zip”). When you use that word you know it’s time to change your mind and to distract yourself with new thoughts or activities.

Develop your ability to clear your mind. Paying attention to the present moment is one way to distract yourself from negative thoughts and create a sense of calm. There are several kinds of meditation practices you can use for this purpose. One strategy is simply to pay attention to your breath. Focus on the air as it passes through your nostrils. Feel yourself relax as you breathe cool air in and warm air out. Try that for two minutes when you are feeling stressed.

Change your thinking patterns by reciting affirmations. By focusing on your strengths and positive attributes, you combat internalized stigma. Some positive affirmations include: “I am a good person.” “People care about me.” “I am worthy of love.” Come up with some affirmations that counteract the negative tape of stigma. Practice them in front of a mirror and say them to yourself throughout the day, or when you are experiencing stigmatizing thoughts.

Get Support
The presence of a strong support network can help you manage the challenges of living with HIV and of aging in general. Peers who understand your experience are vitally important when you are dealing with stigma. Even the sense that someone cares is often enough to counteract the negative impacts of stigma on your emotional and physical health.

The gay community once provided a safe haven from homophobia. Gay friends and colleagues offered opportunities for building pride and empowerment. But many older gay men have lost most or all of their social networks to AIDS. How do you rebuild your supports at this stage of your life? Here are ten suggestions for widening your social network:

1. Renew old acquaintances.
2. Seek out people with whom you have things in common.
3. Strike up a conversation with someone you’ve never met.
4. Make friends with someone different from yourself.
5. Don’t wait for people to contact you.
6. Consider professional support through an agency, support group, or therapist.
7. Adopt a pet.
8. Pursue a romantic relationship.
9. Use the internet to cast a wider net.
10. Form a reading group or some other type of social activity.

Be of Service

“Mature man needs to be needed” (Erikson, 1963). Helping others through productivity, creativity, and passing on knowledge is the primary way you can fight off stagnation in mid-life. By demonstrating your value to others you challenge stigmatizing ideas by reaffirming your self-worth. Stigma tells us that we are no good – that we have nothing to offer and no one wants to hear from us. That is not true. Age and experience have left you with hard-earned wisdom. Through mentoring, coaching, leading, or consulting, you remind yourself of the skills you have to offer.

Consider how you can get involved in your community. What skills do you have to offer a younger person through teaching or tutoring? Can you help someone who is in need? Have you ever thought about being an HIV peer educator, or participating on an advisory board or advocacy group? What is one step you can take today toward getting more involved?

Have Some Fun

Stigma takes a toll on your mental and physical health. The fatigue and pain of stigma can wear you down without your awareness, leading to isolation and depression. So you need to recharge and replenish yourself with some positive energy. Do you have enough play time in your life?

It may seem out of place to end an article on HIV and aging by discussing play. But the ability to play is probably one of the most influential factors in development across the lifespan. When we play we can:

- Learn new skills.
- Make friends and socialize.
- Immerse ourselves in creativity.
- Channel our energy toward a productive goal.
- Get our heart rate up.
- Work out anger.
- Manage losses in a less charged atmosphere.

Your options for play are as boundless as your imagination. Learn a sport. Take a dance class. Pick up a paint brush. Play a board game. Write a story. Care for animals. Garden. I love giving a toy to kids only to watch them invent a game involving the box it came in.

Conclusion

Optimal aging with HIV involves managing the triple threat of homophobia, HIV stigma, and ageism. When you take care of yourself you counteract the negative messages of stigma. Let’s keep a conversation going about HIV and aging that fosters resilience and empowerment in ourselves and our communities.

James Masten, the author of Aging with HIV: A Gay Man’s Guide, is the Director of Action for HIV and Aging (ahaproject.org) and a psychotherapist in New York City.
We start the focus groups we run on our social messaging campaigns with this request. We ask our participants, who are 55 to 70 years old, to think back to when they were three decades younger – when they were at their sexual peak and first heard about the catastrophic damage AIDS was causing across the country.

What they learned about AIDS at that time often defines what they think about it today, especially among heterosexuals. It is remarkable that even 30 years later, many older adults in New York City still think HIV is a concern only for gay men, drug users, and sex workers. This lack of knowledge is the main cause of new infections in older adults – not only HIV but other STDs as well.

