

GROWING OLDER WITH THE EPIDEMIC: HIV AND AGING



FIGHT AIDS. LOVE LIFE.

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Executive Summary

As we approach the fourth decade of the HIV epidemic, about one-third of all people living with HIV/AIDS in the United States are 50 years of age or older, a figure that will grow to one-half by 2015. The development of Highly Active Antiretroviral Therapy (HAART) in the 1990s changed what it meant to be diagnosed as HIV-positive, making it possible not only for people to live with HIV, but to thrive well into their 50s, 60s, 70s and beyond. This is a remarkable transformation of a situation that not so long ago was fraught with panic, stigma, fear and the overriding reality of suffering and death. “Living with HIV”—an unthinkable notion in 1981 when the epidemic first emerged—is more and more the usual course of events.

This is a welcome development, but aging with HIV also brings another set of issues to the table. Some are common to those faced in managing of any chronic condition or late-in-life illness, which present a growing challenge to the health and human services system across all sectors, at all levels. In the case of HIV, the ultimate effect of years or even decades of HAART on bodies and lives is still unknown, and the situation only becomes more complicated when we add to the mix the general physical and social effects of aging itself. The specific demographics and characteristics of people living with HIV and AIDS present other issues related to the provision and delivery of services, the regulatory frameworks that govern elder care, and the appropriate training of caregivers and social service professionals. Growing older with HIV brings us into uncharted territory and requires a thorough consideration of what lies at this intersection and how we can best meet the challenges as they appear.

This paper details what we know about HIV among older adults, what we do not yet understand, and what improvements can be made to better prepare the country to care for this population.

- The first section provides an overview of epidemiological trends, including disparities across race and sexual behavior. Here we look at the impact of HIV testing, the role of medical providers, and data about the sexual behaviors of older adults that put them at risk for HIV.

- The second section examines what we know about the biological impact of HIV on aging bodies (including mortality, drug interactions, and impacts on the heart, brain and liver) and comorbidities (such as cancer and other conditions associated with aging). We follow with a review of current research on HIV and aging supported by the National Institutes of Health (NIH), as well as recommendations for research moving forward.
- The third section looks at the context in which older adults with HIV live, including the multi-faceted impact of HIV- and sexuality-related stigma.
- The fourth section discusses social service and healthcare programs designed to care for older adults and people living with HIV (including the Older Americans Act, Medicare, Medicaid, Social Security, Veterans Affairs, and the Ryan White Treatment Expansion Act) and the extent to which they meet the needs of people over 50 living with HIV.

At the end of each section, we provide specific policy recommendations. These are also summarized in a separate section at the end of this paper.

Key Terms

Antiretroviral Therapy (ART): Treatment with drugs that inhibit the ability of retroviruses, such as HIV, to multiply in the body.

Highly Active Antiretroviral Therapy (HAART): Uses a combination of drugs to attack HIV at different points in its life cycle. Sometimes referred to as “cART” (combined Antiretroviral Therapy).

Growing Older with the Epidemic: HIV and Aging

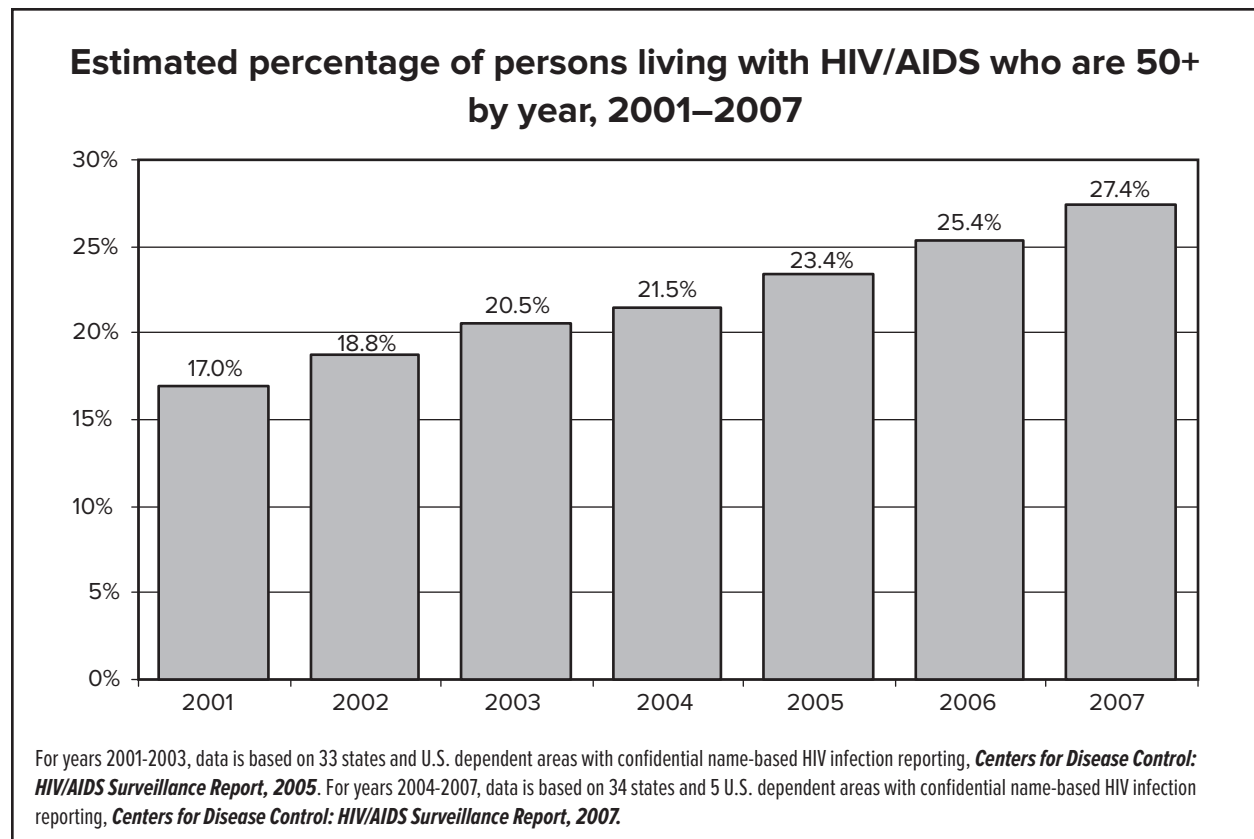
Antiretroviral therapy has been a lifesaving development for people living with HIV. Though life expectancies for people living with HIV/AIDS remain lower than for the general population, the drugs have turned what was once a deadly infection into a chronic, manageable disease. As a result, HIV-positive individuals are living longer than ever before.¹ According to one estimate, more than half of all HIV-positive individuals in the United States will be 50 or older by 2015², but increasing longevity is not the only reason that the population of people over 50 with HIV has been increasing so rapidly. New HIV diagnoses are rising among older adults as well, and this graying of the HIV epidemic has many clinicians and researchers concerned.³

Increased life expectancies bring a suite of new health problems that involve complex interactions between the virus, antiretroviral therapies, the natural aging process, and in some cases, other behavioral risk factors. Some evidence suggests that HIV accelerates the

aging process, and both aging and HIV infection dramatically influence the immune system.⁴ It is well-known that older people in general have more chronic diseases. Finally, we have limited knowledge about the effects of long-term exposure to antiretroviral therapy, drug toxicity, and drug-drug interactions; though much has been documented in research, there is still much to learn. Consequently, service providers will have to manage HIV in the context of a host of other conditions.

I. Epidemiological Data

The number of people in the United States over the age of 50 who are living with HIV/AIDS is growing rapidly. From 2001 to 2007, this segment of the HIV-positive population increased proportionally by over 61%, going from 17% of the HIV-positive population to about 27%.⁵ In New York City from 2001 to 2007 the percentage of people with HIV/AIDS over 50 went from 22 to 35%, an increase of 59%.⁶ In 2007, the last year for which we have figures, people over 50 made up 38% of deaths among those living with AIDS



in the United States.⁷ By 2015, people over 50 will constitute the majority of all people in this country with HIV/AIDS.⁸

People over the age of 50 with HIV break down into three groups: longtime survivors, newly diagnosed individuals, and newly infected individuals. The first group, older adults who were infected with HIV at a younger age, is the largest. This group will continue grow, given that in 2007 over 65% of all people living with HIV/AIDS were over the age of 40.⁹ In the second category, people over the age of 50 accounted for 16% of all new HIV diagnoses and 19% of concurrent diagnoses of both HIV and AIDS in 2007.¹⁰ Finally, we are also encountering significant numbers of new infections among people over 50, which also indicates a need to understand routes of transmission in this population.¹¹

Older African Americans and gay men are disproportionately affected by HIV

Striking disparities exist among older adults living with HIV. Among people who are 50 or older nationally, African-Americans are 12 times as likely as their white peers to have HIV; Latinos are five times as likely.¹² In 2001, African

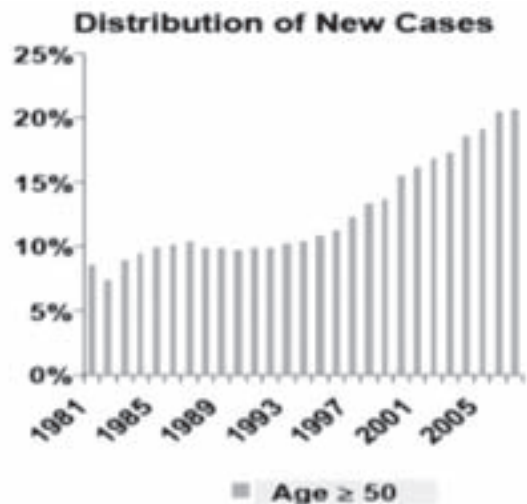
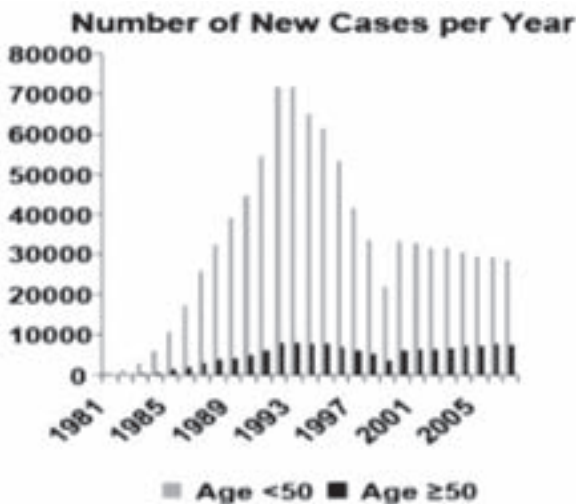
American women accounted for only 11% of women over 50 but made up half of all AIDS cases and more than 65% of all HIV infections among all older women in the U.S.¹³ Among all women over 50, new diagnoses have increased by 40% over the past five years.¹⁴ Men who have sex with men (MSM) are also disproportionately represented among people living with HIV. About four percent of men (two percent of all adults) report having sex with other men, but according to the Centers for Disease Control and Prevention (CDC), 48% of people living with HIV, and 57% of people diagnosed in 2006, were MSM.¹⁵

Key Terms

MSM: Men who have sex with men.

Risk Factors: Behaviors that increase a person’s chance for contracting HIV/AIDS. Examples include having unprotected sex (especially vaginal or anal); sex with multiple partners or anonymous partners; injecting drugs or steroids, using equipment and blood shared with others; exchanging sex for drugs or money; or having unprotected sex with someone who has any of the risk factors listed above.

Older people are becoming infected: New U.S. AIDS cases



www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/default.htm

Source: Dr. Amy Justice, presentation at NY State AIDS Institute Meeting on HIV and Aging, December 7, 2009

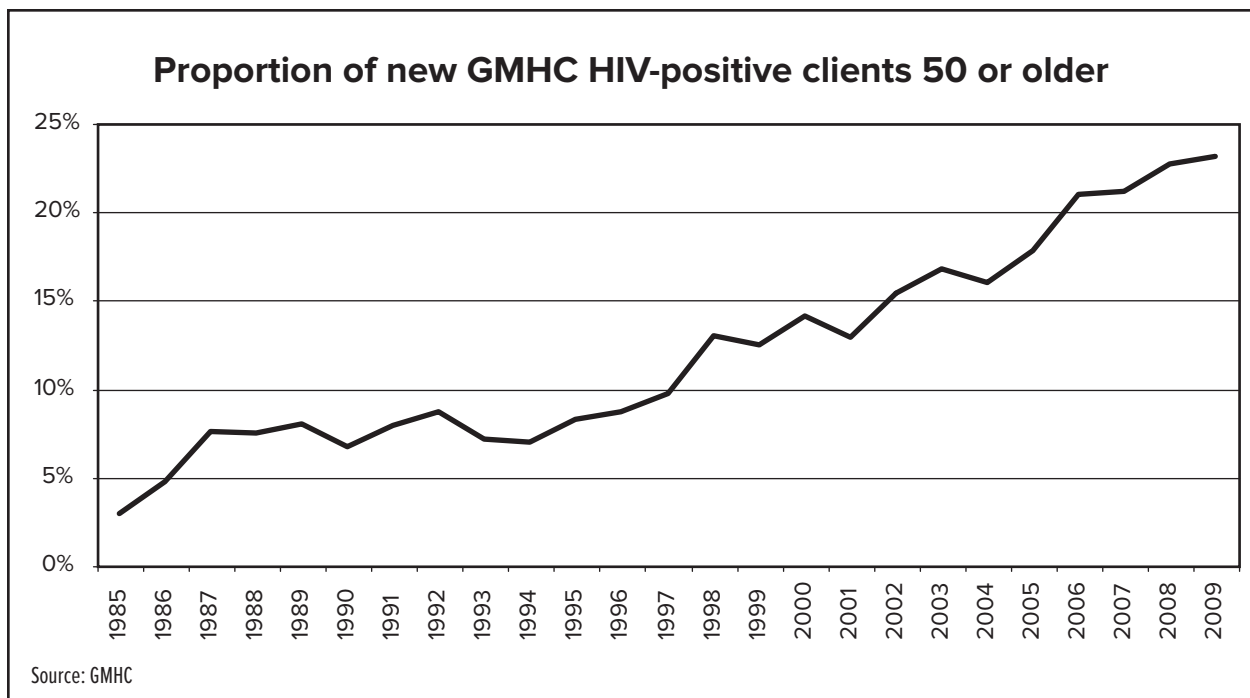
The CDC's epidemiological surveillance systems do not provide specific data broken down by age and risk category for older adults, like they do for youth. At present, more specific data on older adults and HIV are available only by region. In 2009, for example, the New York City Department of Health and Mental Hygiene (DOHMH) released a study that sheds light on the transmission factors in the spread of HIV in the city.¹⁶ For older women newly diagnosed with HIV, unprotected heterosexual sex is the predominant transmission category, followed by injection drug use. Among males, MSM is the largest documented transmission category, followed by injection drug use and unprotected heterosexual sex—but important differences emerge when we compare men over 50 to those who are younger.

Of newly diagnosed men 50 and older in New York City, only 24% reported unprotected sex with other men.¹⁷ Another 15% reported intravenous drug use as their risk factor, and an additional 15% said their risk factor was unprotected heterosexual sex. Over half, however, reported an “unknown” risk factor. By contrast, 61% of newly diagnosed males ages 13 to 49 reported sex with other men as a risk factor; 5% reported intravenous drug use, and another 5% reported unprotected heterosexual sex. Only 28% of newly diagnosed men 13 to 49

reported an “unknown” risk factor. Notably, there is no similar difference in rates of “unknown” risk factors between age groups of women with HIV in New York City.

A similar issue with the self-reporting of sexual risk behaviors and orientation was revealed in another recent study by the New York City DOHMH. Looking at MSM of all ages, the DOHMH found that 39% do not disclose their sexual orientation or risk behaviors to their doctors.¹⁸ The breakdown by race and ethnicity showed that Black, Latino and Asian MSM are much less likely than white MSM to disclose having sex with men to health care providers. In New York City only 19% of white MSM do not disclose to their doctors, while 60% of black MSM, 48% of Latino MSM and 47% of Asian MSM do not discuss their same-sex behavior or identity with their doctor. Those MSM who disclose to their doctors were twice as likely to have been tested for HIV. These racial gaps in disclosure between patient and doctor are probably higher for men over the age of 50.

