

Let's Face It:

Older Adults Speak About HIV



AIDS
COMMUNITY
RESEARCH
INITIATIVE OF
AMERICA



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ACRIA: Who we are, what we do

The AIDS Community Research Initiative of America (ACRIA) is a leading research and education organization, working across New York City and State, nationally and internationally to help people with HIV live longer, healthier lives. ACRIA studies new treatments for HIV and hepatitis C, conducts behavioral research, designs HIV prevention and education programs, and operates a comprehensive HIV health literacy program for people with HIV and their service providers.

ACRIA's HIV Health Literacy Program offers curriculum development, social messaging campaigns, and educational materials and publications on a wide range of topics related to HIV, hepatitis C and other sexually transmitted illnesses with a finely-tuned awareness of the diversity and specific needs of people with and at risk for HIV.

For the past 15 years, ACRIA has also provided technical assistance and capacity building to HIV and other service providers (including aging service providers), especially in communities where resources are lacking. Our services are grounded on health literacy principles, and all of our services and materials are available in English and Spanish, with some materials available in other languages.

All stories in this booklet are the words of the writers. Some names and photos have been changed.

About this booklet

This booklet was created to allow the concerns of older adults living with and at risk for HIV to be heard in their own voices. When we put out a call asking for people over 50 to share their stories, we were gratified not only by the response but also by the number who were willing to include their name and photo. They all expressed the hope that others might benefit from their experiences.

From the lengthy stories they provided, we've included sections that focus on twelve issues that ACRIA's research has found to be particularly common. In an attempt to give older adults and their service providers some ideas on how to address these concerns, experts in the field were invited to offer their responses.

In our work with older adults through trainings, technical assistance, prevention, and research, we have seen an increased awareness of the challenges they face. We hope this booklet may offer some guideposts on the next steps that need to be taken by policy makers, service providers, and their clients.

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Introduction

The first decade of the AIDS epidemic was defined by young gay men dying and an activist response to the crisis. In the second decade, people of color and women made up the majority of those newly diagnosed with HIV. At the end of the third decade, effective antiretroviral drugs have transformed the disease into a chronic illness for many.

But we are now facing a new challenge. The CDC estimates that by 2015, 50% of people with HIV in the U.S. will be over age 50. In New York City, as of 2010, more than 43% of people with HIV are over 50 and 76% are over 40.

While new HIV infections do occur in older adults, the primary reason for the growing number of older adults with HIV is the success of treatments that extend life. We celebrate this extraordinary achievement. But this success has become complicated, as shown by the real stories in this booklet.

The issues addressed here were not chosen out of mere curiosity, but reflect the results of ACRIA's research. Our *Research on Older Adults with HIV* (ROAH – www.acria.org/research) study of almost 1,000 New York City residents living with HIV over age 50 established a comprehensive knowledge

base that identified their characteristics and needs. The data provide valuable information useful for developing strategies to sustain their health and quality of life. ROAH shows that older adults with HIV will confront significant social, public health, and medical challenges as they age.

The people in ROAH were mostly long-term survivors, many living with HIV for 15-20 years – a resilient group whose average age was 55. Over 70% lived alone, isolated from friends and families due to the toxic effects of HIV stigma. Most were afraid to tell others that they had HIV, fearing rejection and even violence. Fewer than 15% had life-partners or spouses. As a consequence most had fragile social networks that would be unable to support them as they age. They withdrew, which contributed to rates of depressive symptoms that are five times higher than their peers without HIV. Mental health issues were complicated by the fact that many continued to use drugs and alcohol. Over half of those in ROAH were engaged in drug and alcohol recovery programs.

Ageism often leads to older adults being seen as being sexually inactive or not using drugs. Consequently, they have not been targeted with HIV prevention and education

efforts. But older adults are sexually active – syphilis and chlamydia increased 43% from 2005 to 2009 among people over 55. Unfortunately, many older adults do not perceive themselves to be at risk for HIV or STIs even when they engage in risky behaviors. As few as 25% of people aged 55-64 in the U.S. have ever been tested for HIV.

Older adults pose unique prevention challenges, including discomfort in discussing sex and condom use with doctors and partners. They are often embarrassed to ask for HIV testing. Sadly, providers also have difficulty asking these questions. The responsibility of discussing this issue largely rests with their health care provider, but both doctor and patient are responsible.

The earlier a person is diagnosed with HIV, the better chance that treatment can improve health and extend life. But since many clinicians consider older adults not to be at risk for HIV, symptoms of HIV often are overlooked or misdiagnosed. Early diagnosis is important, since aging with HIV often involves the early onset of multiple illnesses such as heart, liver, and kidney disease, non-AIDS cancers, osteoporosis, diabetes, high blood pressure, and “frailty.” On average, ROAH participants

were managing three other illnesses along with HIV.

Our research and other efforts show that without functional social support from friends and family, these older adults will need costly home health care or long-term care facilities. Will an already overburdened health care system be able to meet their needs? Their life circumstances mirrors the tsunami-like increase in health care demands that will occur as the baby boomers age.

A decade ago, who would have thought that aging issues would dominate the discussion of HIV? As the stories in this booklet show, it's a conversation that is urgently needed.

Hattie



People think nothing of revering old guys like Hugh Hefner who sleep with women young enough to be their daughters. What irks me is that this is only acceptable for old men – it’s desirable and enviable. I used to buy the common prejudice that old women are basically repulsive. I had heard this throughout my life, so it’s no mystery that I was brainwashed into believing these destructive and stupid beliefs. Now, at 74, after over 20 years of sleeping with young men, I am living proof of the beauty and sexuality of the older woman.

Then, out of the blue I got an email inviting me to spend two weeks with him. Two weeks? Wow – maybe my dream was coming true! I arrived and our time together was glorious. It seemed that our love was rekindled and perhaps we would go on to spend a glorious life together.