That’s the reason we’ve created five different social messaging campaigns about sexual health that target people over 50 of all sexual orientations. We need to inform them that accurate information, safer sex, and regular testing are the key tools to maintaining their health.

As consultants for ACRIA, we’ve created a new “Age is Not a Condom” campaign each year for the last five years. These campaigns consist of 12 to 17 different posters – half in Spanish – that appear on bus shelters in New York City, online at ageisnotacondom.org, and on Facebook, Twitter, and Pinterest.

As consultants, we bring our own expertise, but we do not do it alone. Effective social messaging campaigns are not created on computers in isolated offices. They are created by the audience they are intended for. In small meetings, older adults of all backgrounds shape the look, message, and tone of each ACRIA campaign by honestly, and sometimes forcefully, expressing their opinions.

Creating a Campaign
Our work starts with some simple ideas for a campaign. We come up with a few different ideas, using images and content from brainstorming meetings with ACRIA staff and from earlier research. We then arrange and meet with focus groups, by teaming with organizations that work with older adults and selecting people who are similar in age, race, and where they live. HIV status is not asked nor disclosed in the groups.

We start by warming them up with a conversation about growing older, finding relationships, and, of course, having sex. We spend quite some time on that, asking if they are sexually active, how much they know about safer sex, and how much they share with their doctors about their sex lives. Finally, we show them our ideas and just listen. The participants are always very engaged, strong-minded people, and their ideas and opinions really make a difference in taking our original sketches to the final product that appears on the street. We update the graphics and content based on the group’s suggestions, narrow the campaigns down to one, and then finalize the models, photography, and graphic design.

Strong Feelings
Over the years, the opinions of our focus group participants have left their own stamp on each campaign. In 2011, we were halfway into a meeting with a group of older Latinas when we noticed a common concern among some participants. Turns out they were heterosexual women with HIV who all recalled being infected by their partners or husbands. Rosa, a 62-year-old Puerto Rican, said:

We were shocked to hear this from a 52-year-old AIDS activist: “Hell no! I don’t want to see grandma naked on a poster. We are too old to show that much skin.”

Growing up, we learned from our mothers that a good husband is one who always provides for his family and comes home every night. Mine was a good husband under those principles. I just didn’t know I could get HIV from him.

Rosa’s statement defined our first campaign, titled “I Didn’t Know”, in which we presented Rosa’s story along with five more from other older adults who didn’t know they needed to protect themselves from HIV and other STDs.

Sometimes we faced rejection when putting the groups together. Last year, we were starting a group at OATS (Older Adults Technical Services), an organization that helps older adults improve their computer skills. When we gave out a questionnaire, a white man about 60 years old stood up and said:

Oh, sorry – I just read here that this group is about AIDS. I’m leaving because I am not interested.
But this man was exactly the kind of person we wanted in the group! We need to meet people, especially heterosexual men and women who don’t often think about HIV, and talk about their sexual health and safer sex practices. Unfortunately, many have built up thick barriers that prevent any new information from getting through.

I honestly can’t believe that people over 50 don’t have the information they need to practice safer sex. Everybody knows the rules! For God’s sake, it’s been over thirty years!

That was the statement of a 55-year-old white man who had worked in HIV agencies for years. We were amazed to learn that people working in HIV often think that everyone knows and accepts information designed to change prejudices like “only gays, sex workers, and drug addicts are in risk for HIV.” Through our groups, we’ve learned that’s often not the case.

Hell no! I don’t want to see grandma naked on a poster. We are too old to show that much skin.

We were shocked to hear this from a 52-year-old AIDS activist when we showed images of people over 50 who appeared to be nude. They looked proud of themselves, healthy, and sexy. This reaction—which we considered a little discriminatory toward older women—only made us more determined to portray models in suggested nudity, looking proudly at the camera and delivering the clear message, “If you have sex…Age is not a condom.” Using controversial elements can sometimes be very effective. It’s better to get a negative reaction that none at all.

The groups also allowed people to discuss the effect HIV has had on their sex lives and the difficulties they face discussing that with their doctors. Omar, a 62-year-old gay man with HIV, shared this story:

I was trying to talk to my doctor about sex and ways to prevent infecting others. He looked at me and said, “You just need to make sure you take your meds and take care of your health. At your age there is no time to think about sex.”