In general, doctors tend not to proactively assess older patients for sexual health risks or their sexual activity, regardless of orientation or gender. In Texas, 40% of patients over the age of 50 were never or rarely asked about their risk factors for HIV by a medical doctor; for people under the

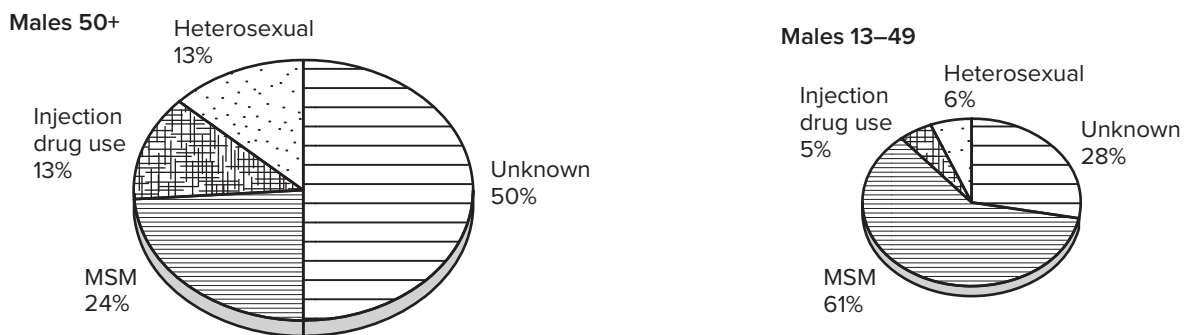


age of 30, the comparable figure is only 7%.¹⁹ A national study found that adults over 50 at risk for HIV were 80% less likely to be tested for HIV as at-risk adults 20 to 30 years of age.²⁰ This is a serious problem with a troubling impact, and the likelihood of receiving a concurrent HIV and AIDS diagnosis increases strikingly with age.²¹ Additionally, studies show that most older adults are diagnosed with HIV while hospitalized for other medical issues, supporting the finding that older adults are disproportionately diagnosed long after their HIV infection, as illustrated in the chart below (see page 6).²²

Conversations about sexuality with older men will require a great deal of sensitivity. Given the

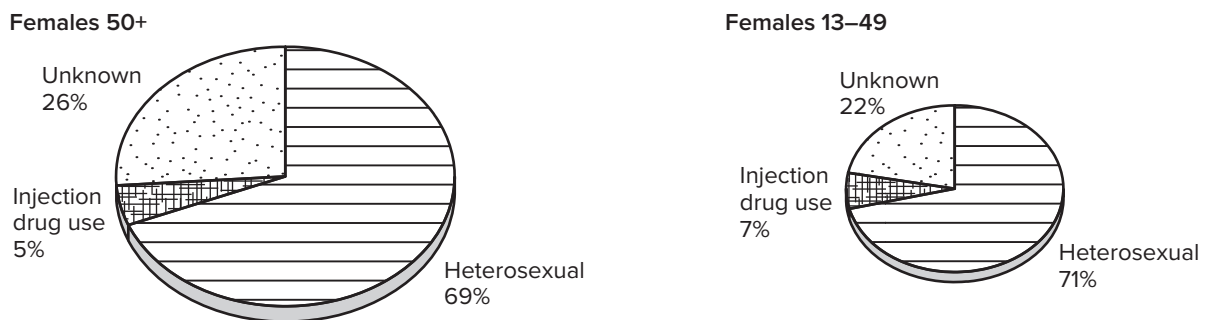
data on the self-reporting of “unknown” risk factors by older men diagnosed with HIV in New York City, and the reluctance to talk about homosexuality in older populations in general, it is reasonable to believe that homosexually active older men will have difficulty talking about these topics with their physicians or in other contexts—but the need to do so is great. Silence lessens their access to information that could help them practice lower-risk activities or know their HIV status. Anti-gay bias and stigmas surrounding an HIV-positive status could be a factor keeping older men from disclosing their sexual risk behaviors, and research has indicated that gay men and lesbians in nursing homes

Transmission risk category of males diagnosed with HIV in 2007 by age, NYC



Half of males diagnosed with HIV who are 50+ years old do not have a documented transmission category. MSM is the largest documented category. As reported to the New York City Department of Health and Mental Hygiene by September 30, 2008.

Transmission risk category of females diagnosed with HIV in 2007 by age, NYC



Heterosexual is the predominant transmission category among females diagnosed with HIV who are 50+ years old. As reported to the New York City Department of Health and Mental Hygiene by September 30, 2008.

face discrimination, bias from staff and residents, and increased risk of neglect.²³ Another study from the mid-1990's found significant anti-gay bias in senior centers funded through the Area Agencies on Aging (AAA).²⁴

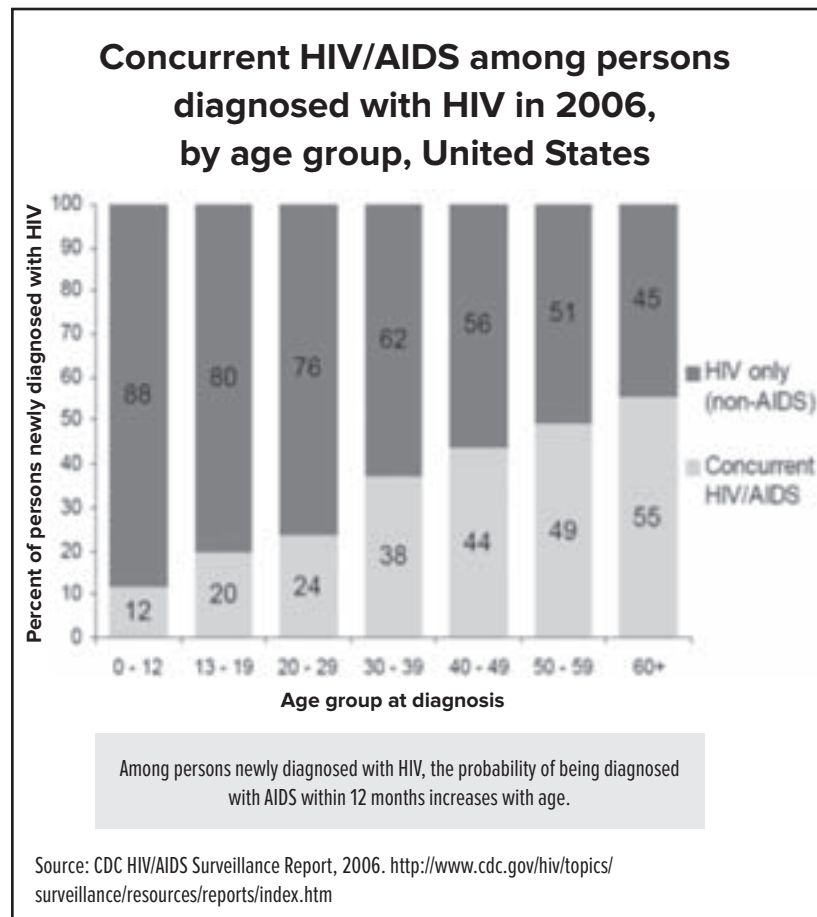
The CDC does not ask people about gender identity and includes transgender people with MSM, but we know that transgender women are at higher risk of HIV than other subpopulations. A study of 515 transgender persons in San Francisco (392 male-to-female, MTF; 123 female-to-male, FTM) found that 35% of the MTF sample were HIV-positive (compared to 2% of the FTMs).²⁵ Of the 137 MTFs who were positive, 35% were unaware of their status at the time the survey was conducted.²⁶ The study showed much higher prevalence of HIV-positive status—65%—among African-American MTFs, which was consistent with observations by other researchers in Atlanta.²⁷ Among MTFs, emotional dynamics (including the desire for love and acceptance by a male) and behavioral risks (related to drug and alcohol use, sex work, and

multiple partners) are compounded and give male partners a much more powerful bargaining position in negotiating condom usage, increasing the probability of unprotected sex and the transmission of STDs.²⁸ Because studies of HIV in the transgender population are regional and rely on convenience sampling, generally associated with clinics or service agencies, there are no reliable national statistics available for the population as a whole or for racial and ethnic subpopulations. However, a review of several regional studies shows a consistent trend in the prevalence of HIV among racial and ethnic groups of MTFs: 44–63% of African-American MTFs are HIV-positive, 26–29% of Latinas, 16–22% of whites, and 4–27% of Asian/Pacific Islanders.²⁹

Older adults remain sexually active and engage in risky behaviors

Contrary to stereotypes of older people, there is substantial evidence that significant numbers remain sexually active. An AARP study found that of adults between the ages of 45 and 59, 55% of men and 50% of women reported being sexually active in the previous six months. In the next cohort of older adults ages 60 to 74, 31% of men and 25% of women reported being sexually active in the prior half year.³⁰ A different study conducted by the National Council on Aging reported that among those over 60, 61% of men and 37% of women report being generally sexually active, with people in their 60s being the most sexually active, and people above 80, the least.³¹

In 2006, the AIDS Community Research Initiative of America (ACRIA) published its landmark study, “Research on Older Adults with HIV” (ROAH), which was based on interviews with 914 HIV-positive adults over 50 in New York City. The study revealed that many older adults partake in high risk activities, lack sexual health knowledge, and are unaware



of the need to protect themselves from STIs and HIV. Of participants who reported being sexually active, 47% used drugs or alcohol before sexual intercourse. While national studies have found that older drug users are less likely than their younger counterparts to partake in sexual activity, those older adults who do use drugs engage in high risk sexual behaviors (multiple partners, the exchange of sex for money or drugs, and sexual intercourse with other drug users) at rates comparable to younger drug users and much higher than people over 50 who do not use drugs.³² Additionally, older adults are less likely to be offered treatment for substance abuse issues than younger people.³³

Thirty-three percent of HIV-positive persons over 50 surveyed in the ROAH study reported having unprotected insertive sex within the past three months. Half of these encounters (16%) were with partners of unknown HIV status or who were known to be negative.³⁴ A Chicago study found that 60% of non-married women over 60 who had been sexually active over the past decade had not used a condom.³⁵ Another study found that over half of older African-American women living in rural areas report at least one risk factor for HIV infection, including unprotected sex.³⁶

Many older people who begin sexual activity with new partners after divorce or the death of a long-term spouse or partner do not know that they may now be at risk for HIV or STIs.³⁷ Several studies have documented misconceptions about HIV transmission and the effectiveness of condoms in preventing STIs and HIV among older adults. A Florida study found that some older adults think that HIV is transmitted through casual contact or blood transfusions.³⁸ Older adults have lower rates of condom use and less knowledge of HIV transmission than younger people.³⁹ Also, the effective use of a condom is substantially more difficult for an individual with erectile dysfunction, which becomes much more common with age.⁴⁰

The gender imbalance among older populations—with women progressively outnumbering men as cohorts age—also affects condom use and risk behavior, leaving older

men with much greater bargaining power in heterosexual sex. This puts women at a disadvantage in their ability to negotiate condom usage, which in one study has been shown to decrease a woman's ability to use a condom during intercourse with a man.⁴¹ Behavioral risks faced by older women are compounded by the fact that postmenopausal women have an increased biological risk of HIV infection (and other STIs), due to hypoestrogenism and the resulting vaginal dryness that occurs with aging.⁴²

Policy Recommendations: Epidemiology

1. The Centers for Disease Control and Prevention (CDC) should improve epidemiological surveillance systems and data collection to provide specific data delineated by age and risk category. Such data would inform HIV preventionists and gerontological health providers on what proportion of older HIV-positive adults get HIV through homosexual sex, heterosexual sex, and injection drug use.
2. The CDC should collect data on gender identity in addition to transmission categories such as MSM (men who have sex with men). This would provide national level data on HIV among transgender persons.
3. The CDC's efforts should fund the development, tailoring, and targeting of HIV prevention interventions for older adults, including MSM, women, and African Americans. They should also target high risk sexual behaviors, both heterosexual and homosexual.
4. Healthcare providers, especially doctors, should proactively assess older patients for sexual health risks and sexual activity, and screen for HIV.

A Chicago study found that 60% of non-married women over 60 who had been sexually active over the past decade had not used a condom.

Double Stigma

By Matt Sharp

I have fond memories of my July birthdays as a kid. Those hot Texas summer days were spent leisurely in my grandparents' backyard making homemade ice cream beside the plum tree weighted down with fruit. Now that I have officially become a "senior," I look back on those times with a mixture of sadness and longing. My time has passed so quickly it is hard to believe that I have had AIDS half of my life.



On turning 50 I was perplexed about exactly how I was supposed to feel. I struggled with the feelings that I am very lucky and privileged to have survived AIDS twenty years, but in reality I still just felt...old.

This time of my life has been thought-provoking yet confusing. Aging has sort of snuck up on me. It has been hard to accept growing older while living with HIV in our judgmental and antagonistic society. As an older person with HIV, I face the unknowns of a longer life with a virus that, despite successful treatment, continues to smolder within an aging body and immune system. There is really no precedent for the situation that many people, like myself, find themselves in. Yet, as the clock ticks on, I remain committed to my own fight against AIDS.

My background in activism started in early adulthood when I wanted to speak out against social injustice. In the early eighties, when I had barely come out, I joined the gay liberation movement. One of my first protests was against the anti-sodomy laws. I remember massive protests in

Greenwich Village following the U.S. Supreme Court's 1986 upholding of these laws in *Bowers v. Hardwick*. We marched through those muggy city streets blocking traffic on each avenue as we marched east across the city.

Gay coming-of-age coincided with my youth. Gay men partied and played before there was the PNP of today (PNP means party and play — code in personal ads for using crystal methamphetamines). Bathhouses were a new revelation. We celebrated our post-Stonewall freedom with guiltless abandonment. Clinic visits for venereal diseases — as we called them then — were common. We took the shots or pills and were back in the mix as soon as the drip was gone.

Then the mirrored disco ball came crashing down. Before we knew it, the horror of AIDS hit us, many in the prime of our lives. There is no way to describe the horror of those times adequately, and all I can offer is my own perspective.

Having lived in New York City and Los Angeles in the late seventies, I was immediately aware of my own risk of contracting what was then called "the gay cancer." I moved to Dallas in 1981, and I remember Larry Kramer's first commentary on the growing numbers of this new rare illness striking gay men in major U.S. cities. A few of us mobilized by drawing chalk outlines on the city hall plaza to symbolize those who had died or would die, and staked white crosses in vacant lots in Oak Lawn, Dallas's gay neighborhood.

We were literally shaken to the core with sickness and death after the abandoned celebrations of sexual liberation and self-indulgence in the '70s. This was a complete shock to our collective being; one that I realize is hard for younger generations to comprehend. Our strategy quickly became learning how not to get infected, and how to find out anonymously if we were.

My own diagnosis was a surprise despite all the fear in the community. I drove home all the way home from the only anonymous test site in Oklahoma City in tears because of my deep denial. I assumed I would be negative but know now that gay men should anticipate a positive diagnosis and not assume otherwise.

We taught ourselves about clinical trials and drug development in order to fight for treatment, as we would wait nearly a decade and a half before the emergence of the effective HIV drugs we have today. People

were trying anything they could get their hands on, even smuggling unproven, yet hopeful, drugs from Japan, Europe, and Mexico.

Tragically, so many are gone now. Yet some have survived and are thriving as we face the unexpected phenomenon of aging with HIV. We are fortunate to be alive, especially when so many of us were unprepared to reach 40, let alone 50 or 60. Those of us who have gotten here wonder where all the time went. Most likely it passed us by while we were fighting to save our friends' lives and worrying about our own survival.

Some in our community have simply lost perspective as the time has flown by, past the ACT UP protests, combination HIV therapy, and the "hit early, hit hard" era. We dealt with the scary body shape changes thought to be caused exclusively by protease inhibitors and partied through the crystal meth maze – losing even more friends and sometimes our livelihood. Then all of a sudden we realized that we had actually survived!

Many of us have regained our health, living on a strict schedule of popping HIV meds and seemingly constant blood draws. Others are less fortunate, often due to socioeconomic factors that limit or deny access to HIV health care delivery and severely curtail the quality of care.

Now we live, only to be stigmatized by our age. There is constant bombardment of cruelty against the aging population, HIV-positive or not. Add an incurable, persistent virus to all the other layers of discrimination, and you have stigma on an overwhelming scale.

Older HIV-positive gay men face further and increased stigmatization within the gay culture where youth, good looks, and a perfect body are valued more than being whole. Gay hook-up sites are rife with the use of blatant language to separate us such as "18-45 ONLY," or "disease-free." Sadly, even HIV-positive men discriminate based on age. I have witnessed guys with lipodystrophy treated as freaks by younger poz men. It is sad. As a former dancer I watch as my misshaped belly grows as I age and remember the days I was younger, agile, and was probably joking about older "trolls." It's a vicious circle, I admit, and maybe our survival may teach us some humility.

This stigma can only create further isolation and loneliness, leading to depression and substance abuse. We have to speak out and tell our community that this behavior by our own is offensive and should not be tolerated.

AIDS activism has led directly to the creation of entitlement programs to support our community. Many individuals depend on these programs to improve their quality of life or to have a safety net against further loss. And as we age with HIV, many more of us will need support. Also, thanks to the success of HIV treatment, some of us are able to participate in a range of social activities. Aging HIV-positive men must make sure to take care of themselves and engage with social networks. Being isolated and immobile creates loneliness and can have a negative impact on mental health. Being active and engaged after all the years of sickness and death will help us support each other through the many healing processes. We must build strong communities and develop the resources to ease many of the problems aging HIV-positive people now face.

Although we do not know all of the medical and social implications of aging and HIV, we must be as positive about the future as possible. We must work, collectively and individually, to change the status quo despite the unknown challenges. There is much hope for people living with HIV as we reach the third decade of the epidemic. Management of chronic HIV will become better understood as information continues to accumulate. HIV meds are becoming easier to take and more tolerable. There is ongoing "functional cure" research that offers the promise of enabling people with HIV to control their virus without the need for daily meds.

There is no question that by working together we can create solutions and break down the barriers that older people with HIV face. We can mobilize and demand the future we envision. That is what we did from the beginning of our movement, and we bring that dedication with us into a new age.

Matt Sharp is Director of Treatment and Prevention Advocacy at Project Inform.

II. Aging Bodies

The relationship between HIV/AIDS, HAART, and aging is complicated, and in this section we look at the available research on the ways in which HIV impacts aging bodies. Some facts are clear. The greater the count of CD4 cells (the immune system T cells targeted by HIV) at the time of HAART initiation, the longer a person will live, and life expectancies for people with HIV can be predicted with some precision. In 2008, the Antiretroviral Therapy Cohort Collaboration (a multi-national collaboration of HIV cohort studies in Europe and North America) found that HIV-positive people on antiretroviral therapies can live well into their 60s, even if they started therapy with severely depleted immune systems. Those who begin therapy with CD4 counts over 200 per cubic milliliter can live into their 70s.⁴³

At the same time, however, life expectancies for people on therapy (and who adhere to their medication regimens) are still only two-thirds that of the general population. For intravenous drug users with HIV, the figure is even lower. These statistics point to important areas of concern as we move forward, for we are only beginning to see the effects of therapy on longevity. Very little is known presently about people over 65 who have HIV, or about the impact of taking antiretroviral therapy for many years or decades, which will be important areas of research in the future.