But after he left for work, I noticed some pieces of paper on the floor. I picked them up, ready to toss them. But they weren’t just scraps – they were labels from prescription bottles that he was throwing out. I had never

“The possibility that I was exposed to the virus frightened me – but even more terrifying was the thought that I could have overlooked having safe sex because it felt as if he truly loved me.”

But I recently learned a lesson that really pulled me up short. I had a superb love relationship until my man moved to the West Coast. I have no idea if it was painful for him, but for me it was agony. I even took an antidepressant to get past my anguish. Like the unrealistic dreamer I am, I held out the hope that one day he would miss me so deeply that he would invite me to join him in L.A.

heard of the drugs, but somehow I had the feeling that he was HIV positive and that this was the “cocktail.” Thank goodness we used condoms, as I knew he was sleeping with other women, and these days we can’t take chances.

When I returned home, I checked with my gay friend who assured me that the drugs were, in fact, for HIV. The possibility that I

was exposed to the virus frightened me – but even more terrifying was the thought that I could have overlooked having safe sex because in our lovemaking, it felt as if he truly loved me. He told me he adored me, treated me like a queen, and responded like a man smitten! When I called to tell him, he assured me he didn't have HIV and that I shouldn't worry. Shouldn't worry?

I took the test, and, thank God, it was negative. But it left me agitated and resolute to warn other women: orgasms last a few magnificent moments – STIs are with us for a lifetime. What feels like love may be lust, which is fine. Just make sure it's protected lust!

Richard Havlik, MD

Hattie's story is both impressive for the sexual energy she displays and instructive about its potential hazards. She confirms what studies tell us: interest in sex does not necessarily decrease with age. In one study, over half of people age 64-75 reported sexual activity in the previous three months, especially if they were in good health. Her use of condoms is important, as older women are at greater risk for HIV and other STIs (sexually transmitted infections) due to thinning of the lining of the vagina. Also, erectile dysfunction may be less common in younger men, which helps with condom use, but it may make their use more difficult for older men.

Hattie had a negative HIV test, but did not mention discussing the risks and realities of the situation with her health care provider. Such a dialogue would have been helpful and made later discussions easier. Her boyfriend likely was HIV positive but not willing to disclose, so she will need to

confront that reality when considering a continuation of the relationship.

If she had discussed this with her physician, she might have been reassured somewhat by new research about HIV treatment and transmission. In a large study of male-female couples in which one partner had HIV and was taking effective treatment, there was a 96% overall reduction in transmission. That's strong evidence that HIV treatment can lower transmission when large groups are looked at. But it does not ensure protection for every individual.

The study also provided free condoms and safer-sex counseling. It showed that early treatment for HIV may be an important prevention strategy. Fortunately, the combination of adequate HIV therapy and condom use appears to have protected Hattie from HIV.

Hattie and other older women deserve the opportunity to enjoy their

sexuality. Certainly, older men have exercised this privilege. Her admonition about "protected lust," however, needs emphasis. Older women need to be empowered to demand safer sex and to know the HIV status of their partners. So, when you have a new love interest, both of you should be tested – just asking if someone is HIV negative is not effective, of course.

"Still got it at seventy!" can become a common and safe experience for older women.

Vaughn



When I found out I was HIV positive, I thought, “But I never slept with a lot of people.” I thought that was what had to happen to get it. Now, I’m like this big tramp. I’m more comfortable in my sexuality. I’m able to say what I want from someone, sexually or otherwise. When I was younger I couldn’t do that. I just did what the other person wanted to do. Now I can pick and choose when I want to have sex.

drink, so my mind is very clear. It wasn’t that they refused to, it’s just that they didn’t. They didn’t initiate wearing the condom, so I didn’t insist. Most guys I’ve been with will say, “Where are the condoms?” but some guys don’t. And if they don’t, I don’t say anything. I let the top take the lead in that.

When I was younger, I was looking for the man of my dreams. Someone once said, “There’s nothing like an old man with a

*“Most guys I’ve been with will say, ‘Where are the condoms?’
But some guys don’t. And if they don’t, I don’t say anything.”*

I don’t feel pressure to have sex if I go to the bars. I don’t feel like I have to go home with somebody. Now, all the men I meet I meet online. I will not get sexual with somebody without revealing my status. But I don’t put my status in my profile – I want people to see me first, and not just my status.

broken heart.” I don’t want to feel that way. I’m too old for that – to be putting my face in the pillow and crying. I do want a companion. A friend, an activity partner. Maybe it is some kind of relationship. But I haven’t formulated it in my head.

There have been a couple of times where I didn’t make the guy wear a condom. They knew I was positive, and they said they were negative. I don’t know how I let that happen, because I don’t do drugs and I don’t

Christine C. Quinn, Speaker, New York City Council

As Vaughn’s experiences show, having safer sex can be complicated by strong emotions. Trust and intimacy can interfere with intentions, along with the partners’ roles. The same roles that heterosexuals may assume can also occur with gay men, where the “active” partner makes the decision about condom use. Men who assume the more passive role may find it harder to insist on a condom, in much the same way that heterosexual women do.

But just as heterosexual relationships vary greatly, so too do gay relationships. Stereotypes about gay relationships abound, fueling homophobia. Not only are they harmful, they’re inaccurate. Lesbian and gay relationships can be short or long, and some people may have multiple partners while others choose to be monogamous.

Regardless of sexual orientation, everyone has their own preferences when it comes to sex, and a person’s

needs may change over time. Both heterosexual and homosexual men can enjoy a wide range of sexual activities. The common perception that gay relationships always involve anal sex is untrue – many gay men do not have anal sex, and need different counseling from those who do.

