



# OLDER PEOPLE AND HIV

## **HOW MANY OLDER PEOPLE HAVE AIDS?**

About 29% of all people with AIDS in the United States are age 50 or over. In 2001, this proportion was 17%. In some cities, as many as 37% of people with AIDS are older than 50.

The number of older people diagnosed with AIDS is increasing. There are three types of older people with HIV: people who have been living with HIV for many years; older HIV-infected people who are just learning their HIV status; and older people newly infected with HIV. About half of the older people with AIDS have been infected for one year or less.

The rates of HIV/AIDS among older people are 12 times higher for African-Americans and 5 times higher for Hispanics compared with whites.

Many people don't consider age 50 to be "old." However, age 50 is being used more often to keep statistics on "older people" with HIV and AIDS.

## **WHY ARE OLDER PEOPLE GETTING INFECTED?**

There are several reasons:

- Health care providers may not test older people for HIV infection
- Older people may lack awareness of the risk factors for getting HIV (see Fact Sheets 150 and 152)
- Many older people are newly single. They get divorced or lose their mates. While they had a partner they may have ignored HIV prevention messages
- Very little HIV prevention education is targeted at older people
- Many older people believe that HIV only affects younger people
- Most older people get no training in safer sexual activities (see Fact Sheet 151)
- Drug use accounts for more than 16% of infections of people over 50
- Unprotected sexual activity. This may be heterosexual or homosexual sex. Viagra and other drugs that help men get and maintain an erection may contribute to increased rates of sexual activity and sexually transmitted diseases among older people, as they do for younger people.
- Physicians may not diagnose HIV infection in older people. Some early symptoms of HIV disease may appear to be signs of normal aging.

- The stigma of having HIV/AIDS may be worse for older people. This can result in hiding their infection from family and friends.

## **IS HIV DISEASE DIFFERENT FOR OLDER PEOPLE?**

The first studies of HIV in older people were done before strong anti-HIV drugs were available. Most of them showed that older people got sicker and died faster than younger people. This was thought to be due to the weaker immune systems of older people. Also, older people usually have health problems in addition to HIV.

Recent research shows that older people respond well to antiretroviral treatment. Most older patients, unless they are drug users or have mental problems, take their medications more regularly than younger patients. They have better adherence (see Fact Sheet 405.)

## **IS HIV THE SAME IN OLDER PEOPLE?**

CD4 cell levels do not recover as quickly in older patients as in younger patients. Unfortunately, we don't have good information on older people because they were usually not included in clinical trials of new drugs.

Treatment side effects may not be any more frequent in older people. However, changes caused by aging can resemble or worsen treatment side effects. For example, older age is a major risk factor for heart disease and for increasing fat in the abdomen. Some older people without HIV lose fat that looks similar to the changes caused by lipodystrophy.

Recent research suggests that many of the health problems of older people progress faster in people with HIV. Inflammation is a major factor in several diseases of aging.

## **WHAT OTHER HEALTH PROBLEMS ARE COMMON?**

As people age, they develop health issues that continue for the rest of their lives. These can include heart disease (see fact sheet 652,) depression (see fact sheet 558,) osteoporosis (see Fact Sheet 557), high blood pressure, kidney problems (see fact sheet 651,) arthritis, diabetes, Alzheimer's disease and various forms of cancer.

Older people often take many different medications to deal with their health problems. This can make it more difficult for a doctor to choose anti-HIV drugs because of interactions with other medications.

## **MENTAL PROBLEMS**

Older people may have more problems with thinking and remembering than younger people. These symptoms can appear the same as HIV-related mental problems. Fact Sheet 505 has more information on HIV and nervous system problems.

These problems, sometimes called dementia, are less severe than they were before the use of strong anti-HIV drugs. It is difficult to know what is causing mental problems in older people with HIV. Is it normal aging, or is it HIV disease? Research studies have linked both age and higher viral load (see Fact Sheet 125) to mental problems.

Rates of depression and substance use haven't been well studied in older people. However, these problems may be related to HIV disease, aging, or both. They need to be diagnosed and treated correctly.

## **THE BOTTOM LINE**

The number of people over 50 with HIV or AIDS is growing rapidly. About 29% of people with AIDS in the United States are over age 50.

Older people get HIV the same way as younger people. However, they may not be aware that they are at risk of HIV infection. They also may not know how to protect themselves from HIV transmission.