Stories like that taught us that our campaigns need to speak not only to people with and at risk for HIV, but also to their health care and social service providers.

What We’ve Learned

Over time, valuable facts that make these campaigns more effective have become clear. Our participants have expressed loudly and clearly that they want to see themselves in the pictures we take, to make sure we are effectively targeting their peers in the campaign.

They want to see regular men and women over 50, not professional models—images they can relate to. For this reason, we’ve done our own photo shoots for the last three years, carefully casting men and women who represent our audience. It’s very rewarding to see these regular folks in high-quality images.

We’ve used photos of gay and straight couples in order to target all communities. And we’ve also learned the value of using an image of one person and broadening the written message to include all sexual orientations. That way, we can reach all of our target audiences without excluding anyone’s sexual behaviors.

These are not big-budget campaigns. Since our target audience is scattered around the city, we use bus shelters in all five boroughs of New York City as the main outlet to display our posters. This allows us to target everyone who rides buses throughout the city, as well as the pedestrians who walk by them. We can also determine the demographics of the area in which each bus shelter is located to ensure that we find the best location for each poster.

All our campaigns remain up at ageisnotacondom.org long after the bus shelter posters are gone. Please visit us there, like us on Facebook, or follow us on Twitter and Pinterest—search for ageisnotacondom. Help us spread the word that older adults have great sex and so need to learn how to protect themselves.

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Who Will Be There For Me?

by Cecilia Chung

I came to San Francisco from Hong Kong in 1984, when I was 19. AIDS was hitting the gay community hard then. But I hadn’t heard anything about HIV – people back home just did not talk about it. I only started hearing about it when I saw ACT UP’s “Silence = Death” posters on the street. I learned bits and pieces of HIV education by reading posters – that you couldn’t get it by sharing a glass of water or a toilet seat. Those were things I would never have asked anyone.

In 1992, I began transitioning to being a woman. When I was growing up in Hong Kong, there were no resources for that, but here there was a community I could go to. I had many questions, and when I saw people like me, I realized that being gay wasn’t the answer for me. That’s how I really started to connect with the transgender community.

I started taking hormones 22 years ago, around the same time I found out I had HIV. But there are very few studies of transgender women who take hormones as they age. We do know that if you’re a smoker, taking hormones can increase your risk of blood clots. I am a former smoker, so I have to watch out for that. I’ve also found that there is no real research on the interactions between estrogen and HIV medications. I also worry that as a woman of color, there could be some differences in how my body reacts to the long-term use of hormones, but I also can’t find any data on that.

As the first HIV generation is getting older, we have different needs – like finding care for our age-related health issues, which may not be about HIV. Sometimes, it can be hard to tell which is which. And the list of my health issues is getting longer. I have an AIDS diagnosis, along with high blood pressure, and I’ve had several episodes of pancreatitis.

I’m grateful that I live in San Francisco, which has culturally competent and patient-centered care. But even in this environment, I have encountered bias. About 20 years ago, I had problems with a surgery that led to a small bowel obstruction. I was in a lot of pain, but when I went to the E.R., they would not admit me. Because I was transgender, they assumed I was just trying to get drugs. Instead of examining me, they had security escort me out! A week later, I developed gangrene and was finally admitted to the hospital. I almost died from that experience.

Now, my doctor has recommended that I have my gallbladder removed, but I’m hesitant to go to the hospital because of my previous horrible experience. I almost died from that experience.

I’ve been lucky to have the same doctor for almost 15 years, but at some point she’s going to retire. Where will I get care then? I’m not afraid to see a new provider that my current doctor recommends, but if I were traveling and something happened I would be very leery about seeking care. I would have to explain who I am to new people, and that can be quite overwhelming.

I admit I’ve been avoiding dealing with aging – that’s my own denial. I never thought I would live this long, so now that I can actually apply for AARP membership, I find myself procrastinating about learning what I need to know about aging. I was caught off guard when I had to add high blood pressure medications...
to the already long list of pills I take. To be honest, I don’t take my blood pressure as seriously as my HIV. I’ve been used to taking the same HIV pills for years, and adding more is tough. I have to take ownership of the fact that I am not as adherent to my blood pressure meds as to my HIV meds. If my doctor reads this, she’s going to lecture me!