HAART is likely to reduce but not eliminate the negative impact of aging on disease progression

Researchers have known since the 1980s that, without treatment, individuals who contract HIV as older adults do not fare as well as those who contract HIV at a younger age: they progress faster to AIDS and die sooner than younger adults.⁴⁴ According to one study of HIV-positive people prior to the widespread use of HAART, the median survival among HIV-positive individuals between the ages of 15 and 24 was 12.5 years, whereas for individuals 65 and older it was 7.9 years.⁴⁵ Median time to a diagnosis of AIDS was 11 years in the younger group and 7.7 in the older group. Moreover, for every 10 additional years of age, there was a 1.5-fold increased risk of death, and a 1.3-fold increased risk of developing AIDS.⁴⁶

As the Antiretroviral Therapy Cohort Collaboration has shown, people with HIV and

AIDS are now living much longer due to the effect of HAART, but there are multiple issues and problems emerging at the intersection of aging, HAART, and HIV. Multiple studies, including the Antiretroviral Therapy Cohort Collaboration, suggest that differences in life expectancy between the HIV-positive and HIV-negative populations persist even with HAART.⁴⁷ Several studies have found that older adults with HIV receiving antiretroviral therapy are at greater risk of dying or contracting new opportunistic illnesses⁴⁸, while other research suggests that there is no difference in survival.⁴⁹ According to one review of HIV and aging, antiretroviral therapy likely reduces but does not eliminate the negative impact of age on disease progression.⁵⁰

Immune systems in HIV-positive older adults respond slower to treatment

HIV and aging have profound effects on the immune system. For different reasons, HIV and aging both diminish the production and health of T cells, a key component of the body's defense against infection. To begin with, as people get older, the organ where T cells mature (the thymus) shrinks⁵¹, and as a result older adults produce fewer T cells than younger people.⁵² HIV infection also depletes T cells, and HIV-positive individuals typically have a "naïve" T cell population similar to someone 20 to 30 years older.⁵³ Older age has also been linked to decreased production of cytokines that regulate T cell production and maintenance, which may also influence immune recovery in older HIV-positive adults.⁵⁴ Aging and HIV also have similar impacts on naïve B cells, which produce antibodies in the immune system.⁵⁵ With HIV infection, the naïve B cells that remain are more active than normal. As a result, older adults with HIV have an increased risk of serious infection, including pneumonia, and a less robust response to the pneumonia vaccine.⁵⁶ Both aging and HIV can lead to chronic immune activation. In older adults, this may be due to recurring infections. In people with HIV, the immune activation is likely the result of viral replication and "leaky gut" syndrome, a condition in which bacteria, food and waste products seep out of the intestines.⁵⁷

Most research suggests that the immune systems of HIV-positive older adults do not recover as quickly as those of younger adults with antiretroviral therapy.⁵⁸ CD4 cells recover in both young and old HIV-positive adults in

response to combination antiretroviral therapy, but older adults seem to have a slower, less robust recovery.⁵⁹ One study found that, for each 10 additional years of age at the initiation of antiretroviral therapy, patients gained 35 fewer CD4 cells per microliter of blood.⁶⁰ This study only looked at the first year of therapy, but these differences appear to persist even after several years of treatment.⁶¹ In one European cohort, older adults were less likely to achieve CD4 increases above baselines of 100 or 200 cells per microliter of blood, and it took them longer to raise their CD4 counts.⁶² In a large, multicenter study comparing different treatment strategies, greater CD4 recovery was associated with being 40 years old or younger, among other things.⁶³

These differences are critical: low CD4 counts have been associated with increased morbidity and mortality.⁶⁴ One study found that a lower CD4 count was associated with an increased risk of heart disease, kidney disease, liver disease, and cancer.⁶⁵ Recovery of CD4 cells depends, to some extent at least, on the body part in question. Cell populations seem to recover slowest in the gut, where HIV replicates most intensely.⁶⁶ Even after three years of HAART, CD4 levels cells in the gut are only half normal levels.⁶⁷

Although older adults seem to have poorer CD4 recovery with HAART than younger people living with HIV or AIDS, several studies indicate that they do a better job, on average, of suppressing viral replication.⁶⁸ One study found that in a cohort of HIV-positive individuals, people over 50 suppressed HIV replication 90% of the time.⁶⁹ In another study, older age was the best baseline predictor of viral suppression over 144 weeks of therapy.⁷⁰ This could, however, be

related to the finding that older adults tend to adhere better to their drug regimens, rather than to age alone.⁷¹

Increased likelihood of comorbidities among HIV-positive persons is compounded by age and reduces clinical research on HIV in older people

Non-AIDS comorbidities are becoming increasingly important. In recent years, less than a third of all deaths in HIV-positive individuals were associated with diseases traditionally linked to HIV infection, such as Kaposi sarcoma.⁷² In many cases, however, it is not clear whether these comorbidities are caused by the virus, aging, antiretroviral therapy, or some other risk factor found among some HIV-positive older adults. What is clear is that HIV-positive individuals are likely to have more diseases than HIV-negative individuals, regardless of age, many of which are not specifically AIDS-related.⁷³

In a large study comparing HIV-positive veterans with age-matched, HIV-negative veterans, those with HIV were more likely to have conditions such as liver and kidney diseases.⁷⁴ Immune recovery, characterized by a high CD4 count, can reduce the risk of non-AIDS diseases, but as previously mentioned, older adults have a harder time achieving high CD4 counts than younger adults.⁷⁵ In the ROAH study, 91% of the sample of 914 older adults living with HIV in New York City had at least one comorbidity; 77% had two or more.⁷⁶ These conditions include hypertension, neuropathy, hepatitis, arthritis, and depression.⁷⁷ In the study, 48% of HIV-positive older adults screened positive for a psychiatric disorder, a condition often associated with substance abuse.⁷⁸ If untreated,

Due to the high prevalence of comorbidities, and because of age limitations, HIV-positive older adults are often screened out of clinical trials.

Life expectancy for people with HIV/AIDS who use HAART

At HAART initiation	CD4 cell count (µl)		
	<100	100–199	>200
A 20 year-old will live to:	52	62	70
A 35 year-old will live to:	62	65	72

Source: The Antiretroviral Therapy Cohort Collaboration, “Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies.” *The Lancet*, 2008 (372), 293–99.

psychiatric disorders can increase non-AIDS related mortality.⁷⁹

Comorbidities require patients to take other, non-HIV/AIDS-related medications, which complicate treatment adherence, drug interactions and clinical research. One study looking at comorbidities in 165 HIV-positive New Yorkers over 55 found that participants had a mean of 2.4 comorbidities and 2.7 non-HIV medications.⁸⁰ Due to the high prevalence of comorbidities, and because of age limitations, HIV-positive older adults are often screened out of clinical trials. As a result, clinical trials for HIV treatments provide few findings on how medications affect older adults with HIV, and those that do include older people often fail to compare their responses with those of younger adults.⁸¹

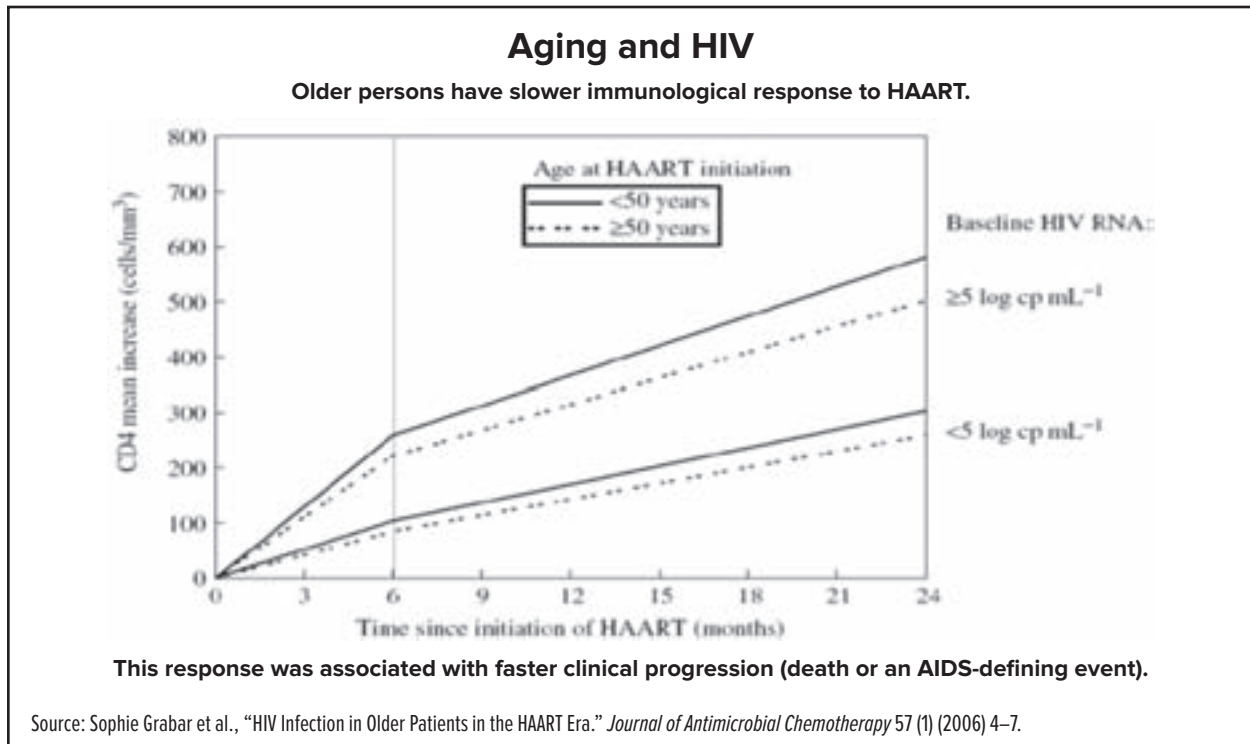
Risk of heart disease is strongly associated with age among HIV-positive individuals

Heart disease is the number one cause of death in the United States, and a significant problem among older HIV-positive adults.⁸² Not surprisingly, the risk of heart disease among HIV-positive individuals is strongly associated with age, as it is among HIV-negative individuals. One group of researchers followed HIV-positive people from 1999 to 2001 and found a 26%

relative increase in the rate of myocardial infarction per year of exposure to HAART during the first four to six years of therapy.⁸³ In another study, older age was associated with higher hospitalization rates for heart disease among HIV-positive individuals.⁸⁴ It is not entirely clear, however, whether older HIV-positive adults have a higher risk of heart disease than older HIV-negative individuals. One study found that they do; another found that there was an increased risk among younger HIV-positive people, but not among older ones.⁸⁵

Specific classes of antiretrovirals appear to increase a person's risk of heart disease.⁸⁶ For example, the common nucleoside analogue abacavir appears to increase risk of heart disease, possibly by increasing inflammation.⁸⁷ One study of HIV-positive patients found that the risk of heart attack increased with longer exposure to HAART, especially protease inhibitors.⁸⁸ Observational studies suggest that HIV-positive individuals taking protease inhibitors have a greater risk of heart attack than those taking non-nucleoside transcription inhibitors.⁸⁹

Two recent studies, however, suggest that exposure to HAART does not increase the risk of heart disease. The findings of the SMART (Strategies for the Management of Antiretroviral



Therapy) Group, published in 2006, showed that patients on suppressive antiretroviral therapy had a significantly reduced risk of cardiovascular events compared with those on interrupted therapy.⁹⁰ Results from studies of 41,213 patients observed at Veterans Affairs medical centers from 1993 to 2003 (published in 2008) reported no increase in cardiovascular problems with long term exposure to HAART, while death rates due to other causes declined precipitously.⁹¹ Whether there is an increased risk of heart disease among HIV-positive individuals unrelated to antiretrovirals is an open question as well.

Some studies have found that HIV-positive individuals taking classes of antiretrovirals not known to increase the risk of heart disease still have a greater risk of heart disease.⁹² Additional evidence comes from studies that show a persistent link between a lower CD4 count and a higher risk of heart disease.⁹³ HIV infection and age also play a role in other risk factors for heart disease. Concurrent with the emergence of effective therapies for HIV, obesity is becoming a more common problem.⁹⁴ An Australian cohort study found that the prevalence of “metabolic syndrome” (defined by a group of symptoms related to heart disease, including abdominal obesity, insulin resistance, and high blood pressure) in HIV-positive individuals rose from 8.5% to 26.5 % after they began antiretroviral therapy.⁹⁵ HIV infection and HAART have also been associated with elevated levels of fats in the blood—hyperlipidemia—which is another risk factor for heart disease.⁹⁶ Both non-nucleoside reverse transcriptase inhibitors and protease inhibitors (especially those with ritonavir) can cause lipid changes.⁹⁷

People living with HIV are increasingly at risk for non-AIDS related cancers

HIV infection has long been linked to cancers such as Kaposi sarcoma and non-Hodgkin’s lymphoma, two of the more prominent “AIDS-defining cancers,” whose skyrocketing incidence among gay men in the early 1980s was one of the first indications of the epidemic in the United States. The arrival of combined antiretroviral therapy has caused a marked decline in AIDS-

defining cancers, though they still occur among HIV-positive individuals at levels higher than found in the general population.⁹⁸ At the same time, recent studies show that people living with HIV may be at an increased risk for developing non-AIDS related cancers (NARCs), which include anal, cervical, lung and liver cancers.⁹⁹ In the HAART era, NARCs have become more common among people with HIV than AIDS-related cancers¹⁰⁰, and some research has shown higher rates of death from NARCs (1.8 deaths per 1000 person-years) than AIDS-related cancers (1.1 deaths per 1000 person-years).¹⁰¹ The most

common cancers involve the lungs, digestive tract, blood, and anal canal.¹⁰² Factors associated with developing these cancers include increasing age, smoking, and chronic hepatitis B infection.¹⁰³

With few exceptions (prostate cancer, for example), people with HIV have an elevated risk of cancer in general.¹⁰⁴ Researchers from the U.S. Centers for Disease Control and Prevention conducted a prospective observational analysis of 54,780 people with HIV from 1992–2003 and found that HIV-positive people had a significantly higher incidence than the general population for several kinds of cancer: melanoma; leukemia; Hodgkin’s lymphoma; and

colorectal, renal, anal, vaginal, liver, lung, mouth and throat cancers.¹⁰⁵ Another study found that seven types of cancer (both AIDS-related and NARCs) were more prevalent in the HIV-positive sample (N=52,278) they observed: Kaposi sarcoma; non-Hodgkin’s lymphoma; cervical cancer; Hodgkin’s lymphoma; and lung, liver, and anal cancer.¹⁰⁶ Although prostate cancer was less common among HIV-positive individuals than the general population, it became increasingly common among HIV-positive men 60 and older.

The relationship of these cancers to HIV is not well understood and findings support contending conclusions. Some scientists hypothesize that HIV is not the main driver of these cancers.¹⁰⁷ For example, people with HIV smoke at higher rates than the general population—84% of the ROAH cohort, compared with about 20% in the general population.¹⁰⁸ In a survey almost 14,000 veterans (3,707 HIV-positive and 9,980 HIV-negative),

Recent studies show that people living with HIV may be at an increased risk for developing non-AIDS related cancers (NARCs), which include anal, cervical, lung and liver cancers.

HIV Nutrition and Older Adults

By Jenny Torino, *Gay Men's Health Crisis*

Many of the health issues faced by HIV-positive older adults can benefit from nutritional interventions. They include metabolic disorders (high cholesterol, triglycerides and blood sugar), unwanted weight loss or gain, and loss of bone mass and muscle mass. These conditions can lead to cardiovascular disease, diabetes, osteoporosis and immune suppression. Modification of diet and lifestyle behaviors to improve these conditions is essential for HIV-positive individuals to achieve successful health outcomes and should be adopted as early as possible.

The risk of developing metabolic disorders increases as people age, regardless of HIV status, and a certain level of bone and muscle loss are thought to be a normal part of aging. However, being HIV-positive may further exacerbate these conditions. Metabolic disorders are a common side effect of HIV medications and the HIV virus. Bone loss is also common but we don't know whether it is caused by the HIV virus or the medications. HIV-positive individuals have to consume more protein and break down the protein in their muscles at a faster rate than HIV-negative people, which can lead to muscle wasting, decreased muscle strength, and immune suppression.

Unhealthy weight loss or weight gain is another major concern among the HIV-aging population. As people age, metabolism decreases and they need less energy or calories, but many people simply continue to consume the same amount of calories they did when they were younger. This is a major reason for obesity in the aging population in general, and excess weight can further exacerbate metabolic problems in older people who are HIV-positive.

Many older people suffer food insecurity (lack of food) due to low income, unstable housing, lack of access to proper food storage, the inability to acquire food items because of lack of transportation, or the inability to shop and cook for oneself. Weight loss, like protein deficiency, can impair the immune system. Access to healthy food and nutrition counseling done by a registered dietitian is imperative for the HIV-positive aging population.

For resources on maintaining a healthy diet and combating metabolic side effects of HIV meds with nutrition, see the GMHC Web site, <http://www.gmhc.org/get-support/stay-healthy/nutrition>.

For further information: *Nutrition Management of HIV/AIDS* by Kristy M. Hendricks, ScD, RD, Kimberly R. Dong, MS, RD and Jul L Gerrior, MA, RD. Chicago, IL: American Dietetic Association, 2009.

researchers at Mt. Sinai School of Medicine were able to isolate the relative impact of HIV and smoking on the development of lung cancer, and they found that while HIV increases the relative risk of developing lung cancer, its impact was quite modest compared to the much higher impact of smoking.¹⁰⁹ Hepatitis B and C infection, human papilloma virus (HPV), and sun exposure are also risk factors for other kinds of cancer—liver, cervical/anal, melanoma—and may play a larger role. Others, however, suggest these NARCS are the result of immunodeficiency.¹¹⁰ Among a group of HIV-positive people taking antiretrovirals, a low CD4 count was strongly associated with greater risk of developing a non-AIDS associated cancer, findings that are supported by studies of transplant patients, who also have an increased risk of cancer.¹¹¹

Anal cancer is generally rare in the U.S., with an incidence of only 4,650 cases per year, but there are marked divergences in the rate of anal cancer for the general public (2 cases per 100,000), HIV-negative MSM (35 per 100,000) and HIV-positive MSM (80 per 100,000).¹¹² Gay and bisexual men are nearly 20 times more likely than the general population to get anal cancer, and HIV-positive men who have sex with men are up to 40 times more likely than the general population to develop anal cancer.¹¹³ Both anal cancer and cervical cancer are caused by strains of HPV, which suggests that anal pap smears would greatly benefit cancer prevention and detection in men. With the advent of routine pap smears among women, cervical cancer incidence and mortality rates have declined approximately 50% in the United State over the past three decades, from around 14 new cases per 100,000 women in the 1970s to less than 8 per 100,000 today.¹¹⁴

Liver related mortality is four times as severe among HIV-positive older adults; kidney disease is also of concern

Liver disease is the most common non-AIDS-related complication as a cause of death for HIV-positive individuals.¹¹⁵ Older patients experience a four-fold increase in liver-related mortality compared with younger adults.¹¹⁶ Causes include hepatitis infection, alcohol use, and diabetes.¹¹⁷ Even in the era of combination antiretroviral therapy, mortality associated with liver disease is high.¹¹⁸ One study found that patients with a low CD4 count had a much higher risk of dying from liver disease.¹¹⁹ Antiretrovirals and cholesterol

medications can also cause liver toxicity in people co-infected with HIV and hepatitis.¹²⁰ Furthermore, liver disease can cause other complications. People with liver disease are at greater risk of diabetes in general, and one study found that the risk of diabetes in older HIV-positive veterans is higher in the HAART era than it was during the pre-HAART era.¹²¹

Injection drug users (IDUs) with HIV are almost universally coinfecting with hepatitis C virus (HCV) and face an elevated level of risk for liver disease. HIV has long been known to accelerate liver disease associated with HCV, and it appears that antiretroviral therapy has not changed this. A recently published study based on a cohort of 1,295 individuals in Amsterdam found that in the HAART era (beginning in 1997, as defined in the study), people who are coinfecting with HCV and HIV continue to be at increased risk for dying from hepatitis when compared with those infected by HCV alone.¹²² This suggests that even in the era of antiretroviral therapy, HIV continues to accelerate the progress of HCV.