Staying safe becomes even more challenging for older adults who are facing shrinking social networks and fewer opportunities for sex. While many are satisfied with their support networks, some have less support from families than other older people. This may be the result of tensions when a person reveals his or her sexual orientation. As a result, many older gays and lesbians rely primarily on partners and close friends for social support. In this situation, pleasing one’s partner may take on much greater significance.

Four issues are of particular concern for older gay men and lesbians. First, the health care system has

been traditionally unresponsive to homosexuality. The inability to communicate honestly with a provider can only negatively affect the ability to remain safe. Second, even long-term gay and lesbian partnerships are often not recognized by governments and institutions. This can have a tremendously painful effect. Third, older gay men and lesbians usually wish to live in communities that are either predominately gay or at least sensitive to their needs. But these options are limited. Lastly, individuals who “come out” or explore their same-sex orientation for the first time as older adults may have difficulty meeting like-minded people to help them adjust.

Terry



Back in 1995, I went through a dark period: I was diagnosed with HIV, my partner of 16 years died of AIDS, and a few months later I lost two of my closest friends. I was left without any support system, since I was never really a part of the “gay community.”

I still live alone, but I find that staying involved and giving of yourself staves off loneliness and depression far more than the crutch of alcohol (been there, done that), drugs, or endless therapy.

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The easiest way back in seemed to be to try the bars. But I now know that only fed the depression and left me feeling “passed over” and “too old” at 48. My bar acquaintances were just that: familiar faces but not real friends.

I’m convinced that focusing on people and things outside myself helped fill the void. Handshakes became hugs as fellow volunteers became friends. Self-pity faded and then disappeared.

Finally, I confided in a physician’s assistant about my loneliness, and he recommended a local HIV support organization. A few visits, meals, and a couple of support groups later, I was volunteering as a Peer Advocate. Before long, I headed a committee, and even joined the Board of Directors!

Mark Brennan-Ing, PhD, Senior Research Scientist, ACRIA

Terry's story points out that many people aging with HIV are long-term survivors who have too often lost partners, friends and significant others to this disease. In certain cities that had a high prevalence of HIV, like New York and San Francisco, an entire generation of gay men was decimated before the availability of effective treatments in the '90s, leaving those who were left behind isolated and often without social support.

Unfortunately, other groups aging with HIV have suffered the same isolation due to the loss of parents, children, or partners from HIV or other reasons, such as being incarcerated or using drugs.

Still others self-protectively withdraw from society because of the stigma attached to HIV and fears of what would happen if their HIV-positive status were disclosed to others. And many face additional isolation because of their age in our

youth-centered society, with this ageism being particularly visible in the gay community.

Our research has found that people aging with HIV are often challenged by inter-related issues of depression, stigma and loneliness. In a recent study, we found that a third of adults over 50 with HIV were extremely isolated, without friends, and virtually cut off from family members and their communities.

Not surprisingly, these individuals reported high rates of loneliness, depression, and HIV stigma. In another ACRIA study for treatment of depression, almost everyone who enrolled was extremely socially isolated.

While this sounds grim, our work has also found some cause for hope. During a recent ACRIA study of depression in older adults with HIV, people who participated in group sessions became friends and rebuilt

their social networks, maintaining contact by phone, visiting each other when sick, and helping each other when possible. As they became less isolated, they were less bothered by depression and loneliness.

So when given a chance in a safe, non-stigmatizing environment, even the most isolated and depressed of those aging with HIV can break out of their situation and have a better quality of life.

We need more programs to help people aging with HIV end their social isolation and reconnect with their communities. Unfortunately, depression and stigma make it very difficult to overcome isolation. If you are feeling lonely and isolated, let someone know and ask for help. As Terry's story shows, reaching out and getting involved can help individuals become less isolated, feel better about themselves, lower feelings of sadness, and enjoy what life has to offer.

Vincente



My doctor is very personal, very involved. But he can scold: “If you run out of meds, you’re supposed to call me!” He stays on you, and I guess I don’t want to be scolded so I just don’t tell him when I miss doses. I just let them think I’m taking them.

He’s much younger than me, and I’ve had to tell him a number of times, “You need to listen to me.” Because he doesn’t always want to listen. He has a thing where he just says,

talked to me. I kept saying, “Talk to me as if I’m an adult. I’m not a child – tell me. That way I can deal. If you hem and haw and hide behind big words, I will panic. You have to talk to me. And you have to let me talk.”

That’s something I can’t tolerate – treating me like I’m stupid. It gets under my craw. Like I can’t understand medical jargon.

“I want a doctor who sees me as a complete person. Talk to me like I’m an adult, not like I’m a child.”

“I’m the doctor and you do what you’re told,” as opposed to just listening. I had to write him a letter to say that even my students sometimes just need to talk. They may not like something I say or do and, yes, I am the teacher, but sometimes to help them to understand I need to step back and listen.

I want a doctor who sees me as a complete person. Talk to me like I’m an adult, not like I’m a child. When I found out I had cancer, I had a problem with the way my doctor

Monica Sweeney, MD, MPH

Assistant Commissioner, Bureau of HIV/AIDS Prevention and Control,
NYC Department of Health & Mental Hygiene

Vincente tells a story that is not uncommon. I've known health care providers who talk to the person with the older adult instead of the senior. So we used to sit with clients and say, "Can we practice what you will say to the doctor next time you go? Let's try to find a way to change the way you're being addressed so you can do what's in your best interest."

People sometimes withhold information because they feel judged by their providers. But once clients know you're interested and are doing things for their benefit, things change.

One clinic I worked at put up a big sign, "Come in and talk to us about Viagra." An older man came in to talk about a wart on his hand, and when we finished I said, "You're the first man who's come in who didn't want to know anything about Viagra." And he said, "I do!" I could

tell that there was more to his visit than the wart. Patients need to feel you care about them as a person.