In Asian cultures, we often don’t speak about issues like sexuality and HIV. A lot of gay Asian people never come out to their parents, especially if the parents are not here in the U.S. It’s an unspoken fact that most Asians view HIV as a moral issue. You’ve done something bad. You didn’t know how to conduct your life. HIV is the consequence.

What really hits home for me is that I don’t know many transgender people who have survived into old age. It’s harder for transgender people to live past 60 because there’s a greater chance we’ll encounter violence.

That same stigma applies to being transgender. It’s not something we talk about. But now my mom lets me know if my aunt tells her she saw me on TV. I hope that means that they’re proud of me.

I don’t come from a big family, and most of them are older than me. My mother used to ask, “Why do you need a partner? Why can’t you just be by yourself?” But I worry that when my family is gone, I will have no one to take care of me when I’m older. That’s a problem for a lot of trans people. They may have no one to take care of them when they age.

What really hits home for me – and this is hard to say – is that I don’t know many transgender people who have survived into old age. It’s harder for transgender people to live past 60 because there’s a greater chance we’ll encounter violence. I’ve experienced violence multiple times, and that’s a common story. Whether it is anti-trans violence, intimate partner violence, or random street violence, the frequency is much higher, especially for trans women of color.

We have to make sure that transgender people with HIV have the opportunity to live to a ripe old age. Right now, that’s a luxury. Many transgender women, because of the stress in their lives, end up choosing to take their own lives, or they lose their lives to violence or health complications like hep C.

If we really want to talk about being transgender and aging, we first need to talk about just giving transgender people the opportunity to age! There’s still a lot of work to be done to get to that place. And when we get there, we need to have a lot of conversations around culturally competent care, not just for trans women, but for all HIV-positive people who survived the first 20 years of the epidemic.
Over half of all people with HIV in NYS are now over 50, and that number will rise to 70% by 2020. How has this changed the work your agencies do?

Dan: First of all, the aging of the epidemic is a sign of success. It’s not that more people are getting infected at an older age; it’s that the people who have HIV are growing older. If you look at where we are in terms of viral suppression, about 63% of people with HIV in NYS between 50 and 59 are virally suppressed, as are 68% of people over 60. That’s far higher than the rates of viral suppression we have for people in younger age groups.

What are the reasons for those higher rates?

Dan: I think older folks are better at taking meds. I certainly take a lot of meds, so I know that being linked to regular health care improves adherence. With younger people, that’s more of a challenge, because they’re newer to the health care system. They don’t always know how to use it, while older adults do. It may also be that things like substance use that can lead to poor adherence are not as common in older adults. I don’t know for sure, so I think it’s a good area for further study.

Corinda: One reason could be that our network of aging providers offers a support system for people with HIV. We work with DOH to provide training and education around HIV and self-management for chronic diseases. Older adults with HIV face the same problems as anyone who’s getting older – diabetes, heart disease, liver disease, cancer – and we’ve educated seniors on those conditions for many years. We’re building on what we learn as the number of older adults with HIV grows.

Have you encountered any resistance on the part of senior service providers in addressing this topic?

Corinda: The only apprehension we’ve received from the providers is, “How do we engage?” They want to, but they want to make sure that seniors are getting what they need. So the education piece is critical. How do you ask seniors about sex, and how do you build enough trust so you can draw that info out of them? We were pleasantly surprised about the receptiveness of senior service providers.

Do we need to work on having more open discussions about sexuality, including LGBT issues, so that seniors are comfortable talking about it with their care providers?

Corinda: We’ve begun that conversation and taken steps to start asking those questions and building that trust. Our questionnaire for services such as Personal Care Aide and home-delivered meals requires a comprehensive aging services assessment, known as our Compass. We’ve included questions about sexuality, including LGBT issues, in the Compass. We’ve had trainings by SAGE [Services & Advocacy for GLBT Elders], on how to ask those questions in a sensitive manner. We’ve had a training, in partnership with DOH, on HIV and hepatitis C. So it’s a continuing effort – not a “one-and-done”. And a number of programs around the state focus specifically on LGBT issues. There’s a senior center in NYC geared to LGBT people, and I believe one recently opened in Suffolk County as well.

The real issue is getting providers to think about HIV in older adults, and for older adults not to think that somehow when they cross that 60-year mark they’ve become immune to STDs.