Both HIV and aging are associated with declining kidney function.¹²³ Not surprisingly, as the HIV-positive population has aged, the prevalence of kidney disease has been rising.¹²⁴ In one study, HIV-positive veterans were more likely than HIV-negative veterans to develop chronic kidney failure, although the relationship was true only for African Americans. White persons did not show any increased risk.¹²⁵ AIDS and hepatitis C co-infection increase the risk of chronic kidney disease.¹²⁶

Older adults with detectable levels of HIV are at increased risk for cognitive impairment and depression

HIV infection and age each can have profound effects on the brain and both appear to be predictors of neuropsychological impairment. In one study from the pre-HAART era, HIV-related dementia was three times more prevalent among HIV-positive people older than 75 than among those under 35.¹²⁷ A more recent study found combined effects of HIV and aging on neuropsychological impairment in a sample of 119 HIV-positive individuals broken into older and younger cohorts.¹²⁸ In the older cohort (50 to 67 years of age, N=67), subjects with detectable levels of the virus in their spinal fluid were twice as likely to have psychological impairment as

those with no detectable virus; in the younger cohort (20 to 35, N=52), however, there was no relationship between viral loads and impairment.

It is unclear what result HAART has on the progression of HIV-associated dementia, as research findings are mixed. One study showed that the prevalence of HIV-associated dementia was 27.3% in untreated individuals, compared with 1.9% in individuals on combination antiretroviral therapy.¹²⁹ At the same time, some research suggests that antiretroviral therapy may cause damage that increases the risk of Alzheimer's disease, a condition not normally associated with HIV.¹³⁰ An analysis of participants in the Hawaii Aging with HIV-1 Cohort showed that HIV-positive people over 50 were 3.26 times more likely to have HIV-associated dementia than younger people, independent of education, race, depression, HAART use, viral load, and CD4 count.¹³¹ A recent study with 26 HIV-positive subjects and 25 HIV-negative controls showed increased aging of the brain among the subjects with HIV. Using functional Magnetic Resonance Imaging (fMRI), the researchers found lower than normal blood flow to the brains of HIV-positive subjects, matching levels normally seen in people 15 to 20 years older.¹³² HIV and aging seem to

Key Terms

T-cells: The T stands for the thymus, the organ in which T cells mature. T cells include CD4 cells and CD8 cells, which are both critical components of the body's immune system.

CD4 Cells: A type of infection-fighting white blood cell. The number of CD4 cells in a sample of blood is an indicator of the health of the immune system. HIV infects and kills CD4 cells, which leads to a weakened immune system.

Cell counts (per microliter): A measurement of the number of CD4 cells in a sample of blood. A CD4 cell count is used by health care providers to determine when to begin, interrupt, or halt anti-HIV therapy; when to give preventive treatment for opportunistic infections; and to measure response to treatment. A normal CD4 cell count is between 500 and 1,400 cells/mm³ of blood, but an individual's CD4 count can vary. In HIV-positive individuals, a CD4 count at or below 200 cells/mm³ is considered an AIDS-defining condition.

have independent but overlapping effects on decreasing blood flow to the brain, but the effect of the drugs used in HAART is unclear.¹³³

Older HIV-positive adults are also more likely to be diagnosed with depression.¹³⁴ In one post-HAART study, HIV-positive veterans had a greater prevalence of depressive symptoms and substance use than age-matched HIV-negative veterans.¹³⁵ Moreover, the rate of depression increased with age in HIV-positive veterans, who were also more likely to be dependent on alcohol.¹³⁶ At least one study suggests that the antiretroviral efavirenz is associated with depression and other psychiatric side effects.¹³⁷ The ROAH study found that 38% of participants were moderately depressed (scoring 16 to 27 on the Center for Epidemiologic Studies Depression Scale [CES-D scale]), while 26% were severely depressed (28 or more on the CES-D scale).¹³⁸ The ROAH study also noted that physicians often focus on HIV and overlook patients' mental health needs, in spite of the fact that depression can exacerbate immune system dysfunction.¹³⁹

HIV infection accelerates frailty; bone loss is also a concern for HIV-positive older adults

Frailty and bone loss are serious concerns among people with HIV. Frailty is characterized by weight loss, exhaustion, inactivity and slowness. In the Multicenter AIDS Cohort Study (MACS), HIV was strongly associated with frailty: HIV-positive individuals were 4.5 to 10 times as likely to be frail as HIV-negative individuals of the same age.¹⁴⁰ A 55-year-old man who had recently contracted HIV had the same risk of frailty as an HIV-negative individual over the age of 65. The likelihood of frailty increases with age, duration of infection, low CD4 counts, and high viral loads.¹⁴¹ Although frailty is less common among HIV-positive individuals than among older geriatric patients, HIV infection seems to accelerate the development of frailty.¹⁴²

Bone loss is also a problem. One study found that HIV-positive people had significantly lower bone density and a higher prevalence of osteoporosis than HIV-negative, age-matched controls.¹⁴³ The researchers also found that osteoporosis was associated with older age. Antiretroviral

therapy undoubtedly has an impact: several studies suggest that initiation of HIV treatment is associated with bone loss, although some drug combinations appear to cause more bone loss than others.¹⁴⁴ Research suggests that some combinations of antiretrovirals can cause abnormal bone metabolism, and continuous therapy is associated with greater annual declines in bone density than intermittent antiretroviral regimens.¹⁴⁵ One study found that patients taking combination antiretrovirals have a two to three times greater risk of low bone density than untreated individuals.¹⁴⁶ In addition, other research has shown that smoking may also be a risk factor for declines in bone density, an important factor given the high levels of smoking among HIV-positive people, as mentioned above.¹⁴⁷

Several studies have shown that older adults adhere to their drug regimens as well as, or better than, younger individuals.

HIV-positive older adults are vulnerable to drug interactions due to comorbidities and age-related toxicities

Antiretrovirals are less toxic than they used to be, but they are not entirely benign: side effects include liver toxicity, osteoporosis, pancreatitis, lipodystrophy (fat loss and redistribution), peripheral neuropathy (numbness in extremities), and buildup of lactic acid, to name a few.¹⁴⁸ Research suggests that older adults may be less able to metabolize antiretrovirals, which can lead to increased toxicity.¹⁴⁹ One study suggests that older people may be less able to metabolize protease inhibitors and non-nucleoside reverse transcriptase inhibitors due to age-related changes in cytochrome p450, a family of enzymes involved in drug activation.¹⁵⁰ Other research shows that lipodystrophy and liver toxicity are more common among older HIV-positive adults.¹⁵¹ In a Spanish study of HIV-positive individuals on HAART, older age was associated with greater liver toxicity.¹⁵² Another study, however, failed to find any age differences in medication-related toxicities.¹⁵³ Overall, there are few available studies of the metabolism of antiretroviral drugs in older adults, and the findings so far remain inconclusive, though suggestive in some areas.

Interactions between two or more drugs may also be more common in the elderly, who

make up 13% of the U.S. population, but utilize 30% of prescription drugs and 40% of over the counter medications.¹⁵⁴ On average, older adults take three times more drugs than younger adults and suffer two to three times the rate of adverse drug interactions.¹⁵⁵ One study found that a hypothetical 79 year-old woman with chronic obstructive pulmonary disease, type 2 diabetes, osteoporosis, osteoarthritis, and hypertension would need a complicated regimen involving twelve separate medications. If the patient were also HIV-positive, several more drugs would be required, increasing the risk of toxic interactions.¹⁵⁶ Cisapride, for example, a medication used to treat gastrointestinal reflux disease, cannot be taken in combination with protease inhibitors, a common class of antiretrovirals, because of increased risk of cardiac arrhythmias.¹⁵⁷

Adherence is higher among older adults

There is some good news, however, with regard to medications and treatment. Several studies have shown that older adults adhere to their drug regimens as well as, or better than, younger individuals.¹⁵⁸ One analysis that included 970 people with HIV showed that moderate to poor medication adherence was associated with younger age, independent of other factors.¹⁵⁹ This may explain older individuals' enhanced ability to sustain suppression of viral replication better than younger adults.

Meeting of experts recommends expanded research on aging and HIV

In 2007, a group of researchers in infectious diseases, geriatrics, immunology, and gerontology gathered in Washington, DC to discuss the issue of HIV and aging in a workshop organized by the Association of Specialty Professors, the Infectious Diseases Society of America, the American Academy of HIV Medicine, the National Institute on Aging, and the National Institute of Allergy and Infectious Diseases. The purpose was to review the current state of knowledge about HIV and aging, identify research gaps, and suggest high priority topics for future research. A year later they published an article outlining the issues emerging as people with HIV and AIDS grow older, concluding with several recommended questions for future research.¹⁶⁰

First among the methodological needs in research on HIV and aging was the selection of control subjects that fit the question being studied. This is an important issue since the combination of HIV and aging brings into play so many overlapping and interactive comorbidities, drug interactions, and life cycle effects. As an example, the workshop cited the Veterans Aging Cohort Study (VA Connecticut Healthcare System, Amy Justice, Principal Investigator), which used HIV-negative veterans with similar risk factors for HIV to control for the effects of substance abuse and psychiatric disorders.¹⁶¹ With respect to HAART, the working group saw a need for more research into whether or not the antiretroviral regimen should be changed for older adults. If the elderly respond differently to HAART than younger adults, separate treatment guidelines may be needed. Physicians could avoid certain drugs classes that tend to cause toxicity and rely on more benign medications. Among the other questions posed by the workshop:¹⁶²

- To what extent do normal aging processes result from viral infection and immune activation?
- How do HIV and aging exacerbate each other?
- What are the age-associated differences in immunologic and virologic response to HAART and toxicities resulting from HAART?
- Should the HIV treatment paradigm change for older patients?

Key Terms

Comorbidity: Any disease or condition that occurs at the same time as another disease or condition.

NARCs: Non-AIDS related cancers, including anal, lung and liver cancer. Distinct from AIDS related cancers, which include cancers such as cervical carcinoma, non-Hodgkin's lymphoma and Kaposi's sarcoma, that are more common or more aggressive in people with HIV.

Viral Load: Measures concentration of virus in a body fluid, most commonly blood plasma or cerebrospinal fluid. Provides information about the number of cells infected with HIV and is an important indicator of HIV progression and of how well treatment is working.

- How can primary care screening and treatment guidelines be appropriately tailored to patients with HIV?
- What can be learned regarding the management of complex chronic diseases in patients aging with HIV, and how does this type of management differ from the management of single disease entities?
- What changes occur in gut associated lymphoid tissues with age?
- What are the biologic characteristics underlying age-associated fibrosis in multiple organ systems?
- What is the role of HIV- or HAART-associated mitochondrial toxicity in age-related illnesses in HIV-positive patients?

The National Institutes of Health has increased attention, funding to HIV and aging

The National Institutes of Health (NIH) is currently funding a number of studies about aging and HIV. The Behavioral and Social Research Division at the National Institute on Aging (NIA) supports research on health and sexuality in the older population and is evaluating the cost effectiveness of interventions. On National HIV/AIDS and Aging Awareness Day on September 18, 2009 Dr. Anthony Fauci, Director of the National Institutes of Allergy and Infectious Diseases, made the following a statement on the importance of research on HIV and aging:

“Aging is an important and expanding focus of HIV/AIDS research at the National Institutes of Health and the NIH-sponsored Centers for AIDS Research. The National Institute of Allergy and Infectious Diseases (NIAID), part of NIH, funds a range of studies to understand the biology of HIV infection in older adults with the goal of improving their medical care. Scientists are studying the interaction between HIV and aging in areas as diverse as diseases of the liver, kidney, brain, heart and lung; cancer; bone density; physical activity; mental health; balance; hearing; response to antiretroviral therapy; immune function; adherence to medical care.”¹⁶³

Every fiscal year the NIH produces a Trans-NIH Plan for HIV-Related Research which provides a framework for formulating their budget for research. The plan guides how research dollars are invested. In this plan the NIH identifies top

strategic priorities and critical needs for HIV-related research that were determined through the annual Office of AIDS Research strategic planning process. The FY 2009 Plan included the following strategies related to aging:¹⁶⁴

- To investigate the relationship between HIV and the spectrum of physical and mental health outcomes that increase with aging, such as cancer, obesity, diabetes, hypertension, anemia (unexplained and anemia of chronic inflammation), emphysema, renal insufficiency, and dyslipidemia, as they affect disease outcomes (e.g., liver disease, cardiovascular disease, and renal disease) and survival.
- To study the incidence and determinants of physical and cognitive decline in aging HIV-positive individuals, and the effect of frailty and functional impairment on HIV, antiretroviral use, and self-care behaviors.
- To evaluate immunologic and virologic parameters of HIV progression and mortality in older versus younger adults receiving HAART.
- To identify treatment guidelines for older HIV-positive patients, including appropriate CD4 counts for initiation of highly active antiretroviral therapy (HAART) in older patients.
- To study the effect of HIV and HAART (e.g., immunologic and virologic response to treatment, adverse effects) in aging populations with coexisting morbidities and polypharmacy.

The NIH's Web-based Research Portfolio Online Reporting Tool provides information on research currently supported by the institutes.¹⁶⁵ Research projects examine HIV and aging in a variety of contexts, including substance use, gender, sexuality, comorbidities, drug interactions, HIV risk for people over 50, aging and physical functioning with HIV, and accelerated aging in people living with HIV. Most address the physiological aspects of HIV/AIDS, though some consider risk factors such as substance abuse or demographic trends. The studies target subpopulations of older adults living with HIV/AIDS including veterans, women, substance users, and MSM. The following are a sample of current projects supported by the NIH:

- Alcohol Associated Outcomes Among HIV+/- Veterans (Amy C. Justice, Yale University and VA Connecticut Healthcare System)

- Genetic and Inflammatory Factors in Anemia in the Elderly (Nancy Berliner, Harvard Medical School and Brigham and Women's Hospital)
- Cardiovascular Disease Mechanisms in HIV Infected and Uninfected Veterans (Matthew Freiberg and Amy C. Justice; University of Pittsburgh, Yale University and VA Connecticut Healthcare System)
- Host Genetic Determinants of HIV-AIDS Susceptibility in a VA Cohort (Sunil K. Ahuja, South Texas Veterans Health Care System)
- Older Drug Users: A Life Course Study of Turning Points in Drug Use and Injection (Miriam W. Boeri, Kennesaw State University)
- Michigan Center on the Demography of Aging (John Bound, University of Michigan, Ann Arbor; funding is for the Center, which includes HIV among its disease-specific research priorities)
- Patterns of Substance Use Among HIV Positive and Negative Aging MSM (Jessica Griffin Burke, University of Pittsburgh at Pittsburgh)
- Focus Issue on HIV and the Cardiometabolic Syndrome (Todd Cade, Washington University)
- Kidney Disease, Antiretroviral Therapy and Cardiovascular Events in HIV Infection (Andy Choi, Northern California Institute Research and Education)
- Age Effects on HIV-Associated Brain Dysfunction (Ronald A. Cohen, Miriam Hospital)
- Risk, Severity and Outcome of Bacterial Pneumonia in An HIV+/- Veteran Cohort (Kristina Anne Crothers, University of Washington)
- The Mucosal Immune System: Effects of Aging and Chronic Antigenic Stimulation (Rita Brickman Effros, UCLA)
- Cardiovascular Disease Mechanisms in HIV Infected and Uninfected Veterans (Matthew S. Frieberg, University of Pittsburgh at Pittsburgh)
- Alcohol and Coronary Heart Disease in People with HIV (Matthew S. Frieberg, University of Pittsburgh at Pittsburgh)
- Epidemiology and Mechanisms of Accelerated Aging in HIV Infection (Gregory D. Kirk, Johns Hopkins University)
- Aging and Physical Functioning in HIV (Krisann K. Oursler, University of Maryland, Baltimore)
- Sex, Aging and Antiretroviral Pharmacology (Kristine B. Patterson, University of North Carolina, Chapel Hill)

- HIV Infection, Antiretroviral Therapy, Cancer Incidence and Progression (Michael J. Silverberg, Kaiser Foundation Research Institute)
- Dementia in HIV Patients Over 60 (Victor Valcour, University of California, San Francisco)
- Chronicity of HIV and Aging on Neuropsychological and Everyday Performance (David E. Vance, University of Alabama at Birmingham)

The Office of AIDS Research Priorities for 2010 and Guidelines for the Prevention and Treatment of Opportunistic Infections

The Office of AIDS Research (OAR) is located within the NIH and coordinates the scientific, budgetary, legislative, and policy elements of the NIH HIV/AIDS research program. Through its annual comprehensive trans-NIH planning, budgeting, and portfolio assessment processes, OAR sets scientific priorities, enhances collaboration, and ensures that research dollars are invested in the highest priority areas of scientific opportunity that will lead to new tools in the global fight against HIV/AIDS. Among OAR's priorities is investigating the effects of HIV on older adults.¹⁶⁶

On March 18, 2010, OAR convened a day-long Advisory Council meeting to discuss HIV and aging. The convening, titled "HIV and Aging," brought together specialists from various fields, including cardiology, oncology, and mental health, to discuss the relationship among HIV and their respective disciplines. The meeting was open to the public. Participants were encouraged to engage guest speakers in a dialogue regarding issues related to HIV in the aging community, including increased rates of new HIV incidences among older adults, the impact of long-term use of antiretroviral therapies in older adults with HIV, premature aging in HIV-positive individuals, and other topics.