We need to find a way to be more people-centered to get over these hurdles. If I was ever embarrassed by a patient's question, I would say, "No one's ever asked me that before! That really took me back, so give me a second." And people appreciate that kind of honesty. You're not "up here" in some ivory tower and they're not "down there."

I was going over the lab tests of an older man with diabetes and said, "Something here doesn't make sense. Are you taking your insulin?" He later told me that's when he knew I was going to be his doctor forever, because he hadn't taken one bit of insulin from the day he was discharged from the hospital. He had been drinking before he ended up in the hospital with high blood sugar, so he was sure he wasn't

diabetic. He filled every prescription, but no one had ever asked him if he was taking his medication! We need to create the kind of personal connection that allows people to be honest with their clinicians.

David



When I approached my 50th birthday, I was in a state of limbo. On one hand I was happy about still being HIV negative and reaching an age that most of my friends and lovers never did, having lost their battle to AIDS before they reached 30. But I was depressed because I could count on both hands the number of people I wanted to invite to a birthday bash. So I turned 50 at home with my godson, and we just ate dinner and watched television.

enjoy my own company. But as a person who lives alone, I often skip cooking for one, which causes poor eating habits.

In the past few years, I've faced becoming older and not being able to share the "old stories" with anyone who knew me when. I have to deal with the sense of loss that I have been avoiding for years. I recently saw *Priscilla: Queen of the Desert*, and was so happy to hear the music of my coming-

"In the past few years, I've faced becoming older and not being able to share the "old stories" with anyone who knew me when. I have to deal with the sense of loss that I have been avoiding for years."

I am no longer involved with organization such as GMAD and GMHC for the simple fact that I am burnt out. My social life now consists of having dinner with family members that I ignored during my wild and crazy days. Since I have become a reclusive, mature gay man, I only socialize when I am volunteering at cultural events or organizations. I actually am learning to

of-age years, like "I Will Survive" and "I Love the Night Life." But I was with a young family member who could not share the stories of what we did when those songs first graced the dance floor in the Disco Era.

I have chosen a kind of self-imposed isolation. I have dealt with sleeping all day and staying up to the wee hours of the

morning. I have dealt with not wanting to eat, incontinence (which limits my socializing), and always needing access to a public restroom. This has also spilled over into my dating. I'd just rather not put myself through the issue of having to explain everything to a potential partner.

Stephen Karpiak, PhD, Associate Director for Research, ACRIA

Although David is HIV negative, he faces challenges that our research has repeatedly found in people aging with HIV. The lack of a social network can be traced to the absence of spouses, partners, children, and other relatives, and the fact that HIV has often claimed many friends, particularly among older gay men. Older adults with HIV may find themselves with fragile social networks and feeling increasingly isolated. Still, they have much to share and want to be supportive of others, and like David are looking for the evidence of self-worth that age, homophobia, and HIV stigma have damaged.

Isolation contributes to poor physical health – not to mention sexual health – especially for older adults with HIV. Passivity will not solve these challenges. We must be proactive. AIDS service organizations need to partner with older adults, taking the time to listen to their needs and develop programs that will help them to socialize.

Their health depends on addressing their isolation.

When a person with HIV is younger there are many outlets for socializing. But as they age these options may become fewer. In one of ACRIA's recent research efforts, socialization was the number one reported need by older adults with HIV. The buddy systems of the '80s, as well as phone trees, connected isolated people with HIV to the outside world. Similar programs need to be created, tested, and implemented to address the problem of isolation today.

There is an interdependence that exists between older people and their families and friends. This is often absent for older adults with HIV and for the older LGBT community. This challenge also occurs in the larger society, as family members move away or families break up due to divorce.

Service providers and the community need to create a culture that places

value on older adults and intergenerational support. Resources, technology, and the creativity that once pervaded the gay community must be called upon to address the human need to be connected. Those of us who work in HIV are aware of the joys of diversity and inclusiveness. Sadly, those we serve are too often left out of the rich fabric of that network.

Carolyn



I think it is easier for older men to find partners. Men can usually find a woman with low self-esteem who will accept whatever they are offering. Gender inequality issues do not stop at age 65, nor do sexist attitudes. Most people do not realize that older people need love, relationships, and intimacy just like everyone else.

fueled drug addiction and drug addiction fueled lust.

Now I don't feel lustful like I used to, but I do wish that there was someone who shared my interests and who would find me appealing and a joy to be with. And I think it is just as difficult for older men who are looking

“I think it is easier for older men to find partners. Men can usually find a woman with low self-esteem who will accept whatever they are offering.”

Although I have not been sexually active for more than seven years, there was a time when I was very active. Like so many women's relationships, mine was quite dysfunctional. In fact, I saw dysfunction in the relationships of my grandparents (they were married 65 years and my grandmother was abused the entire time) and my parents.

The thirteen years of my marriage and then ten more years with a different partner were never what I thought love should be. In both relationships, each of us was struggling to overcome various experiences and addictions. We were addicted to sex, drugs, and dysfunction! For several years, lust

for a committed and quality relationship. If I were to meet someone, I would not be concerned about HIV or other STIs because I would disclose my status if the relationship became serious. I don't engage in casual sex, so that's not an issue. If we were intimate, we'd absolutely use protection. I am willing to use the female condom – in fact, I look forward to it one day!

Maria del Carmen Arroyo, Chair of Health Committee, New York City Council

People aren't well informed about the challenges and issues older women face when it comes to sex. We don't want to talk about it – it makes us uncomfortable. A few years ago, my husband kissed me, and my 17-year-old son said, “Ewww!” And I was 43 at the time! For some reason we just don't think about older people having sex, and that's part of the challenge of this conversation.

And the conversation has to happen in different settings. It can't just happen once at a senior center and never again. It has to come from health care providers, social service providers, senior centers, case management programs, churches – wherever the audience is.