What programs are effective in educating older adults about HIV prevention?

Dan: I haven’t seen any evidence-based HIV prevention models that are targeted to older adults. The number of new HIV diagnoses among people over 60 is fairly low – 5% of our total – so if you go and talk to older people specifically about HIV, it may not resonate with them. Instead, we need to talk to them about sexual health in general. Certainly testing people for STDs, including HIV, makes a lot of sense. NYS recommends HIV testing for anyone up to age 64, and people who have risks – say, those who have sex with multiple partners – should be tested at any age. The real issue is getting providers to think about HIV in older adults, and for older adults not to think that somehow when they cross that 60-year mark they’ve become immune to STDs.
We’ve heard that there has been some resistance to routine HIV testing on the part of providers. Any thoughts on that?

Dan: Eliminating written consent was widely applauded by medical providers, so we’re hoping that has an impact. But beyond hoping, we’re doing reviews of the policies and procedures of all hospitals in the state. We’re doing 5,000 medical chart reviews to determine how well the new law has been implemented. Overall, we get the sense that many hospitals and primary care providers are doing a good job, but certainly there is more work to be done. The Blueprint of the NYS Plan to End AIDS included a statement that we need to make routine testing truly routine. We’re working to make sure that routine testing is being done, and we’re having conversations with those who are not doing it.

Speaking of the Blueprint, it didn’t have any specific recommendation on programs for older adults – it just included them in a list that mentioned “young adults, adults, and older adults”. Does it need more specific recommendations for older adults?

Dan: Well, if each recommendation said, “This is how it’s going to work for Asian-Pacific Islanders” or “This is how it’s going to work for older adults”, the document would have been impossible to construct or to understand. So that section you mentioned listed older adults as being a specific concern. Two recommendations have language about older adults – for example, that the HIV testing law should not stop at age 64. And the Blueprint is a living document. We have a committee in the AIDS Advisory Council for people to put new recommendations on the table. We’re happy that the Blueprint generated so much support from the community and that people want to continue working with us on it. People are really invested in making this thing work.

How can SOFA and the AIDS Institute collaborate on HIV and aging issues?

Dan: More concentration on getting the issue out there. We don’t need to create new systems – we need to make sure the systems that are already in place do what they should be doing. We must make sure providers know that taking a sexual history is not just for people in certain age groups – it’s for people who have certain behaviors. The only way to know about their behavior is to ask, and to have an environment that is welcoming and safe. An older adult needs to feel comfortable bringing those issues up. And they may not do that if they get the sense that the provider thinks that sex is over for someone their age.

Corinda: I agree. You don’t want to create whole new systems – that becomes very confusing. Existing senior centers can include information in our education programs, and so can our settlement houses and our supportive services programs. They can all be used to educate older adults, and we can adjust our existing services to allow for the increase in the number of older adults with HIV.

GMHC just restarted its buddy program. Do you think that type of program might be able to give people more informal caregivers, rather than relying on formal networks?

Dan: I think it’s a perfect example of programs evolving to meet the needs of people coming through their doors. The buddy programs were first used when people were extremely sick and there was a lot of isolation. People were afraid to come into contact with somebody with HIV. That’s not the situation we’re facing now. We’re looking at an aging population, so I think it’s pretty smart to use buddy programs to limit social isolation and meet the needs of older adults with HIV.

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There are programs that match up seniors with younger people. Could you see that as another way as enhancing support for adults with HIV?

Corinda: Absolutely, and I see it as a dual track. Not just matching up older and younger people, but also matching somebody who has had HIV for a long time with a younger person who is newly diagnosed. They could provide support for them, especially since we are seeing that older adults are better at adhering to medication. A mentorship model would be a great way to use their expertise to help younger people.

What’s your vision for what NYS should do as the aging of the epidemic continues?