The OAR Advisory Council also publishes guidelines for the prevention and treatment of opportunistic illnesses in people with HIV/AIDS, through its Working Group for Treatment and Prevention Guidelines. The Working Group is currently reviewing a forthcoming revision of the guidelines, which would replace the existing version from 2009.¹⁶⁷ The revision will better address the needs of all people living with or at high risk of acquiring HIV, including older adults and people with comorbidities. The guidelines

are developed through a collaborative effort among NIH, the CDC, and the HIV Medicine Association of the Infectious Diseases Society of America, to provide health care practitioners with recommendations for treating and preventing opportunistic infections in HIV-positive individuals aged 13 and older.

Policy Recommendations: Aging Bodies

1. More clinical research relevant to and including people over 50 living with HIV is needed to better understand how antiretroviral medications interact with aging bodies. Clinical researchers should be encouraged to develop trials that obviate the need for exclusions based on comorbidities in people over 50, whether by designing research that takes account of comorbidities, or by loosening comorbidity-based exclusions for older HIV-positive individuals.
2. Clinical research should explore how treatments for comorbidities interact with antiretroviral medications and what effects these interactions may have on older adults. The U.S. Food and Drug Administration (FDA) should require more active post-marketing follow-up and research for all drugs to better understand interactions.
3. Further clinical research will increase understanding of what risks older people with HIV face in developing non-AIDS related cancers.
4. Standards of care for older adults living with HIV should be changed to encourage health care providers to screen people for comorbidities, particularly those found to be more prevalent among older adults living with HIV.
5. Doctors treating patients living with comorbidities found more frequently among people living with HIV, such as anal or cervical cancer, should regularly offer their patients an HIV test.
6. Senior healthcare providers, including nurses and volunteers in medical, social, and housing facilities should be trained on factors that affect older HIV-positive patients: sexuality, social isolation, stigma, comorbidity issues, and others.
7. HIV medical providers should screen for depression and other mental health and substance use problems and refer patients to appropriate treatment.

Stepping Back, Looking Forward

by Ed Shaw

I have lived in Manhattan for 50 years. I was diagnosed with HIV in 1988, but I'm sure I was positive before then. During the first five years after my diagnosis I spent very little time thinking about HIV. I was healthy and had a good job and a fulfilling social life to keep me busy. I was doing administrative work at a job placement firm in the city and spent the majority of my time working or having fun.



When I was first diagnosed with HIV in 1988 at the age of 47, never in my wildest dreams did I expect to live past 48. As I grow older, HIV remains a top priority because of its virulent behavior. I always wonder how the disease will affect my life at the age of 70, 80, or even over 90. I also have to spend time thinking about the other issues that come with aging, such as affordable housing, access to health care, and, equally important, financial independence.

We all make decisions based on historical experiences – so it's important to look back in order to move forward. From living with HIV through the decades, volunteering with an incredible spectrum of people, and my experience as a social worker, I have a prism of experiences to share.

Prior to being diagnosed, HIV and AIDS were like foreign words to me. I never would have imagined how personal they would become. I worked in the social service field, lived in a co-op with full amenities, and drove a company car. My life was filled with joy and happiness – but that would change forever. Living with HIV brought new and unexpected health challenges, along with intense stigma and discrimination.

When I was first diagnosed in the summer of 1988, my life was turned upside down. I thought I was going to die instantly – we all did. From 1988 to 1993 I lived in denial and isolation. Those five years were driven by drug and alcohol use, promiscuity, and other ill-conceived plans. Many nights I was scared that if I went to sleep, I would not wake up in the morning. I gave up on life, spent all my savings, and wouldn't tell anyone about my HIV status. There was so much stigma about having "The Big A" – I felt like someone would beat me up if they found out.

It was also hard for me to overcome my fear of the medical establishment. Many of us were concerned about interacting with doctors because of the Tuskegee medical experiment. We were well aware of how the government-run project had denied treatment and information to black men used for syphilis research, up until 1972. Many of the people with AIDS I knew feared they might be subjected to this same type of "treatment."

Then, in 1993, I had a mild heart attack and found myself in the hospital. Everything changed. I met with a counselor who told me straight up, "Mr. Shaw, you have AIDS." I was petrified, but I took the bull by the horns and started asking questions. Though the process of building trust was slow at first, I can now say unequivocally that my reservations and fears of the medical establishment have disappeared. After all these years, I still have the same clinician. While we do not always agree, we work together to keep my T-cells high and my viral load undetectable, and so far we have managed to accomplish the task.

Living with HIV over the past twenty years has changed my life. The keys to my survival have been having support from my family and friends and staying politically active. Ever since I was asked to go to my first HIV meeting back in 1993, activism has become a constant and sustaining part of my life. I take advantage of every opportunity to provide workshops and presentations, engage politicians, and speak to the issues. I also make sure to have a laugh every now and then.

Although I overcame many of the all-too-prevalent obstacles and barriers, it was a long process. While sometimes the challenges can feel insurmountable, it is important not to give up. In order to live a long life

continued

with this virus, you also have to make the right choices. That means not doing drugs, not drinking, and not having unsafe sex. Every time I see someone on a risky path I say, "I've been there, done that," and I let that person know that there are other ways to lead a healthy, fulfilling life.

For those of us who have been living with HIV for decades, it is important to take some time to enjoy life. You have to find a range of new interests to replace the things you cannot do any more, either because of age or health. Go sit in the park, read the paper, play cards, treat yourself to a show. I play chess in the park every week, and have met many wonderful people there.

If you are new to the world of living with HIV, talk to someone. People call me Dr. Ed, because I am always on call, as are many other people who are ready and willing to offer support. Also, you cannot beat yourself up. Instead, reach out. There are many people and organizations dedicated to working with and for people living with HIV and AIDS.

The more you learn, the more you can accomplish. Education is the key to advocacy. Never stop learning. Wisdom is elusive; just when you think you know it all another challenge presents itself and the process of education starts all over again. When you commit to continuously learning, it helps you and everyone around you.

Notwithstanding all the successes, there are constant challenges, such as the new rates of infection. I hope that one day the city, the country, and the world will take an approach outside the box and not just stick to the status quo. We need to get people of all generations conversing with one another. If we open up the conversation in this way we can get rid of stigmas about the virus and increase shared knowledge about prevention. We must reach across the ethnic and age barriers to get everyone talking.

Ed Shaw is Chair of New York Association on HIV Over Fifty (NYAHOF).

III. Context of HIV-positive Older Adults' Lives

The physiological challenges presented by growing older with HIV—including comorbidities, the effects of antiretrovirals and other medications, and the relationship of HIV to the aging process itself—are matched by issues in the social and human services contexts of HIV care and management. As with our understanding of HIV and aging bodies, more reliable research is needed to understand the context of HIV-positive older adults' lives. Where there is little relevant data, for example on senior housing and congregate living facilities, we must rely on existing knowledge about the experiences of older LGBT persons as a proxy, given the fact that roughly half of all people living with HIV in the U.S. are gay and bisexual men.¹⁶⁸ Along with the aging population in general, the numbers of older people with HIV will continue to grow and place increasing pressure on human services in all areas, and in this section we summarize some of the challenges we will face.

Older adults living with HIV are doubly stigmatized

“HIV stigma” is a critical issue that impacts the quality of life of all persons living with HIV. It involves prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV or AIDS. Stigma may be enacted through sanctions such as discrimination or prejudice and applied to individuals or groups. Stigma singles out the HIV-positive person and draws attention to his or her status as different or even “untouchable,” running the gamut from being served with paper plates and disposable cups at family gatherings (while everyone else has china and glasses) to outright aggression and hostility. Emotionally, HIV-positive individuals often internalize stigma in feelings of shame, guilt, anger, fear, and self-loathing.¹⁶⁹

Stigma has a negative effect on behaviors across the context surrounding HIV infection, transmission and care, including HIV test-seeking, willingness to disclose HIV status, health-seeking behavior, quality of healthcare, and social support.¹⁷⁰ This is true for older adults as well, though they face other concerns related to the specific context of being older with HIV and the double stigma of age and HIV-positive

status. The existing body of research and writing on HIV/AIDS stigma is large, but research into the stigmatization of *older people with HIV* is relatively new. University of Washington researcher Charles Emlet has provided one of the few studies aimed at understanding stigma in this population, in which he surveyed 25 older adults living with HIV who were recruited from a local AIDS Service Organization (ASO).¹⁷¹ In this sample, 96% reported having experienced HIV stigma itself, and 71% of these individuals reported the combined experience of ageism and HIV stigma.¹⁷² For example, older gay and bisexual men with HIV mentioned a strong sense of ageism and rejection by younger gay men; others, across gender and sexual orientation, reported that people in general—including medical staff and physicians—fail to understand how an older person can have HIV, much less how they might have acquired it.¹⁷³

The experience of dual HIV and age-related stigma cuts across race, gender and sexual orientation, involving themes of rejection, stereotyping, internalized stigma, employment

Caring for the Aging of the HIV-positive Population

By Dr. Amy Justice, Yale University School of Medicine

As the number of individuals over 50 living with HIV rises, our capacity to provide care is declining—both among those seeking training in HIV and in geriatrics. Vanishingly few individuals are trained in both disciplines. Similarly, despite the rising number of individuals aging with HIV who will require assisted living, nursing home, and hospice placement, staff at these facilities have no formal training and little experience in providing care. Due to these constraints in capacity and training, HIV care may be “mainstreamed” into primary care. However, the spectrum of disease and its appropriate treatment are not the same among HIV-positive and negative individuals. Unless the staff of these facilities receive formal training and guidance on special issues regarding HIV, the potential for major mistakes is substantial.

—Amy Justice, “Aging with Complex Chronic Disease: The Wrinkled Face of AIDS,” *Treatment Issues/POZ Magazine* June 2010 (forthcoming).

discrimination, fear of contagion, homophobia, and violations of confidentiality.¹⁷⁴ In Emlet's study, 56% of those interviewed reported experiencing rejection from a variety of sources, including service providers, family, friends and church members, as well as potential sexual partners.¹⁷⁵ Many older adults also reported feeling separate, alone or isolated from society, family and friends. Stereotyping involves attitudes about aging and sexuality or assumptions about how one becomes infected with HIV. Public opinion shows that people expect older adults to be more knowledgeable about HIV/AIDS simply because they are older,¹⁷⁶ and stigma can result from the assumption that older adults were infected through unprotected homosexual sex, rather than other known transmission routes.

Research has shown that public opinion about AIDS is strongly associated with homosexuality in perceptions and attitudes, and older adults living with HIV experience anti-gay bias, or stigma related to their real or perceived sexual orientation. Many older men living with HIV are presumed to be gay men, when in fact they may be heterosexual and acquired HIV through sharing needles.¹⁷⁷ A large body of research over several decades has found that older adults are more conservative on issues of gay rights and less approving of homosexuality, which may affect both an older HIV-positive person's relations with age-peers and their own internalized feelings of guilt or shame.¹⁷⁸ In the ROAH study of HIV-positive older New Yorkers, about 46% told all their family members of their HIV status, and only 35% told all of their friends.¹⁷⁹ Of those who revealed their status, whites were significantly more likely than blacks or Latinos to do so.¹⁸⁰

Public perception about responsibility for infection blames MSM more for infection than other groups, such as heterosexuals.¹⁸¹ Again, in Emlet's study, 12% of interviewees reported experiencing stigma related as much to sexual orientation as to HIV itself, and 40% of participants experienced fear of contagion (i.e., others perceived them to be highly contagious).¹⁸² Twenty-four percent of participants discussed the unwanted and unauthorized sharing of their HIV status. The violation of confidentiality sometimes took the form of casual conversation or was associated with insensitive institutional practices.¹⁸³ A common mechanism

for managing the fear of anticipated stigma of HIV is "protective silence," or the nondisclosure of one's serostatus to others, and 60% of Emlet's respondents utilized this as a method of stigma management.¹⁸⁴ The intrapersonal response of feared stigma and rejection could result from previous experiences of actual rejection.

Social isolation is a significant factor of vulnerability for HIV-positive older adults, as revealed in the ROAH study of HIV-positive older New Yorkers. Seventy percent of 914 respondents lived alone, as compared to 39% of all New Yorkers over 50.¹⁸⁵ A lack of social networks and supports leaves older adults with less resources, making them more susceptible to issues such as depression, bereavement, poor mental health, and substance abuse, which are all commonly associated with aging and HIV. The gender and sexual orientation of older adults may affect their likelihood of being partnered, a factor of considerable importance given that roughly half of all older adults living with HIV are gay and bisexual men. According to a New York-based study of housing in the elderly gay and lesbian community, lesbian women over 50 are more likely to be partnered than older gay and bisexual men, 54% of whom are single.¹⁸⁶ Only 36% of MSM in the study had a partner late in life, as opposed to 51% of women. Women are also more likely than men to live with their partner (41% of women versus only 25% of men). Similarly, men are more likely than women to live alone: 66% of older gay men and 52% of older lesbians do not live with a partner. For the disproportionate number of LGBT elders who live alone, therefore, innovative support networks and systems based on community building principles are critical.¹⁸⁷

Lack of support for nontraditional caregivers and same-sex spouses or domestic partners compounds the challenges of caring for people living HIV

The complicated and expensive nature of HIV care warrants recognition of the caregiving trends and issues for older adults living with HIV. Because of the unique context surrounding HIV, the acquisition and use of social support for caregivers might be influenced by special circumstances. Caregivers to persons with HIV have to deal with the responsibilities of caregiving as well as the pervasive stigma associated with HIV, possibly making it difficult to obtain social

support.¹⁸⁸ Caregivers for people with HIV/AIDS tend to be different than caregivers for people with other illnesses, who have traditionally been middle-age females, related to the patient by marriage or blood, caring for an older family member. By contrast, caregivers for people with HIV/AIDS have tended to be younger (less than 40) and much more heavily male (up to 40%). Male caregivers to people with HIV/AIDS have tended to be friends or domestic partners instead of blood relatives. Finally, caregivers for people with HIV/AIDS who are blood relatives tend to be older, as in a parent or aunt caring for a younger person with HIV/AIDS.¹⁸⁹

The burden of providing full care to someone who is living with HIV can be overwhelming. In some cases, caregivers must assist with all daily activities—eating, bathing, dressing, transportation, housekeeping—all while maintaining their own lives and activities. In one study it was shown that the stress of being a caregiver for someone living with HIV actually begets additional stress.¹⁹⁰ The available literature on the unique needs of caregivers of people living with HIV shows that emotional support is lacking. In a study of 642 caregivers of people living with HIV, 46% of respondents reported receiving no informal assistance with caregiving. Fourteen percent felt they had no person to go to when feeling down. The social support available to the caregiver differed based on the demographics of the caregiver: female friend caregivers reported the highest level of emotional support, and male family members reported the lowest. Finally, “family of origin” caregivers for people living with HIV (children, siblings, etc.) reported greater social isolation than nontraditional caregivers, especially those who were part of a larger gay or HIV-affected community.¹⁹¹ This is related possibly to the stigmatization of homosexuals and/or people with HIV/AIDS, estrangement between an HIV-positive person and his or her family, and the separate community (and/or family of choice) that many gay people depend on in light of sometimes difficult relationships with their family of origin.

Caregivers in same-sex couples face extra challenges that caregivers in married, heterosexual couples do not. Same-sex couples lack important supports available through Social Security spousal benefits, Medicaid spend-down provisions, and family and medical leave policies.¹⁹² They cannot be named as

beneficiary of a partner's pension under most plans and are susceptible to a tax penalty on 401(k) distributions. The Family Medical Leave Act of 1993 (FMLA) does not allow employees to take unpaid leave to care for a same-sex domestic partner or spouse, though this policy is under pressure for change. The Family Medical Leave Inclusion Act, currently before the U.S. Congress, would increase the availability of caregivers for people with HIV by allowing an employee to take up to twelve weeks of unpaid leave from work if his or her domestic partner or same-sex spouse has a serious health condition, as well as permitting employees to take unpaid leave to care for a parent-in-law, adult child, sibling or grandparent. Eight states and the District of Columbia have extended their respective state-level FMLAs to include benefits to: registered domestic partners (California and the District of Columbia¹⁹³); parties in a civil union (Connecticut, New Jersey and Vermont); reciprocal beneficiaries (Hawaii); family members, including same-sex domestic partners (Oregon and Rhode Island); and same-sex spouses as long as they were married out-of-state in a state that recognizes marriage for same-sex couples (New Mexico).¹⁹⁴ These issues will be increasingly important to people with HIV as they age, since evidence shows that high numbers of LGBT individuals serve as primary caregivers for friends and family, including partners with HIV. One study of caregiving among older gays and lesbians found that one in three provide some kind of caregiving assistance, either to children or to adults with an illness or disability.¹⁹⁵

Congregate living facilities often provide insufficient support for older adults living with HIV

As individuals age, there is often a need for a

Key Terms

HIV Stigma: Prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV or AIDS.

Caregivers: People who take care of other adults who are ill or disabled.

Congregate Living Facility: A non-institutional, independent group living environment that integrates shelter and service needs of elders.

change in their current living situations. Many transition into either nursing homes or assisted living, depending on their needs. Nursing homes differ from assisted living facilities in terms of the level of medical care and services they provide. Nursing homes provide 24-hour medical care to people with chronic medical conditions who do not require the acute care a hospital may provide.¹⁹⁶ Assisted living facilities provide a combination of housing, support services and some level of health care, and individuals in assisted living facilities are given more flexibility as to the type of assistance they desire.¹⁹⁷ Assisted living facilities are also required to provide a daily resident check-in system, two meals per day for residents, weekly housekeeping services, assistance with daily living activities, and certain health related services with administration of medications. Unfortunately, nursing homes and assisted living facilities may not be supportive environments for older adults with HIV.