There was a gentleman in a senior center who died of AIDS. He was also really busy in the building, because he was one of the few men who was available and interested. It was

a rude awakening to discover that he had been involved with at least seven women. No one knew, because there's often the attitude that, “We are ladies, we are not promiscuous. If I'm having sex and I'm not married, I'm loose.” They want to be seen as “Doña” and very proper. “Talk to me about a condom? I don't need to use a condom.” That's the persona they feel the public has to see.

Older women outnumber older men by a significant number. So the opportunities for sex may not be regular – it may be someone just coming to chat and it ends up being sexual. Women who are not in regular relationships, who are widowed or divorced, whose partner is incarcerated – whatever the reason – need to be prepared for those unexpected encounters. Women may feel that being prepared makes you a different person. If you have sex spontaneously, that's different than having condoms ready.

In a perfect world, your provider would have this conversation with you – that's a good start. But that often doesn't happen. If I'm a young doctor who just came to this work, and I'm seeing a 79-year-old patient, I don't know that I'm going to feel comfortable having a conversation about sex: “You have a partner – do you know where he's been? What precautions are you taking?” But often the conversation never starts.

If your provider brings it up, that means you're still in the group that's having sex. But often it's not discussed. Society reinforces that you're supposed to be over it. And people somehow think that age is a vaccine – that it protects you against the things that happen to young people, or that it doesn't happen to your group. Whether it's class or age or race, somehow you're separate and apart. A lot of older people are guilty of that, and we need to let them know that we're all at risk.



I've had a problem with drinking, and spent time at Alcoholics Anonymous to get it under control. I like being in a 12-step program where I can share what's going on in my recovery, and hear others' stories as well. I don't drink anymore, and now I can go into bars with social groups and just have a soda, which is more refreshing for me. I'm aware that alcohol can have negative effects on medication in the body so I don't want to mess with my health that way, either.

surprise. For years, I had been tested regularly. I had sex with men I knew had HIV, but we had always used protection. But I admit I may be looking for love in all the wrong places, especially as I grow older. And, my attractions are to younger guys.

I'm not as sexually active as I was when younger, and it dropped more dramatically after reaching 70. Sometimes I think that not having sex at all is a way to avoid any

“I had a few too many beers and it got in the way of thinking clearly. I had sex with a guy I met in a bar out there, and we didn't use a condom.”

A miscalculation made after drinking a few beers during a trip to the Northwest was likely to blame for my getting HIV. Yes, I had a few too many beers and it got in the way of thinking clearly. I had sex with a guy I met in a bar out there, and we didn't use a condom. Even though I knew all about HIV and had talked a great deal with the AIDS service organizations in my community, I made that mistake and became infected. It was a complete

sharing of the virus, yet I do like just cuddling or body massage as an alternative. I tell anyone having intimacy with me that I am HIV positive. Usually, there's no negative reaction to that, but I've had experiences with guys who are immediately repulsed. While I feel rejected, I also know that it's the other person's lack of sex education and, maybe, ignorance.

Allen Kwabena Frimpong, Harm Reduction Coalition, New York City

The most important parts of Lee’s story are his acknowledgement of his struggle with alcohol and how his desire for sex with younger men affected his ability to stay safe. Sometimes providers find it difficult to create a space where people can disclose their risk behaviors, especially if they are already HIV positive and must daily overcome stigma and disclosure issues. The judgments made about older adults and what activities are deemed appropriate for them – like sex with younger men or with men who are already HIV positive – only compound these issues.

We have been bombarded with messages like “Just Say No”. But when a person dealing with alcohol use and unsafe sex walks into a clinic or agency, providers must ask, “What kind of environment am I creating? Will it help, or create barriers to discussing their

risk behaviors? What are the possible steps to safer sex and drinking practices?”

Harm reduction is a strategy that aims to help people lessen or eliminate some or even all of the harms associated with substance use. It does not work from a “disease” model, but deals holistically with the reality of their circumstances. Engaging clients about their experiences with drug and alcohol use and their impact on sexual behaviors is important when working with them toward healthier lives.

People can have the resiliency to overcome the behaviors that put them at risk for HIV due to substance use. For people with HIV, alcohol can interfere with adherence to HIV treatment and can cause liver complications, affecting how meds are broken down by the body. This can worsen the side effects of their meds. Providers can

create a game plan, pose questions, and help people sort through their options: when they drink, how they drink, why they drink, and what can be done to reduce the chance that their alcohol will be a barrier to HIV prevention and treatment.

Douglas



I'm dealing with HIV, depression, kidney cancer, high blood pressure, lipodystrophy, and now my doctor tells me my cholesterol is going up. I'm supposed to take medication for it, but I won't. I have to take five different medications just for my blood pressure because it won't control itself. Now I have to go to a retinologist because the blood vessels in my eyes started to burst from the high blood pressure.

Part of my problem is that I refuse to deal with my conditions. I just take the medicine and that's it. Or sometimes I won't take

I'm 52 years old and my parents are in their 70s, but when we talk it's like I'm in my 70s with them. All the different medications I'm taking, all the doctors I have to see. And then there are things the medications are messing with. Like, it's hard to get an erection, I have stiffness in my legs, dry mouth, my feet and hands swell, I have to take naps – so with all of that going on, to try to work is very difficult. That's why I'm not working – the meds have affected me that way.

“I'm 52 years old and my parents are in their 70s, but when we talk it's like I'm in my 70s with them.”

it because I just have to take too much. I mean, five blood pressure medications, two anti-psychotic medications, three antiretrovirals, something for cholesterol – when I get tired of taking all of them, I just won't do it. And I haven't told my doctor. But then something happens. You know, I can't feel the high blood pressure so it doesn't really bother me. But when I don't take the meds, I know because it feels like my heart is going to come out of my chest.