Dan: Addressing the aging of the epidemic is key if we are to reach the historic goal Governor Cuomo has set for the end of 2020. I’m confident that our HIV services will evolve to meet the ever-changing challenges this epidemic presents. The programs we had in the ’80s, when HIV was very often a death sentence, were not the same as they were in the late ’90s, when new medications began to significantly reduce deaths and disease progression. Since the early 2000s we’ve seen new diagnoses fall to levels we never dreamed of, and the changes made in our programs helped this happen. And we’re still evolving. Program changes don’t happen in a vacuum, but as a result of a dialogue among community members, service organizations, and government about people’s needs and the best practices to address them. If there is something we can do better, it is to have the conversation about aging more explicitly and more immediately. We owe it to those who have lived so long with this disease to be ready with care and support services that are both welcoming and age-appropriate.
The NYS Plan to End AIDS relies on increasing the number of HIV-positive people in the state who have an undetectable viral load, since being virally suppressed both improves their health and lowers the chance of HIV transmission to their partners.

Mathematical models estimate that to achieve the state’s goal of only 750 new HIV infections per year, the percent of people virally suppressed will need to be over 80%. Since only an estimated 42% were virally suppressed in 2013, the state had a long way to go to achieve its goal.

But NYS recently lowered its estimate of the number of people with HIV in the state, which significantly increases the percent who are virally suppressed. Let’s examine how that was done.

The Old Numbers

Until July of this year, NYS reported the number of people with diagnosed HIV by looking at the number of people with a confirmed positive HIV test minus the number of confirmed deaths.

In 2013, that was reported to be 134,000 people.

But we know that there are people who have never been tested and don’t know they have HIV. How can that number be estimated?

NYS estimates the number of undiagnosed people by using a study done at Jacobi Medical Center in the Bronx, in December of 2009. Of 3,373 people who were tested for HIV in the E.R., 111 had a positive result. Of those 111 people, only 14 (13.5%) were unaware of their infection.

Based on that one study, NYS estimates that only about 86% of people with HIV in NYS have been diagnosed. So, adding undiagnosed people to the 134,000 diagnosed cases:

In 2013, this led to an estimate of 155,000 total people with HIV in NYS.

The New Numbers

Now, NYS has decided to revise the number of people who have been diagnosed with HIV, using two new criteria:

1. Last address: It was found that about 1,600 people with HIV had moved out of the state, and about 5,600 people diagnosed elsewhere had moved to the state. That leads to an increase of 4,000 people.

2. Last HIV-related lab test: People with an HIV diagnosis who have not had an HIV-related test in the last eight years were presumed to no longer be living in NYS and were dropped. Likewise, people with an AIDS diagnosis who have not had an HIV-related test within five years were dropped. This led to 26,000 people being removed.

So the math works out like this:

| 2013 estimate of people diagnosed with HIV: | 134,000 |
| Added due to address checks: | +4,000 |
| Removed due to lack of HIV-related tests: | - 26,000 |
| New estimate of people diagnosed with HIV: | 112,000 |

Since NYS continues to estimate that only 86% of people with HIV have been diagnosed, the estimate of diagnosed people (112,000) increases to 131,000 when undiagnosed people are added. So the current estimate of people with HIV in NYS has dropped from 155,000 to 131,000 – 24,000 fewer people.

Since all the percentages in the Cascade above are based on the number of people presumed to have HIV, the percent of people who are virally suppressed has now increased from 42% to 54%.

CDC’s Number

To further confuse things, the CDC uses an entirely different method, estimating that there are 177,000 people with HIV in NYS, and that only 7% of those have not been diagnosed. Since that number is used to determine how much Ryan White funding NYS receives (not the estimates done by NYS), federal funds for NYS will not decrease.
Aging by the Numbers

+ 50% of persons living with HIV in 2015 are over 50

+ 70% of persons living with HIV in 2020 will be over 50

1 in 6 HIV infections occur in people over 50

AIDS Diagnosis by Age

Testing by Age

% Condom Use by Age

Male
Female
Newly Diagnosed?
Had HIV for a while but have questions?
Come to ACRIA’s new series of

**Living with HIV**

workshops, designed for people with HIV who want to learn more about how to manage their HIV.

The two-hour workshops are held at 575 Eighth Ave (at 38th St.), Suite 502, NY, NY 10018, at 6 pm.

Topics will include:

- HIV and the Immune System
- HIV Transmission and How Treatment Can Prevent It
- The New HIV Meds: They Ain’t What They Used To Be!
- HIV Drug Resistance and Adherence
- Lab Results: What You Need to Know
- Hepatitis C Treatment Update

Space is limited! Please contact West at 212-924-3934 x134 or training@acria.org to register.

Metrocards and snacks will be provided.

www.hiv-age.org