There are presently no studies on the experiences of HIV-positive older adults in nursing homes and congregate living situations, but the experiences of older LGBT adults are instructive. Given the legacy of harassment and discrimination endured by many LGBT elders, along with the combined effects of HIV/gay stigma in the older population, issues of housing and LGBT elders warrant special consideration.¹⁹⁸ At present, only one LGBT-targeted retirement community in the nation—Santa Fe, New Mexico’s for-profit RainbowVision—offers assisted living for residents.¹⁹⁹ LGBT elders entering assisted living facilities and other institutions open to the general population are often presumed to be heterosexual and may feel compelled to hide their sexual orientation.²⁰⁰ Transgender elders may not be allowed to live in their appropriate gender identity. Long-term relationships may be devalued and unrecognized, and some nursing home staff treat clients presumed to be gay in a discriminatory manner, including abuse and neglect.²⁰¹ Assisted living centers, congregate housing, nursing homes, and home health care services need to take proactive steps to minimize discrimination, abuse, and neglect directed at LGBT and HIV-positive older adults.²⁰²

Staff training and changes in policy could help create a more culturally inviting and inclusive

environment. In one survey of 127 LGBT elders published in 2005, a large majority felt that staff diversity training that included a lesbian and gay component could help not only with mitigating discriminatory treatment by staff but also in building tolerance among the resident community as well.²⁰³ This belief is well-founded. In Boulder, Colorado, the Boulder County Aging Services has had demonstrated success with its “Project Visibility,” a program that trains assisted living and elder service providers on LGBT issues. Evaluation surveys of trainees showed that 84% of 110 respondents reported “an increased awareness of LGBT aging issues,” while 78% “better understood the fears experienced by some LGBT elders.”²⁰⁴ As a result, 24% of agencies participating in Project Visibility altered some of their marketing and other materials, while 18% changed internal policies.²⁰⁵

Policy Recommendations: Context of HIV-positive Older Adults’ Lives

1. The challenges of providing care to people living with HIV—both for traditional and nontraditional caregivers—require considerable support and assistance. AIDS Service Organizations (ASOs), LGBT community centers, and other community-based organizations should address these challenges through programming that supports caregivers for people living with HIV.
2. ASOs and other community-based organizations should educate people living with HIV and AIDS about the resources available under the National Family Caregiver Support Program, which uses an inclusive definition of caregiver encompassing same-sex partners and close friends. ASOs should apply for caregiver support funding through Area Agencies on Aging and state Aging Departments.
3. Home healthcare aides, who provide critical support to homebound elders and their caregivers, should be trained in the particular experiences and needs of HIV-positive elders and LGBT elders to ensure culturally competent and nondiscriminatory care.
4. The Administration on Aging and the Department of Health and Human Services should fund social marketing campaigns that challenge HIV stigma and stigma related to homosexuality.

5. Researchers should study the experiences of older HIV-positive and LGBT populations in congregate living facilities. Such research is a necessary prerequisite to the development of services appropriately tailored to these specific populations.
6. The geriatric workforce is not at all prepared to accept the growing number of older adults living with HIV. There are not nearly enough well trained medical providers to care for the elderly, in general, let alone hundreds of thousands of elders living with HIV. Very few medical schools even have a geriatric focus. More health care providers must be trained in the unique needs of HIV-positive elders, including cultural competence programs and on-going technical assistance and capacity building assistance to support the integration of new knowledge and skills into the work of elder care.
7. The Family Medical Leave Inclusion Act should be passed to modify the 1993 Family Medical Leave Act to allow employees to take unpaid leave to care for same-sex partners and other family members. This would guarantee that workers retain their employment while acting as a caretaker to a same-sex partner, parent-in-law, adult child, sibling, or grandparent living with HIV/AIDS. This extension of FMLA is very important to gay, lesbian, and bisexual older adults who are living with HIV/AIDS and are more like to be socially isolated at a time when caregiver support is absolutely necessary.

Taking Care of Myself, Taking Care of Others

by Carol Logan

In 1990 I was 40 years old, in love, and celebrating the birth of my daughter. I was not considered at high risk for HIV. I was not using drugs and was married. After my daughter was born she started having health problems and was in and out of the hospital. At 11 months she was diagnosed with HIV, and I knew that I was positive as well. I found out that the man I was in love with was out there. He had fathered children with three other women while we were married.

At first, the only person I told was my older sister. Back then it meant you had done something wrong. I was afraid my family would look down on me. After a year went by, I started to tell them. My six children struggled with my HIV diagnosis, but were always supportive. My mother and my other siblings disowned me completely.

At first I thought I had been given a death sentence but, after the initial shock, I realized that I was still healthy. At the same time, people with HIV/AIDS were dying all around me. I wanted to start taking medication as soon as possible. I wanted to stay alive. I did not know about all the negative impacts of the medications that were available in the early 1990s. I started having all types of side effects and illnesses from the toxicity levels, but I thought it was the virus. I was unable to maintain my health because I lacked knowledge. I did not know what numbers to look for, or what my charts and levels meant. That is when I started to read more about HIV medications and treatment. I got actively involved in my treatment and learned to advocate for myself.

I came to GMHC through the Childlife program. GMHC became my support system and my home away from home. Childlife provided daytime care and support for HIV-positive children. The kids would play and eat while the mothers accessed services and went to support groups. Most importantly, the kids got to be around other children who were living with HIV, as well as staff they could talk to. The kids could always talk with someone about HIV, but you could also bring your kid there and no one would tell them they had HIV. Having support systems at GMHC were so important because my family was not there for me.

One of the hardest times was when my daughter died at age 7. I had to go through it without the care and support of my family. When my daughter was in the hospital I was also sick with PCP (*pneumocystis pneumonia*). But I refused to go to the hospital. I believed that no one could take care of my daughter like I could. There were doctors and nurses with her, but I had to be there. By the time I realized that I needed to take care of myself, I literally had no other choice, and my health was at a critical point.

PCP was the first serious ailment I got. Back then it was very common, although you don't hear about it much anymore. One of the major challenges I faced in staying healthy was the lack of knowledge on how HIV affected women. Everything in treatment and diagnosis seemed geared toward men, and the doctors had a harder time figuring out what was going on with us because women's bodies are so different. Either the doctors would treat us the same as men and miss important signs of HIV progression because they showed up differently in women, or they would dismiss our issues as "a woman's thing". While a commonly known symptom for men was humps on the shoulders, women had similar lumps showing up on their chests and faces. The medication would hide in our breasts, while it would hide in men's livers. For all these reasons, it took them a long time to figure out what was wrong with me.

Being in a community of people my age provided me with support and education. We could talk about issues and share information. I really grew by being in the midst of other women and parents like myself. We always had something to learn from each other. Even though we had so many different issues (some women had been incarcerated, some women had been addicted to drugs or alcohol) and we all had different symptoms, I learned so much from listening. Maybe I didn't have the same history or symptoms as the others, but I might later.

I started volunteering and then became a peer health educator. People my age still believe that you are not at risk for HIV if you have only had one partner, are not promiscuous, and are not a partier. So many

people believe their partner or husband when they say that they do not mess around. Women need to be more empowered in these situations. Blind trust of partners and misleading information are huge issues. Women need to be empowered to take control, and have honest and open conversations about sex with partners. People need to be educated to understand transmission, risk and how to practice prevention. It is important for older adults to be empowered to talk with their doctors. Most people, doctors included, really believe that after a certain age people are not having sex, and that is just not true. Whether it is about taking their medications or about their sex life, often people will not talk to their doctor honestly.

After two decades of living with HIV I have learned how important it is to take care of myself. Women are often caregivers and put ourselves last. I used to take care of everyone else in my family, and put my own health on the backburner. Women need to learn to take better care of themselves along the way. Then they will be healthier, and better able to care for their families.

There is still so much work to do. At my church they do not want me to give out condoms. There are so many people at risk for HIV, but they do not want to talk about safer sex. They will not talk about sex at all.

Carol Logan is a peer health educator in the Women's Institute at GMHC.

IV. Healthcare and Senior Services

Over the next decade, the aging of the HIV-positive population will place great demands on the health care and social service systems. Some of these demands will reflect the general needs of our aging population, but some will be specific to the needs and demographics of the HIV-positive population, which tends to include higher concentrations of racial and ethnic minorities and people with low incomes. In this section, we review programs and policies related to social services and health care for older people with HIV and AIDS. These programs and policies target issues of aging (Older Americans Act); the economic welfare of those who have left the workforce due to age or disability (Social Security); and health care for the elderly (Medicaid), people with low-incomes (Medicaid), veterans (the Veterans Administration hospitals), and people with HIV/AIDS (Ryan White CARE Act).²⁰⁶

This review is current to the time of this writing (March 2010), but we note that programs may be affected by the recent passage of health care reform legislation in the Congress. On March 21, 2010 the House of Representatives passed the health care reform bill approved by the Senate on December 24, 2009. President Obama signed the bill into law on March 23, 2010. The bill will extend insurance to an estimated 32 million Americans currently uninsured, require larger employers to provide coverage for employees, and prohibit insurers from denying coverage based on gender or pre-existing conditions, including HIV. The bill will also limit increases in premiums by insurance companies in light of the evolving nature of the reform, this review will refer to programs and policies as they existed prior to 2010 unless otherwise noted.

The Older Americans Act could increase programs and services relevant to HIV-positive older adults

In 1965 the United States Congress passed the Older Americans Act (OAA).²⁰⁷ The Act authorized grants to states for community planning and social services, research and development projects, and personnel training in the field of aging. It also established the Administration on Aging to administer the grant programs and to serve as the federal agency to oversee matters that pertain to older adults. Eligibility for benefits and services begins at 60. Today, the OAA

and Administration on Aging has an extensive national network, providing service programs to 56 State agencies on aging (50 states plus D.C., Puerto Rico and territories), 629 area agencies on aging, nearly 20,000 service providers, 244 Tribal organizations, and two Native Hawaiian organizations.²⁰⁸ The OAA is the major source of funding and support for social and nutritional services to the elderly and their caregivers, including a wide variety of programs related to elder abuse and neglect, mental health, benefits counseling, civic engagement, nutritional services, healthy aging, evidence-based health promotion and disease prevention, adult day care, transportation, and caregiving.²⁰⁹

Since 1965, Congress has continued to appropriate funds and update the OAA through periodic amendments to the act, including programs to respond to specific needs and formula-based and discretionary grants. All programs are administered at the federal level by the Administration on Aging, except for the Title V community service employment program, which is administered by the Department of Labor (DOL). The Older Americans Act Amendments of 2006 reauthorized all programs under the Act through FY 2011 and expanded the role of federal, state, and local agencies in promoting home and community-based long-term care services. In addition, the Amendments of 2006 authorized funds for competitive grants to states to promote a comprehensive elder justice system and required the federal Administration on Aging to develop demonstration programs to help older people age in their homes as well as systems for mental health screening and treatment services. The fiscal year (FY) 2009 federal funding level is \$2.3 billion, with almost two-thirds of the funding going to support state and community grants for multiple social service programs.²¹⁰ Considering the broad sweep of services included in its mission, the Act's reach is constrained by modest resources.²¹¹

Although we have no data on the extent to which senior centers treat those living with HIV in culturally competent ways, there is evidence that senior centers do not adequately serve LGBT elders.

A 1994 study with 24 Area Agencies on Aging (AAAs) and 121 lesbian and gay elders aged 60 and older who lived in those 24 regions found that almost all of the AAAs (96 percent) did not offer any services specifically designed for gay elders,

and did not target outreach efforts to gay seniors. Only 17 percent reported staff training in the area of sexual orientation, but half said they thought there was a need for such training; 88 percent said they would be willing to provide an in-service training to staff were it available.²¹² Because many LGBT elders do not utilize services on which other seniors thrive because of a fear of discrimination, outreach to LGBT seniors and cultural competency training of staff would make senior centers and senior services more able to access LGBT seniors. Senior center staff should also be trained in the particular needs of elders living with HIV, and take steps to decrease HIV-related and anti-LGBT stigma among senior center clients.

In order to direct resources to those most in need, the Act indicates the importance of meeting the needs of specific vulnerable populations, including frail elders, older women, racial minorities, rural elders, and the growing number of the “oldest old” (85 years and older).²¹³ Neither LGBT elders nor HIV-positive older adults are explicitly listed as vulnerable populations. The upcoming 2011 reauthorization of the Older Americans Act presents unique opportunities for change that could impact HIV-positive older adults. Given its vast scope and access to diverse communities, the OAA could contain educational and programmatic aspects that address HIV-related and anti-gay stigma as it is experienced by older adults. There are also countless opportunities for HIV prevention interventions that OAA could support. Such interventions could be replicated in senior and community centers funded through the OAA nationwide.

Medicare provides crucial medical coverage for people living with HIV

Medicare is the federal government health insurance program for people who are 65 and over, for some younger people with disabilities, and for people with end-stage kidney disease.²¹⁴ Thirty-four million people, including almost all of the nation’s elderly population, have health insurance coverage through Medicare. Medicare is especially important for low-income elderly people, who are generally in poorer health than higher-income elderly people.²¹⁵ Elderly people who are poor or nearly poor are also more likely to suffer from chronic conditions that require on-going medical treatment, including arthritis, hypertension, and diabetes. Low-income

Medicare beneficiaries who are also covered by Medicaid are typically in poorer health, and are more likely to be over age 85, female, and living without a spouse than other Medicare beneficiaries.

From 1991 to 1996—in the pre-HAART era—approximately 95,000 people with HIV and AIDS had some part of their health care paid by Medicare (\$3.8 billion). Since antiretroviral therapy began, the population of Medicare beneficiaries with HIV or AIDS increased by over 80%, to include today at least 10% of all people living with HIV or AIDS.²¹⁶ HIV-positive

Key Terms

Older Americans Act (OAA): A federal act that authorized grants to states for community planning and social services, research and development projects, and personnel training in the field of aging.

Area Agencies on Aging (AAA): Agencies established under the OAA in 1973 to respond to the needs of Americans aged 60 and over in every local community.

Social Security Disability Insurance (SSDI): A monthly benefit for people who have worked in the past and paid Social Security taxes and are unable to work for a year or more because of their disability.

Medigaps: Various private supplemental health insurance plans sold to Medicare beneficiaries in the United States that provide coverage for medical expenses not covered or only partially covered by Medicare.

“Coverage Gaps” and “Doughnut Holes”: Periods during which time the beneficiary is responsible for the costs of health care and/or medications. During a “coverage gap” a person is in between coverage from one insurance policy to another. During a “doughnut hole” a person is in between levels of service eligibility.

Ryan White CARE Act: Federal legislation that addresses unmet health needs of people living with HIV/AIDS by funding primary health care and support services that enhance access to and retention in care.

AIDS Service Organizations (ASO): A health association, support agency, or other service actively involved in the prevention and treatment of HIV/AIDS.

Medicare beneficiaries are more likely than other beneficiaries to be male, under the age of 65, disabled, black, and to live in an urban area. Notably, however, the rate of increase among HIV-positive female beneficiaries is higher than males. People living with HIV can qualify for Medicare coverage in two ways: based on age, like most people; or by having received Social Security Disability Insurance (SSDI) for a span of two years, after which 93% go onto qualify for Medicare coverage.²¹⁷ Medicare spending for people with HIV comprises the largest portion of federal spending on HIV/AIDS care, surpassing Medicaid spending on HIV/AIDS for the first time in 2006. This increase was due to the inclusion of prescriptions in the new Medicare Part D coverage, which now provides subsidies for extremely costly and vital HIV medications.²¹⁸

Medicare provides coverage of basic health care services through several different programs, each of which covers a different component of health care (inpatient, outpatient, prescription drugs, etc.):

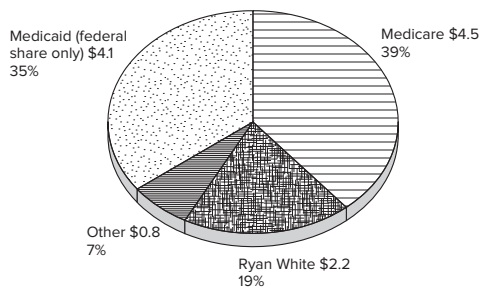
- Original Medicare: Part A (Hospital insurance) and Part B (medically necessary doctor services and outpatient care)
- Medicare Advantage Plans: Medicare Part C (private insurance for managed care and coverage of out-of-pocket expenses associated with Parts A and B)
- Medicare Supplement Insurance: Medigap Plans (private insurance to cover out-of-pocket expenses and gaps in original Medicare)
- The Prescription Drug Benefit: Medicare Part D

Original Medicare

Medicare Parts A and B are known as “Original Medicare.” These were the program as it was created in the 1960s in order to provide elderly Americans with secure and reliable health care options not available through private insurers. Medicare Part A helps to pay for inpatient care in a hospital, skilled nursing facility, or hospice. Under certain conditions, Part A will also provide some portion of home health care. Most people do not have to pay a monthly premium for Medicare Part A if they or a spouse paid Medicare taxes while working in the United States. Medicare Part B helps pay for medically-necessary doctors’ services and other outpatient care, including some preventive services, such as flu shots and other services that keep certain illnesses from getting worse. Most people who utilize Part B pay the standard monthly premium, which will be \$110.50 in 2010 for individuals with an income of \$85,000 or less annually.²¹⁹

Original Medicare does not cover all health care costs, and patients are left with a variety of out-of-pocket expenses including coinsurance, deductibles, 20% of the cost of procedures and treatment under Part B, and, notably, the cost of prescription medications. Also, many forms of preventive care are not covered under Part B. The cost of services not covered by Medicare, such as skilled nursing or long-term care, fall to the patients and their families. To deal with these costs, different Medicare supplement programs—Part C, Medigap Programs, and Part D—have been developed, which offer elderly people a variety of ways to customize their health care.

Federal funding for HIV/AIDS care by program, FY2008



Source: Medicare and HIV/AIDS, February 2009. The Henry J. Kaiser Family Foundation.