Jerry Ernst, MD, Medical Director, ACRIA

HIV, depression, kidney cancer, high blood pressure, lipodystrophy and high cholesterol. That's a lot. Enough to make anyone depressed.

In fact, older adults with HIV often find themselves facing HIV as well as heart problems, cancer, diabetes, bone fractures, and depression.

ACRIA researchers and others have found that people over 50 with HIV have on average at least three conditions in addition to HIV. This is three times greater than what is seen in adults over 70.

Many people with HIV have had a good response to antiretrovirals, essentially turning HIV into a chronic disease, and their care has been taken up by the primary care providers (PCPs) who are best suited to the task. Specialists, such as infectious disease physicians, have either become PCPs or have become consultants for those needing more specialized HIV care. People with multiple conditions

(“comorbidities”) who are under the care of an infectious disease specialist should ask if that doctor is interested and has the time and skills to care for their other illnesses. If not, they should ask for a recommendation to a good PCP or seek other sources for a referral.

Whether or not HIV advances the ailments of aging, their management is something PCPs are well trained to do. Time that used to be spent dealing with the complications of uncontrolled HIV disease now needs to be dedicated to managing other conditions and illnesses. Those who provide medical care, however, will need to change their health delivery approach from focusing on one illness, defined by CD4 counts and viral loads, to the management of many chronic illnesses.

ACRIA's research has also found that multiple health problems and depression are strongly related. And the single best predictor of

nonadherence to HIV treatment is depression. We need to change how care is provided for older adults with HIV and to address pre-existing mental health issues. Depression must be managed if better health outcomes are to be achieved for those with HIV and its comorbidities.

While the visits to different specialists may appear to be a burden, they need not be frequent. The PCP's role is to manage all of these conditions with advice from the specialists. Chronic diseases require regular attention to how patients are living with their illnesses. There are no easy or quick solutions. A caring PCP, specialists, and good health insurance are all essential to managing multiple comorbidities.

Anna



My gynecologist never expressed any concern about my risk for STIs, even after my husband died. I think she simply assumed I was not sexually active because I was a widow. When I asked to be tested, she sent me to a public health clinic because she wasn't sure if my insurance would cover the test.

The people there approached me as if I were

not allowed to leave until I assured them that I had support at home

But I was never offered an HIV test before I asked. When my brother asked for a test, his doctor said it wasn't needed since he was married. My brother insisted, because I had just disclosed my status to him and he was married to his third wife.

“I was never offered an HIV test before I asked. Most doctors I’ve seen do not think patients over a certain age are at risk. Before my test, I had never received any counseling about risky behavior.”

extremely promiscuous, and seemed to think that anyone who entered the premises was a prostitute, drug user, or homeless. I was asked invasive and rude questions about my sexual activities, so I walked away without getting tested.

Five years later, when I turned 59, I began to suffer from fatigue. I went to a different provider and asked to be tested, and I was treated humanely. When they told me I was positive, I was offered counseling and I was

Most doctors I’ve seen do not think patients over a certain age are at risk. Before my test, I had never received any counseling about risky behavior. But I knew I was at risk because I had a partner who was hospitalized with pneumonia. When I asked whether he had HIV, he was honest – but I had to bring it up. I’m not sure if he was ashamed, embarrassed, or simply thought I’d be angry and abandon him as his wife had.

I think most doctors are uncomfortable asking someone who is old enough to be their parent or grandparent questions about their sex life. Although I have no problem discussing this with them, I usually have to initiate the conversation. Many doctors I've seen assume that older patients do not engage in substance use or risky behavior, or that they know about the risk factors, but I find that seniors are often the least educated about HIV and STIs.

Monica Sweeney, MD, MPH, Assistant Commissioner, NYC DOHMH

Anna's story reveals how uncomfortable some providers, and people in general, are with older adults who are sexually active. I recall asking a class of high school seniors, "At what age do people stop having sex?" Their answer? 40! Then another group said, "That's wrong!" And guess what they said: 45. So, we as health care providers, have a lot of work to do on ageism and sexism.

And I don't want to pretend it's just the students. I recall one young doctor who thought that asking if you were married was a sexual history. Older people have ageist and sexist attitudes, too – if you don't bring up the subject, they don't feel free to talk. But once you do, and make them feel comfortable, they tell you everything. So we need to make it easier for older people to talk about sex. Asian clinicians have asked me about the new HIV testing law, because if they offer an HIV test to 60-year-olds, their patients are insulted.

When I want to bring it up, I say, "There are some questions I want to ask that

may make you uncomfortable, but let's just do it and get it over with. And if you forget anything, tell me later." I put it out there at the beginning of the conversation. And once I ask, older people want to talk about their sexuality. They still have needs. They often don't have regular partners, or they have biological issues – women who are post-menopausal, men who have problems keeping their erection with a condom – all of these things came up all the time in my practice, because we created an environment in which people could talk.

We also changed our intake form to include sexuality. In the "activities of daily living" section, we added a question about sexual activity – it's a natural flow in the progression. There should be posters, too. The day after we put up posters about domestic violence, the number of clients who talked about it increased by 50%. Just putting up a poster in the waiting area gave them permission to talk about it.

Rayford



About 16 years ago, when I turned 48, I began to have anxiety and feelings of guilt, worthlessness, and hopelessness. It took a month before I was diagnosed and got on medication for it. I was probably susceptible to it due to early childhood trauma – my mother was killed in a car accident when I

become irritable. And my definition of safe sex begins to wobble.

But with help from great doctors, therapists, medications, family, friends, and dogs, determination, luck, and, I guess, genes, I'm alive, healthy, and have a great job working with great people, and I've been able to work

“Sometimes I see beautiful younger men there, who are healthy and happy, and I just stare. They rarely look back, except to express irritation that I’m staring at them. I don’t feel 64 inside.”

was 11. I’d had a therapist off and on since I was a senior in high school because I was worried about my sexual feelings. But major depression was another animal. It came on like a horror movie.

Soon after I began taking Zoloft, my psychiatrist decided I had bipolar II, which is mostly depression but occasionally leads to flights of mild mania and compulsive behavior. When it happens, I spend too much money, buy lots of books and tickets to things, get grandiose, think I am always right, and

full time throughout the epidemic. After losing two partners to the plague, I met someone online, and we’ve been together nearly five years. I began facilitating a support group for recently diagnosed people with HIV and another one for gay men over 50. I started going regularly to a great, gay-affirming, social justice-focused church.

I’ve got a lot of scars, inside and out, but I decided to make the most of what is left of me and started working with a trainer at my gym. Sometimes I see beautiful younger men there, who are healthy and happy, and I

just stare. They seem like gods from another planet. They rarely look back, except to express irritation that I'm staring at them. I don't feel 64 inside. I have to look in the mirror to remind myself.

But, there's so much suffering in the world it seems like it's on fire. I'm still here and I feel like I should just stop the negativity and join the water bucket line. Figuring out how I can be the most help, put aside the delusions of grandeur and feel good knowing I'm doing what I can – that's harder.

David E. Vance, Ph.D., MGS

As Rayford's story shows, aging with HIV presents its own set of challenges. In addition to keeping track of medication schedules, understanding lab results, and worrying that something may go wrong, people have to confront stigma, changes in appearance, and intimacy issues.

HIV can seem like an insurmountable obstacle. And true, once you have it, there's no getting rid of it. But instead of focusing on what they can't do, many people are successfully aging with HIV by focusing on what they can do. They can take their medications consistently. They can exercise. They can eat well. They can get enough rest. And most importantly, they can keep a positive outlook on life. It is these simple things that help to maintain good mental health.

Good mental health is essential in confronting stressors like financial concerns, relationship problems, or HIV. "Hardiness" is how we describe the ability to maintain good mental

health in the face of these stressors. Studies show that those who are hardy have a better outlook on life and a stronger immune system than those who are not.

Studies also show that hardiness can be developed. One way is to have a steady diet of positive thoughts from inspirational readings, humorous books and movies, uplifting music, and prayer and meditation. Another way is to surround yourself with hardy people, such as a support group, social club, or religious organization. In fact, many adults aging with HIV find spirituality to be a strong source of hardiness and well being.

In one study, I interviewed 50 older adults with HIV and asked them if their spirituality changed after being diagnosed – 72% said yes. I then asked if they considered HIV to be a blessing. I was astounded to find that 44% did! When I asked them why, they told me that HIV helped them to appreciate life more – they couldn't

take it for granted. They had to dig deeper into their faith to find what was truly meaningful in their lives.

When I analyzed the data further, I found that those who found HIV to be a blessing were also the ones more likely to consider themselves to be aging successfully with this disease. Clearly, a positive and hardy outlook on life, whether one has HIV or not, is essential to living well and aging successfully.

Charles



Living with HIV is a challenge, but as a black man in his mid-50s I'm reminded every day that I can't take my civil "rights" as a given. The reality for people of color with HIV is far different than that of whites. Most black folk I know are barely scraping by, and to pretend that race doesn't affect who is poor in America is naive at best and racist at worst. The fact that virtually every black American will experience poverty at some point speaks volumes about AIDS in America.

I recently was asked to participate in an HIV research study. At the end of the interview, the researcher asked me if I had any questions. I sure did. But when I asked them, he looked at me and said, "Someone of your race and age usually doesn't ask those questions." Should I have apologized for not fitting his stereotypes?

The head of one AIDS organization I worked for never called me by my name for the entire year I worked there. I had so unconsciously accepted this insult that I never

"One of the nurses said, 'You are so articulate!' On the surface that sounds like a compliment, but the hidden meaning behind it – the condescension – is highly offensive."

Each year, I see more friends in my age group being diagnosed with HIV. When I go to the clinic, it seems like everyone looks like me. The last time I went, one of the nurses said, "You are so articulate!" On the surface that sounds like a compliment, but the hidden meaning behind it – the condescension – is highly offensive. I feel like a perpetual alien in my own country. The same goes for, "Where did you learn to speak English so well?" Need I say more?

gave it a thought until I left that job. I now see it for what it was: a slight that in essence enabled a white man to not fully acknowledge my status as his equal. Not calling me by my name rendered me invisible and of little consequence, and constantly reminded me of my subordinate role.

Finally, I was passed over for a promotion that I had been promised. It was instead offered to a white co-worker I had trained and mentored. He was told not to reveal the

backdoor deal to me. But one night he got drunk and told me the truth.

Despite these daily reminders of racism, I've developed my own coping toolbox. Aging has afforded me resilience and resistance. I refuse to be defined by those who require invisibility and subordination. I expect the insults and aggressions, yet as I mature I also know how to reframe and deflect. In America, race, ethnicity, age do have an impact on the information we receive, the services that we receive, and our health outcomes.

In the words of RuPaul: "Your opinion of me is none of my business!"

Luis Scaccabarozzi, MPH, Director of HIV Health Literacy, ACRIA

People of color make up about 28% of the U.S. population and more than 15 million of them are unable to speak the same language as their health care providers. While the health of people in the U.S. has improved over the past few decades, not all have shared in these improvements. About 17% of Latinos and 16% of blacks report fair or poor health, compared with 10% of whites.

Studies have found that African American and Latino men are less likely to disclose their HIV status to friends than white men. At the same time, they receive significantly more support from family members. This is not surprising, since it has long been known that the immediate family is a strong source of emotional support in their communities. Unfortunately, when racial identity combines with HIV, it creates a "double stigma" that can be difficult to overcome.