Medicare Advantage Plans: Medicare Part C

Medicare Part C regulates and approves “Medicare Advantage Plans,” which are provided by private insurers primarily through Health Maintenance Organizations (HMOs) or Preferred Provider Organizations (PPOs). Advantage Plans manage a person’s coverage through Parts A and B, pick up other costs associated with Medicare, provide preventative and other doctor services not covered by Part B, and usually offer a prescription drug (Medicare Part D) package. With an Advantage Plan, the patient consolidates all Medicare functions and payments in the one HMO or PPO network.²²⁰

While Medicare Advantage Plans bridge the gaps in Medicare’s original coverage, they come with

limitations. Patients are typically restricted to care within the Advantage Plan’s HMO or provider network, which can be severely problematic for people over 50 living with HIV who have a broad range of medical needs due to the complications of aging with HIV and high rates of comorbidities. Medicare Advantage plans vary by region, and they do not transfer across regions. Advantage Plans are required to cover the same services as original Medicare, but they may include additional co-pays and fees. Once someone is enrolled in a certain Advantage Plan they are only allowed to switch plans within a set period of time. Advantage Plans may change catchment areas for their coverage, forcing enrollees to change plans over and over again. The variety of plans and features they offer—to say least of the cost of different features—can be bewildering, and Advantage Plans actually cost the government more than Medicare itself.²²¹

Medicare Supplement Insurance: Medigap Plans
A second option for covering expenses associated with Original Medicare is Medicare Supplement Insurance (Medigap) purchased through private insurers. Supplement insurance policies, called

“Medigap Plans,” cover some of the out-of-pocket expenses associated with Original Medicare, including copayment, coinsurance, and deductibles. Federal regulations provide for up to twelve different Medigap plans (distinguished as Medigap A, B, C, through L), which offer different packages of benefits but must include at least three basic services: Medicare Part A coinsurance and the cost of an extra 365 days of hospital care after Medicare ends, Part B coinsurance (to cover the 20% gap), and the first three pints of blood used in a treatment or procedure. For the other out-of-pocket expenses associated with Medicare (deductibles and specific services such as skilled nursing), Medigaps A through L each offer different packages of coverage that a person can choose according to his or her own needs. As with Advantage Plans, Medigaps have limitations. None of the standard Medigap policies will cover long-term care to help with basic living needs like bathing, dressing, eating, vision or dental care, hearing aids, or private-duty nursing. Medigaps will not cover health care costs for a spouse or prescription drugs.²²²

Medicaid eligibility pathways for people living with HIV/AIDS²³³

Category	Criteria	Mandatory/ Optional
SSI beneficiaries	Disabled (having a physical or mental impairment that prevents one from working for a year or more, or that is expected to result in death) AND low-income with few assets (standard=74% of federal poverty level, PFL). ²³⁴	Mandatory (all states must cover)
Parents, children, pregnant women	Low-income; income and asset criteria vary by category and state	Mandatory; states have option to offer higher income thresholds (expanding eligible pool)
Medically needy	Allows those who meet categorical eligibility, such as disability, to spend down on medical expenses to meet state’s income criteria	Optional; 35 states currently use option for the disabled
Disabled workers	Disabled; low-income	Optional
Poverty-level expansion	Allows for income above SSI levels up to the poverty level	Optional; 19 states use option
State-Supplemental Payment (SSP)	Allows for coverage of those receiving SSP	Optional; 23 states use option for disabled

Source: The Henry Kaiser Family Foundation

The Prescription Drug Benefit: Medicare Part D

Part D took effect in 2006 and is administered through private plans by contract through Medicare (like Part C, Medicare Advantage). Beneficiaries may obtain Part D coverage through stand-alone Prescription Drug Plans (PDPs) that can be purchased along with other Medicare Supplement Insurance (Medigaps), or they can add Part D coverage under a Medicare Advantage Plan (Part C). Due to the high costs of antiretrovirals, Part D benefits are very important to people living with HIV, but while Part D plans cover all approved antiretroviral therapies, they do not always cover other drugs that HIV-positive older adults need due to comorbidities.²²³

Part D coverage is complicated and includes a deep “coverage gap” that is very costly to people who need expensive medications, such as antiretrovirals. To begin with, beneficiaries pay a standard Part D monthly premium that may be as low as \$40 a month or less. After meeting an annual deductible of around \$300, the beneficiary then pays only a percentage of the cost of the prescription drugs, up to a total prescription cost of \$2,830. Once this threshold is reached, the beneficiary is responsible for 100% of prescription costs until the annual total reaches \$4,550, at which point “catastrophic coverage” begins and the beneficiary pays no more than 5% of the prescription costs for the remainder of the year. The coverage gap between \$2,830 and \$4,550 is commonly referred to as the “doughnut hole,” and this feature of Part D wreaks havoc on the lives of people with high-cost prescriptions—which includes anyone on antiretroviral therapy—who must find a way each year to cover a couple thousand dollars’ worth of prescriptions to bridge the doughnut hole.²²⁴ Additionally, not all drug costs will count toward bridging the doughnut hole; only payments for drugs on the Medicare formulary (i.e. drugs that would be covered under Part D rules) will count toward the “True Out Of Pocket” (TrOOP) expenses that must reach \$4,550 for catastrophic coverage to take effect. Thus, the costs of new drugs, experimental drugs, over-the-counter products, and drugs

Commonly referred to as the “doughnut hole,” this feature of Medicare Part D wreaks havoc on the lives of people with high-cost prescriptions—which includes anyone on antiretroviral therapy.

purchased abroad (which are usually much cheaper than those purchased in the U.S.) are not normally applicable to TrOOP.

“Low income subsidies” (LIS), which are also known as “extra help,” are available to beneficiaries who meet eligibility requirements and do not exceed a specified amount of assets (around \$11,000 at the time of this writing). LIS will pay the Part D premium, eliminate the doughnut hole, and reduce co-payments for drugs to less than \$4.00. Medicare beneficiaries who are also enrolled in Medicaid are eligible for LIS. HIV-positive Medicare beneficiaries who do not qualify for LIS may obtain prescription drug assistance through the AIDS Drug Assistance Program (ADAP), which is administered by states under the Ryan White Care Act (see section below on Ryan White funds and ADAP).

The Medicare Improvements for Patients and Providers Act of 2008

Under the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA), the Centers for Medicare & Medicaid Services (CMS) has the flexibility of adding to Medicare’s list of covered preventive services, if certain requirements are met. This includes coverage for HIV infection screenings for Medicare beneficiaries who are at increased risk for the infection. Prior to this law, Medicare could only cover additional preventive screening tests when Congress authorized it to do

so. Under MIPPA, CMS can consider whether Medicare should cover preventive services that Congress has not already deemed as covered or non-covered by law, as long as these services are “strongly recommended” or “recommended” by the U.S. Preventive Services Task Force. CMS uses the national coverage determination process to make decisions on these types of preventive services. This process provides transparency about the evidence that CMS considers when making its decisions and allows opportunity for the public to comment on the proposals.

The complicated structure of Medicare does not allow for a strong degree of provider choice. Given the lack of HIV and LGBT sensitivity of

many providers, older adults living with HIV may have difficulty in accessing the highest quality of care. The required waiting period of 24 months for someone on SSDI to access Medicare is a barrier to adequate health care for some people living with HIV. Additionally, the coverage gaps, especially in Medicare Part D, need to be addressed. The current policy of not counting ADAP payments towards TrOOP expenses shifts a cost burden from Medicare to ADAP. This should be changed so that money paid to ADAPs by Medicare clients will count towards their TrOOP limit. While the coverage of currently approved antiretrovirals is comprehensive, it will be important to continue monitoring the inclusion of new antiretrovirals medications that come out. Simultaneously, the need for extended coverage of prescription medications which many people living with HIV need due to comorbidities is a continuing issue.

Given current trends, Medicare will need to be more responsive to the needs of older adults living with and at risk for HIV. The December 2009 decision by CMS to cover HIV screening tests for Medicare beneficiaries announced in is a step in the right direction and is vitally important for the health of older adults. Expansion of coverage must be coupled with efforts by older adults, doctors, and service providers to increase awareness of the change and encourage utilization of testing.

Medicaid provides vital medical coverage for most elderly Americans, including many with living with HIV and AIDS

Medicaid is a means-tested program providing health care for specific categories of eligible persons, mainly the disabled, low-income children and their parents, and the medically needy. The program is jointly funded by the federal government and states, and program requirements are a mix of, federally mandated standards and individual state programs and requirements. The program was created as part of the War on Poverty package of legislation in 1965, and it is the nation's primary health insurance safety-net for low income Americans. Medicaid finances health and long-term care

services for more than 59 million people, 6 million of whom are elderly people who also have coverage with Medicare.²²⁵ Medicaid covers somewhere between 200,000 and 240,000 people living with HIV or AIDS across the nation.²²⁶ Because most HIV-positive Medicaid beneficiaries are not dually eligible for Medicare, Medicaid is a critical source of funding for antiretroviral prescription drugs.²²⁷ The combined federal and state Medicaid spending for beneficiaries with HIV is around \$8 billion, making Medicaid the largest source of public funding for HIV/AIDS care in the country.

Medicaid is a state administered program, and each state sets its own guidelines regarding eligibility and services.²²⁸ In order to be eligible, low-income families must have limited assets and be included in a group that is "categorically eligible." All states must cover mandatory eligibility groups in order to receive matching federal funds; however, states can also choose to cover optional eligibility groups, in which case they can access more federal matching funds.²²⁹ Once approved for Medicaid, payments for a client's healthcare costs are sent directly to the health care provider. Depending on the state, a client may be asked to pay a small amount for some medical services (i.e. co-payment).²³⁰

Federal law prohibits childless adults in all states from Medicaid benefits unless they are disabled, which has a painful impact on low income people with HIV.

Federal regulations prohibit childless adults in all states from Medicaid benefits unless they are disabled, which has painful impact on low income people with HIV.^{230a} The infection itself does not necessarily qualify for disability status, which for the most part is met only with an AIDS diagnosis, but the federally recommended antiretroviral therapies that prevent rapid progression to AIDS are too costly for most low-income people.²³¹ This problem may soon be rectified with healthcare reform, through a provision in proposed legislation that includes previously independent legislation called the Early Treatment for HIV Act. This provision will give states the option to expand Medicaid eligibility to people with asymptomatic HIV infection. This will lead to more reliable medical care for many people living with HIV and less strain on under-resourced discretionary care programs like the Ryan White Treatment

Extension Act (formerly called the Ryan White CARE Act).

Currently there are five state demonstration projects which work to address the lack of access to medication for low-income people living with HIV until their health deteriorates significantly enough for them to be considered “disabled.” Currently three states have been authorized to use Section 1115 vouchers of the Social Security Act to extend Medicaid to people living with HIV who meet all criteria besides the legal definition of disability. Additionally, two states utilize demonstration grants through the Ticket to Work/Work Incentives Improvement Act of 1999 to provide access to people living with HIV whose short-term health has improved, thus causing them to become ineligible for the legal definition of disability and the benefits of treatment which allowed the improvement in health outcomes.²³² These demonstration projects provide a model for how Medicaid policy can be successfully expanded. Increasing early access will ensure better health outcomes for people living with HIV.

Medicaid has long served as support for seniors struggling to meet long-term care needs while trying to stay financially afloat. The coverage that Medicaid provides to seniors takes two forms: (a) payment for health and long-term care services that Medicare does not cover, notably outpatient prescription drugs and long-term care; and (b) assistance with the costs of Medicare premiums and co-insurance requirements. Most low-income Medicare beneficiaries are eligible for both forms of Medicaid coverage; the rest are eligible only for assistance in meeting Medicare premium and cost-sharing requirements.²³⁵ Medicaid eligibility policy is complex, making the program difficult for elderly and other low-income Americans to understand and for state Medicaid officials to administer. This is a major battle for a significant number of eligible elderly people who—in the face of burdensome application forms, complicated procedures and negative perceptions of Medicaid among their peers and families—simply do not enroll.²³⁶

For seniors who lack long-term care insurance, the need to enter a nursing home presents a

dual crisis in personal finance and health care. Because Medicaid eligibility is based on need, they must spend virtually all of their assets on care before Medicaid can step in, essentially impoverishing themselves in order to qualify for assistance. For heterosexual couples who are married and own their own home, Medicaid regulations will allow one member of the couple to remain in the couple’s home for the rest of his or her life without jeopardizing the other spouse’s right to Medicaid coverage. Upon the survivor’s death, the state may then take the home to recoup the costs of terminal care. However, since federal law does not recognize the marriages of same-sex couples, Medicaid regulations do not afford this protection to same-sex spouses, even if they have spent their entire adult lives together. As such, same-sex partners have to choose between giving up a home and a life’s savings in

order to afford medical coverage to meet a partner’s health care needs, or forsaking medical coverage in order to maintain the home and savings.²³⁷ Legislators in Vermont and Massachusetts have devised a way to circumvent this inequality in federal Medicaid policy, in part because states match Medicaid dollars one-to-one. Vermont allows couples in civil unions to be treated as married opposite-sex couples under its Medicaid policy. Because the Vermont policy is paid for through the exclusive use of state

funds, the federal government has not objected. Similarly, the MassHealth Equality Bill, signed into law on August 1, 2008, uses state funds for Medicaid to extend benefits to same-sex couples who are married.²³⁸

Social Security provides a safety-net for people living with HIV who qualify as disabled

Although Social Security is an important insurance program for people of all ages, people ages 65 and over are the largest single demographic group of recipients at any given point in time.²³⁹ Sixty-five percent, or 15 million, of these older adults rely on Social Security for over half of their income and 33% rely on Social Security for over 90% of their income. Nationally, the median married couple or individual recipient age 65 and over relies on Social Security for 67% of income.²⁴⁰ As with Medicaid, people

Same-sex partners have to choose between giving up a home and a life’s savings in order to afford medical coverage.

living with HIV must be considered disabled under the definition of the law to access Social Security benefits, but all people living with HIV do not meet this definition. Under the current law people living with HIV have to experience a decline in their immune systems to a point where they receive an AIDS diagnosis and/or are unable to work.²⁴¹

The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities.²⁴² A person is considered disabled if (a) they cannot do the work they once did before, (b) the Social Security Administration decides that they cannot adjust to other work because of their medical condition(s); and (c) their disability has lasted or is expected to last for at least one year or to result in death. Under the law, disability payments cannot begin until a person has been disabled for at least five full months. Payments usually start with the sixth month of disability and continue indefinitely, depending on the disability.²⁴³ Each January, benefits will increase automatically if the cost of living has gone up. For example, if the cost of living has increased by two percent, a person's benefits also will increase by two percent. People who have limited income and resources may qualify for Supplemental Security Income (SSI). SSI is a federal program that provides monthly payments to people age 65 or older and to people who are blind or disabled. Approved applicants may also be able to get other benefits, such as Medicaid and food stamps.²⁴⁴

Because federal law does not recognize same-sex marriages, same-sex partners are not eligible for either spousal benefits or survivor benefits. Survivor benefits allow widows, widowers, and dependent children to put food on the table following a partner's or parent's death by accessing the retirement savings a spouse or parent collected while paying into the Social Security system throughout his or her whole working life. The unfairness of excluding same-sex partners from accessing these savings was particularly poignant following the attacks of

September 11, 2001, when same-sex survivors of victims were denied survivor benefits as well as workers compensation.

Similarly, same-sex partners also are denied access to the spousal benefit, which allows husbands and wives to receive an amount equal to 50% of their spouse's monthly Social Security check, if that amount is higher than the amount for which their own earnings would make them eligible each month. This benefit is particularly important in partnerships in which one partner earns significantly less than the other.²⁴⁵ The lack of eligibility for these income support programs costs LGBT elders hundreds of millions of dollars in unaccessed income per year. Same-sex

couples should be treated the same as opposite-sex married couples under Social Security policies.

There is a concern about the interplay of Social Security benefits with long term disability insurance. For some individuals who have purchased private long term disability insurance, when they become disabled they receive a portion of their prior income amount, which is comprised of their private insurance and Social Security Disability Insurance. In some cases one can be receiving 65% of their prior income amount. However, once an individual reaches "retirement age," the private insurance discontinues. The age at which this occurs is determined by the private insurance policies, and at

times will coincide with Social Security benefits, but not necessarily. What this means is that older adults living with HIV could be living with a steady income until they reach "retirement age," at which point their income, and presumably their ability to access quality healthcare, drops significantly. Additionally, if an individual was disabled for a number of years prior to that time, he or she was probably unable to adequately save finances for a healthy retirement. This issue is affecting many individuals with long term disability insurance, and could have grave implications for their ability to manage their HIV infection.

AIDS service organizations, LGBT centers, and others serving people living with HIV should

Older adults living with HIV could be living with a steady disability income until they reach "retirement age," at which point their income, and presumably their ability to access quality healthcare, drops significantly.

educate their clients considering going on disability about the discontinuation policy held by the insurer. Education about retirement planning and the potential loss of income should be addressed for people living with HIV before they reach the age at which this could be problematic.

The Department of Veterans Affairs is the largest single provider of medical care to people with HIV

The U.S. Department of Veterans Affairs (VA) is the largest single provider of medical care to people with HIV in the United States. Since 1981, over 62,000 veterans with HIV or AIDS have been treated at VA hospitals; currently, over 20,000 HIV/AIDS patients are treated or cared for by the VA each year.²⁴⁶ The VA's efforts in this area are led by the office of Clinical Public Health Programs, under the direction of the Public Health Strategic Health Care Group (PHSHG), whose mission is to provide the highest quality, comprehensive care to veterans and to set the standard by which all health care in the United States is measured. This includes patient care activities, clinician and patient education, prevention activities, and research directed at continuous improvement of medical and preventive services and delivery of care to veterans.²⁴⁷ VA medical facilities screen for risk of HIV infection, test those at risk, educate patients and their families, give providers access to the best available information about HIV and support research to improve clinical care.²⁴⁸

The VA provides a Medical Benefits Package to all enrolled veterans. This comprehensive plan provides a full range of preventive outpatient and inpatient services within the VA health care system. Once enrolled in the VA healthcare system, a patient can be seen at any VA hospital throughout the United States.²⁴⁹ The VA operates an annual enrollment system that helps to manage the provision of health care by providing an overall population of beneficiaries. Additionally, the enrollment system ensures that Veterans who are eligible can get care and

ensures that care is given to veterans who are eligible. The VA applies a variety of factors in determining veterans' eligibility for enrollment, but once a veteran is enrolled, that Veteran remains enrolled in the VA health care system.²⁵⁰

In addition to being a crucial provider of care for HIV-positive people and veterans of all ages, the VA is an important resource for Americans over 65, about one-third of whom (11.5 million people) are eligible for VA benefits. The "Veterans Pension" is a needs-tested benefit (low-income and low-assets) that can provide up to \$1,843.00 per month to qualified veterans, who can use the money to pay for eldercare services at home.²⁵¹

With appropriate documentation of need and care given, payments can be made to children, relatives, friends, home care companies, or domestic workers.²⁵² The Veterans Pension is a little-known benefit, but with the appropriate documentation and counseling even veterans or their spouses who would fail the needs-based tests can qualify for the pension. Domestic partners are not eligible to receive the pension, although married opposite-sex partners are—with the consequent unequal and disproportionate effect on gay and bisexual veterans and their long term partners or same-sex spouses

Overall, the VA is an excellent, and sometimes under-utilized, method of receiving reliable and quality healthcare, but veterans living with HIV are frequently unaware of their ability to access VA benefits.

There is often confusion about

eligibility as it relates to time of service; status of discharge; or being gay, lesbian, or bisexual. As noted above, only married opposite-sex partners are eligible as spouses for the veteran's pension. Veterans who receive an "other than honorable" or "dishonorable" discharge are often ineligible for most VA benefits, which has a disproportionate effect on drug users, many of whom were dishonorably discharged.²⁵³ Under the military's "Don't Ask Don't Tell" policy, openly gay, lesbian and bisexual soldiers can be dismissed for revealing or being found to be gay. The level of discharge is determined

Veterans who receive an "other than honorable" or "dishonorable" discharge are often ineligible for most VA benefits, which has a disproportionate effect on drug users, many of whom were dishonorably discharged.

by the commanding officer.²⁵⁴ Under these circumstances, though most soldiers receive an honorable or general discharge, some soldiers can receive an “other than honorable” discharge or a “dishonorable” discharge if they are charged for sodomy or if they challenge their discharge under the policy and lose their appeal.²⁵⁵ The “Don’t Ask Don’t Tell” policy applies only to those serving active duty, so gay and lesbian veterans can openly access VA benefits.²⁵⁶

HIV-specific healthcare programs help fill in the gaps of medical coverage for people living with HIV

In addition to the myriad healthcare programs and benefits available to older adults, there are other programs that specifically address the care of people living with HIV and AIDS. Chief among them are the programs funded by the Ryan White CARE Act, which was first passed in 1990. The Ryan White CARE Act has been reauthorized several times across the span of four different presidents, most recently in 2009, and includes a budget of about \$2.3 billion. Altogether, programs

Ryan White HIV/AIDS treatment programs, funding by part, FY2008

Types of Grants		Appropriation (in millions)
Part A	Formula grants to eligible metropolitan areas and transitional grant areas; competitive supplemental grants	\$627.1
Part B	<ul style="list-style-type: none"> • Formula base grants; supplemental base grants; emerging communities grants • AIDS Drug Assistance Program (ADAP); ADAP supplemental grants 	\$386.7 \$808.5
Part C	Competitive grants for early intervention and core medical services	\$198.8
Part D	Competitive grants for women, infants, children, and youth	\$73.7
Part E	N/A – guidelines and internal procedures	N/A
Part F	<ul style="list-style-type: none"> • AIDS education and training centers • Dental reimbursement • Special projects of national significance 	\$34.1 \$12.9 \$25.0
Total		\$2,166.8

Source: National Health Policy forum, “The Basics” (The Ryan White HIV/AIDS Treatment Program).

Federal funding for HIV/AIDS by category, FY2006–FY2010 (USD \$Billions)

Category	2006	2007	2008	2009	2010
Care/Treatment	\$10.3	\$11.0	\$11.7	\$12.5	\$13.2
Cash/Housing Assistance	\$2.1	\$2.2	\$2.3	\$2.4	\$2.5
Prevention	\$0.878	\$0.900	\$0.872	\$0.875	\$0.929
Research	\$2.6	\$2.7	\$2.7	\$2.8	\$2.8
Global	\$3.2	\$4.4	\$5.9	\$6.4	\$6.5
Total	\$19.2	\$21.2	\$23.4	\$24.9	\$25.8

Source: Kaiser Family Foundation, “U.S. Federal Funding for HIV/AIDS: The Presidents FY2010 Budget Request,” *HIV/AIDS Policy Fact Sheet* (November 2009), <http://www.kff.org/hivaids/upload/7029-05.pdf> (accessed March 17, 2010).

affiliated with Ryan White serve well over 500,000 clients each year, almost half of the entire population of people living with HIV and AIDS.²⁵⁷

The CARE Act was established to meet the healthcare needs of people living with HIV. Its structure reflects the epidemiologic trends of infection across the country, and it is divided into several individual parts.²⁵⁸ Part A is directed to cities with disproportionate rates of HIV, deemed “eligible metropolitan areas.” Part B is allocated to states and territories for HIV care, and it includes the ADAP, which is the largest single program of the CARE Act. Funding for ADAP in 2008 stood at \$808.5 million and was increased to \$835 million for 2010.²⁵⁹ Part C supports community health centers with competitive grants for early intervention and other core medical services, and Part D provides competitive grants to programs that serve women, youth, and families. Part E concerns federal procedures and coordination of the act and federal agencies, and it does not allocate funding to services. Part F primarily contains funding for dental care, and training and education facilities. The CARE Act is administered by the Health Resources Services Administration (HRSA), a branch of the Department of Health and Human Services.

In addition to the CARE Act, there are also cash and housing assistance programs available to people living with HIV, currently funded at \$2.4 billion.²⁶⁰ Housing assistance is available through the Housing Opportunities for People with AIDS (HOPWA). This program is administered through the Department of Housing and Urban Development (HUD). The federal government provides \$2.8 billion for research mainly through the NIH and \$745 million in for prevention programs mainly through the CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention. The Minority AIDS Initiative was created in 1998 and will receive about \$414 million for FY2010. In all, the total federal funding requested by the president for HIV/AIDS programs in 2010 stands at \$25.8 billion, of which approximately \$19.4 billion is domestic programming, with \$6.5 billion going to international programming in PEPFAR-supported countries and other initiatives.

The way in which CARE Act programs impact accessibility of other benefits can be problematic. For example, for those people accessing

prescription coverage through Medicare Part D and “catastrophic coverage,” ADAP can cover some co-payments, deductibles, and other cost sharing. However, these expenses do not count towards the True Out Of Pocket (TrOOP) costs which must be met before a recipient can climb out of the Medicare Part D “doughnut hole” and become eligible for catastrophic drug coverage. Consequently, ADAP may be covering beneficiaries’ entire prescription drug costs for the remainder of a given calendar year, and the beneficiaries are limited to more restrictive ADAP formularies. In this sense, ADAP is underwriting Part D programs. This use of ADAP is both unfair and inefficient—if ADAP were counted toward TrOOP costs, Medicare catastrophic coverage would kick in and ADAP dollars would be freed up to help other needy individuals who cannot qualify for Medicare. As this paper goes to press, the TrOOP issue is being addressed by the health care reform proposal before the U.S. Congress.

Policy Recommendations: Healthcare and Senior Services

1. HIV-positive elders and LGBT elders should be listed as vulnerable populations in the 2011 reauthorization of the Older Americans Act (OAA).
2. The OAA should be revised to include educational and programmatic aspects that address HIV related stigma as it is experienced by older adults.
3. Leaders of senior centers and other institutions serving older adults should make clear that all clients deserve equal and respectful treatment, regardless of sexual orientation or gender identity. Staff training in this area is sorely needed.
4. Staff at nursing homes, long-term care facilities, and senior centers should be trained in the particular experiences and needs of HIV-positive elders to ensure culturally competent and non-discriminatory care. AIDS Community Research Initiative of America (ACRIA) and Services and Advocacy for GLBT Elders (SAGE) offer excellent cultural competency trainings in these areas. Such interventions could be replicated in senior and community centers funded through the OAA nationwide.

5. As the HIV-positive population ages, Medicare will need to be more responsive to the needs of older adults living with and at risk for HIV. The December 2009 decision by the Centers for Medicare and Medicaid Services to cover HIV screening tests for Medicare beneficiaries is an essential step in both treating and preventing the spread of HIV. This expansion of coverage should be coupled with efforts by older adults, doctors and service providers to increase awareness of the change, and encourage utilization of testing.
6. The required waiting period of 24 months for someone on Social Security Disability Insurance (SSDI) to access Medicare should be decreased to eliminate barriers to adequate health care for some people living with HIV.
7. The coverage gaps in Medicare Part D need to be addressed. Under Medicare Part D the continued inclusion of new antiretroviral medications is necessary to ensure the best health outcomes for people living with HIV. Simultaneously, Part D should cover medications needed to treat comorbidities. *Note: Under the health care reform legislation signed into law on March 29, 2010, antiretrovirals as a class are required to be covered by Medicare Part D prescription drug plan (PDP) sponsors. The new law does not address medications needed to treat comorbidities beyond their possible inclusion in categories or classes of drugs required to be covered by a PDP sponsor.*
8. ADAP payments for antiretroviral drugs should be counted towards the True Out-Of-Pocket (“TrOOP”) costs of Medicare Part D beneficiaries. *Note: The health care reform legislation passed by the U.S. House of Representatives on March 23, 2010 may address this issue by closing the “doughnut hole” in Part D coverage, but the specifics of the final legislation await Senate action and implementation as we go to press.*
9. The federal government should grant states the option to expand Medicaid eligibility to people with asymptomatic HIV infection. This would lead to more reliable medical care for many people living with HIV, and less strain on under-resourced discretionary care programs like the Ryan White Treatment Extension Act (formerly called the Ryan White CARE Act). *Note: This recommendation was included in the initial health care reform proposals before Congress in 2009, but it was not in the bill signed into law on March 21, 2010.*
10. Marriage equality should be enacted to allow same-sex partners to access the many health related benefits now afforded to heterosexual couples. In the meantime, Medicaid regulations should be changed to provide same-sex partners the ability to remain in their homes without jeopardizing their partners’ right to Medicaid coverage.
11. AIDS Service Organizations (ASOs), LGBT centers, and others serving people living with HIV should educate their clients who are considering going on disability about the discontinuation policy held by the insurer. Education about retirement planning and the potential loss of income should be addressed for people living with HIV before they reach the age at which this could be problematic.
12. Same-sex couples should be treated the same as opposite-sex married couples under Social Security’s spousal and survivor benefit policies.
13. The “Don’t Ask Don’t Tell” policy of the United States military should be repealed as soon as possible. In the interim, the military should stop giving dishonorable discharges to service members accused of homosexuality who challenge their dismissal.
14. Veterans living with HIV should be aware of their rights and opportunities to access Veterans Administration (VA) benefits . In order to eliminate the confusion many veterans feel about eligibility as it relates to time of service or being gay or lesbian, the VA should expand outreach efforts in order to enroll more veterans and eligible family members.

Summary of Policy Recommendations

Epidemiology

1. The Centers for Disease Control and Prevention (CDC) should improve epidemiological surveillance systems and data collection to provide specific data delineated by age and risk category. Such data would inform HIV preventionists and gerontological health providers on what proportion of older HIV-positive adults get HIV through homosexual sex, heterosexual sex, and injection drug use.
2. The CDC should collect data on gender identity in addition to transmission categories such as MSM (men who have sex with men). This would provide national level data on HIV among transgender persons.
3. The CDC's efforts should fund the development, tailoring, and targeting of HIV prevention interventions for older adults, including MSM, women, and African Americans. They should also target high risk sexual behaviors, both heterosexual and homosexual.
4. Healthcare providers, especially doctors, should proactively assess older patients for sexual health risks and sexual activity, and screen for HIV.

Aging Bodies

1. More clinical research relevant to and including people over 50 living with HIV is needed to better understand how antiretroviral medications interact with aging bodies. Clinical researchers should be encouraged to develop trials that obviate the need for exclusions based on comorbidities in people over 50, whether by designing research that takes account of comorbidities, or by loosening comorbidity-based exclusions for older HIV-positive individuals.
2. Clinical research should explore how treatments for comorbidities interact with antiretroviral medications and what effects these interactions may have on older adults. The U.S. Food and Drug Administration (FDA) should require more active post-marketing

follow-up and research for all drugs to better understand interactions.

3. Further clinical research will increase understanding of what risks older people with HIV face in developing non-AIDS related cancers.
4. Standards of care for older adults living with HIV should be changed to encourage health care providers to screen people for comorbidities, particularly those found to be more prevalent among older adults living with HIV.
5. Doctors treating patients living with comorbidities found more frequently among people living with HIV, such as anal or cervical cancer, should regularly offer their patients an HIV test.
6. Senior healthcare providers, including nurses and volunteers in medical, social, and housing facilities should be trained on factors that affect older HIV-positive patients: sexuality, social isolation, stigma, comorbidity issues, and others.
7. HIV medical providers should screen for depression and other mental health and substance use problems and refer patients to appropriate treatment.

Context of HIV-positive Older Adults' Lives

1. The challenges of providing care to people living with HIV—both for traditional and nontraditional caregivers—require considerable support and assistance. AIDS Service Organizations (ASOs), LGBT community centers, and other community-based organizations should address these challenges through programming that supports caregivers for people living with HIV.
2. ASOs and other community-based organizations should educate people living with HIV and AIDS about the resources available under the National Family Caregiver Support Program, which uses an inclusive definition of caregiver encompassing same-sex partners and close friends. ASOs should apply for caregiver support funding through Area Agencies on Aging and state Aging Departments.
3. Home healthcare aides, who provide critical support to homebound elders and their caregivers, should be trained in the particular

experiences and needs of HIV-positive elders and LGBT elders to ensure culturally competent and nondiscriminatory care.

4. The Administration on Aging and the Department of Health and Human Services should fund social marketing campaigns that challenge HIV stigma and stigma related to homosexuality.
5. Researchers should study the experiences of older HIV-positive and LGBT populations in congregate living facilities. Such research is a necessary prerequisite to the development of services appropriately tailored to these specific populations.
6. The geriatric workforce is not at all prepared to accept the growing number of older adults living with HIV. There are not nearly enough well trained medical providers to care for the elderly, in general, let alone hundreds of thousands of elders living with HIV. Very few medical schools even have a geriatric focus. More health care providers must be trained in the unique needs of HIV-positive elders, including cultural competence programs and on-going technical assistance and capacity building assistance to support the integration of new knowledge and skills into the work of elder care.
7. The Family Medical Leave Inclusion Act should be passed to modify the 1993 Family Medical Leave Act to allow employees to take unpaid leave to care for same-sex partners and other family members. This would guarantee that workers retain their employment while acting as a caretaker to a same-sex partner, parent-in-law, adult child, sibling, or grandparent living with HIV/AIDS. This extension of FMLA is very important to gay, lesbian, and bisexual older adults who are living with HIV/AIDS and are more like to be socially isolated at a time when caregiver support is absolutely necessary.

Healthcare and Senior Services

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institutions serving older adults should make clear that all clients deserve equal and respectful treatment, regardless of sexual orientation or gender identity. Staff training in this area is sorely needed.

4. Staff at nursing homes, long-term care facilities, and senior centers should be trained in the particular experiences and needs of HIV-positive elders to ensure culturally competent and non-discriminatory care. AIDS Community Research Initiative of America (ACRIA) and Services and Advocacy for GLBT Elders (SAGE) offer excellent cultural competency trainings in these areas. HIV prevention interventions should be supported by OAA and should be implemented. Such interventions could be replicated in senior and community centers funded through the OAA nationwide.
5. As the HIV-positive population ages, Medicare will need to be more responsive to the needs of older adults living with and at risk for HIV. The December 2009 decision by the Centers for Medicare and Medicaid Services to cover HIV screening tests for Medicare beneficiaries is an essential step in both treating and preventing the spread of HIV. This expansion of coverage should be coupled with efforts by older adults, doctors and service providers to increase awareness of the change, and encourage utilization of testing.
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beneficiaries. Note: *The health care reform legislation passed by the U.S. House of Representatives on March 23, 2010 may address this issue by closing the “doughnut hole” in Part D coverage, but the specifics of the final legislation await Senate action and implementation as we go to press.*

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9. The federal government should grant states the option to expand Medicaid eligibility to people with asymptomatic HIV infection. This would lead to more reliable medical care for many people living with HIV, and less strain on under-resourced discretionary care programs like the Ryan White Treatment Extension Act (formerly called the Ryan White CARE Act). Note: *This recommendation was included in the initial health care reform proposals before Congress in 2009, but it was not in the bill signed into law on March 21, 2010.*
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In October 2009, AARP hosted a meeting of the partnership and other policy makers in Washington, DC. The meeting included representatives from the White House Office of National AIDS Policy, the Health Resources Services Administration, and the Administration on Aging, along with a number of people from national HIV/AIDS organizations and national aging organizations. Following this meeting, the partnership hosted a Congressional briefing on HIV and aging. In addition to remarks by GMHC, AIDS Action Council, and ACRIA, Dr. Amy Justice of the Yale School of Medicine spoke about her research on HIV and aging. The briefing was well attended by Congressional staff. GMHC and ACRIA took the issues surrounding HIV and older adults to the broader public we serve in a jointly produced issue of *Achieve* magazine (Fall 2009), a quarterly publication on HIV prevention, treatment, and politics read by over 35,000 people. Finally, in February 2010 the partnership presented a briefing in Albany for policy makers and legislators in New York State.

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Written by: Sean Cahill, PhD; Blair Darnell; John A. Guidry, PhD; Alana Krivo-Kaufman; Nathan Schaefer, MSSA; Lyndel Urbano; Cassandra Willyard; and Robert Valadez, MSW.

Edited by: Sean Cahill, PhD; Nathan Schaefer, MSSA; and John A. Guidry, PhD.

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GMHC is a not-for-profit, volunteer-supported and community-based organization committed to national leadership in the fight against AIDS.

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GMHC
The Tisch Building
119 West 24 Street
New York, NY 10011

gmhc.org



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