The fact that blacks take longer to seek HIV medical care and have lower CD4 counts at the time of diagnosis speaks to issues of stigma, poor access to care, and mistrust of the medical establishment. Even when they are receiving care, people of color are less likely to take HIV medications.

Recent studies have found a link between poverty and HIV in America's urban communities, and communities of color are disproportionately affected by poverty.

Many older adults face harsh economic realities, with 19% living in or near poverty. Older adults of color have long been affected by poverty, especially women, with 54% of black women who live alone falling below the poverty line.

It's impractical, if not impossible, to understand every aspect of cultural influences. Instead, providers should look at the cultural challenges that

are likely to arise and address them as they appear. Misunderstanding often reflects differences in cultural values, and can range from mild discomfort to a major lack of trust that disintegrates relationships.

But if these issues are recognized, providers can ask clients about their beliefs and values, and begin a valuable conversation that will help both client and provider achieve better health outcomes.

Lorena



I was a sex worker for 15 years, and along with being transgender, I've struggled with substance use and mental health issues. In 1998 I was diagnosed with HIV and AIDS at the same time. At my first clinic, I had problems because the nurse who worked there never called me to arrange appointments. When I asked why, he said, "I did call you. I think you're having problems with your memory because of your homosexuality."

and said, "Is this a man or a woman?" Instead of looking at my file and seeing that I preferred my female name, he used my male name in front of everybody in the waiting room.

I keep silent when they call my male name. I wait a few minutes and then go up to the desk and ask if I was called. When they ask my name, I say, "It's Armando, but I would like to be called

"When I asked the nurse why he hadn't called, he said, 'I did call you. I think you're having problems with your memory because of your homosexuality.'"

Also, every time I was admitted to the hospital I would be placed in the men's section because they said I was not a woman. I don't feel comfortable being placed in a room with another man. Then they would ask how many partners I had sex with and how many were unprotected. If had six or eight partners, they would suddenly put on rubber gloves and treat me differently.

I recently went to a new doctor, and although my female name is on my file, he didn't use it. He looked at me

Lorena." Often they won't do that – they say they can only use the name that is on my Social Security or Medicaid cards. They won't put my preferred name in the medical file. So I won't go back to that clinic, because it's embarrassing. It's psychologically damaging, being called by a name I don't want.

Many transgender people don't have health insurance because they use a different name or can't find jobs. And once we do find a clinic, we're often asked too

many questions about being transgender or are rejected because we are.

We need a place just for transgender people who are aging – a community center where we can gather and socialize and enjoy activities. A lot of us who are positive and over 50 have no means of socialization and we just remain at home with little contact. So once a month, I run a small support group where people share their own story. When I tell mine, others talk about their own experiences living with HIV. The good thing is that many who are recently diagnosed turn to those of us who have had it longer for advice and support.

Tarynn M. Witten, PhD, LCSW, FGSA

Lorena's story is not uncommon in the transgender community. Stories of trans-abuse by health care workers have been well documented in the scientific literature. What was once anecdotal is now backed up by solid evidence.

But the experiences of transgender people remain sorely lacking in studies on LGBT aging. To complicate things further, older adults may not identify as transgender, as this term has only recently entered the mainstream. Consequently, it can be challenging to provide adequate services for “gender-different” older clients who are at various stages in their transitions. In addition, many may not wish to be identified due to a lifetime of fear.

Transgender people who don't visibly conform to gender norms face particularly difficult psychological, medical, social, and economic barriers when accessing health services,

since they cannot easily alter their transgender status to match the perceptions of their providers. This lack of sensitivity means that they are more likely to delay the care and medications they need – particularly dangerous for those with HIV.

Since we are only now seeing a substantial number of older transpersons, very little is known about the interaction of aging, disease, and longevity among trans-identified individuals. Long-term hormone use, along with normal aging processes, can create a complex set of health issues. Interactions of hormones and medications might also be problematic. Adding the effects of HIV clearly makes matters worse.

Medicare, which many transgender people rely on for their health care, generally does not cover medical care related to their gender needs. This means transgender older adults who have taken hormones for years may

suddenly find they cannot afford them, despite the fact that abruptly stopping them may be physically and emotionally traumatic. As a result, there is now increasing anecdotal evidence of the phenomenon of “de-transitioning” and even suicide as a way to avoid the fear of the future.

Transgender seniors face many forms of stigma. Aging, racial expectations, dress, hormones, surgery, and the subsequent expectations of health care workers require trans-community members to be vigilant with respect to their futures if they are to age with honor and grace.



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ACRIA is an independent, not-for-profit, community-based AIDS research and education organization committed to improving the length and quality of life for people with HIV through medical research and health literacy.

We provide essential HIV health and prevention information to disadvantaged people and communities around the world; conduct group- and individual-level self-management sessions for people living with HIV and hepatitis C; undertake primary and secondary prevention campaigns; and strengthen community-based groups across the U.S., Latin America, and the Caribbean through a program of tailored capacity building, technical assistance, and training.

Additionally, through its Center on HIV & Aging, ACRIA is a recognized leader on the emerging issue of older adults and HIV. ACRIA's Older Adults Training and Technical Assistance Program offers similar services locally and nationally with a focus on the prevention, treatment and care needs of older adults at risk and living with HIV.

To learn more about ACRIA's research studies or the HIV Health Literacy Program, please call or email us at treatmented@acria.org. Information about our programs and copies of all of our publications are also available on our website, www.acria.org.

This booklet was funded by the New York City Department of Health and Mental Hygiene.

Free distribution of this booklet was made possible in part by generous donations from U.S. government employees to ACRIA through the Combined Federal Campaign (CFC). CFC #11357

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