Older people have to deal with other health issues. These can complicate the selection of anti-HIV medications. They can also be confused with some of the side effects of HIV drugs.

HIV drugs seem to work as well in older people as in younger people, although their CD4 cell counts may be lower. Also, older people may be better about taking their medications than younger people.

*Revised May 27, 2011*



## Daniel Tietz

Executive Director, AIDS Community  
Research Initiative of America

# Aging & HIV: The New Face of HIV

Posted: 12/01/11 09:55 AM ET

It is estimated that by 2017, and possibly as early as 2015, more than half of all individuals with HIV in the U.S. will be age 50 or older. This wonderful increase in life expectancy is largely due to effective treatment, which has created a rapid rise in the number of people over age 50 with HIV. Thirty years into this epidemic, this good news is tempered by other, more troubling facts. Approximately one out of every six new HIV diagnoses is among adults over age 50. In 2009 there were 34,995 new cases of AIDS in the U.S. with nearly one-quarter of these occurring in those aged 50 or older. So while AIDS diagnoses may be decreasing overall, it is of great concern that AIDS diagnoses among older adults are rising.

ACRIA has been at the forefront of HIV and aging, conducting groundbreaking research. Our *Research on Older Adults with HIV* (ROAH), the largest study ever conducted on older adults with HIV, used a nearly 1,000-person cohort in New York City to examine a comprehensive array of issues, including health status, stigma, substance use, depression, social networks, and spirituality. ROAH was unique in the kinds of questions it asked, for the first time probing in-depth the sexual and drug-taking risk behaviors of older people with HIV, as well as gathering data on medical and psychosocial issues. Following ROAH, we've conducted more in-depth research on HIV, older adults and depression and partnered with others on related studies across the globe, including the Terrance Higgins Trust and Chelsea Westminster Hospital in the United Kingdom, the Center on Halsted in Chicago, Gay Men's Health Crisis in New York City, and Syracuse University, among others.

What we've learned may surprise you. Providers often underestimate the desire for and level of sexual activity in older adults, and maybe especially among gay, bisexual and transgender older adults who are at high risk for HIV, thereby neglecting their STI risk. While many older adults are sexually active, they often do not perceive themselves to be at risk for HIV or other sexually transmitted infections (STIs), if only because HIV disease is largely and wrongly associated with youth. Thus, prevention messages have not targeted this older population and, as a result, they unwittingly engage in high risk behaviors. We also know that many older adults with HIV who know their status continue to engage in high risk conduct at rates comparable to other high risk groups.

Nonetheless, older adults are much less likely to be tested for HIV than younger adults, with many being diagnosed with HIV only when receiving treatment for other medical conditions. Lower rates of testing and delays in detection not only facilitate the spread of HIV, but increase the likelihood of progression to AIDS resulting in increased illness and death rates as well as decreased effectiveness of anti-HIV treatment. Indeed, the likelihood of receiving a concurrent HIV and AIDS diagnosis increases strikingly with age. In light of such data, the need for routine testing to ensure early diagnosis is evident as is the need for a better understanding of HIV transmission among older adults.

Through innovative research, education and advocacy, ACRIA is improving lives by influencing public policy, identifying unmet needs, bringing together HIV, aging and other service providers to improve life-saving services, and identifying research gaps in this understudied population. For example, ACRIA joined an expert panel from across the U.S. to craft the first-ever recommended treatment strategies for older adults with HIV, in collaboration with the American Academy of HIV Medicine and the American Geriatrics Society. This just-released report can be found at [www.aahivm.org/hivandagingforum](http://www.aahivm.org/hivandagingforum).

In addition, via a partnership with Gay Men's Health Crisis (GMHC) and Services and Advocacy for GLBT Elders (SAGE), and with support from the MAC AIDS Fund, we initiated a public policy and advocacy effort in early 2009 to highlight the needs and challenges of an aging HIV population. Among other actions, we helped to organize and participated in the first-ever White House meeting on HIV and aging in October 2010. Following this meeting, the Office of AIDS Research at the National Institutes of Health created a research advisory group on HIV and aging, which includes an ACRIA researcher.

On this year's World AIDS Day, with more hope than ever that we might in our lifetime bring the AIDS epidemic to an end, much remains to be done. We must maintain (indeed, increase!) our investment in prevention, including routine testing and access to prompt treatment for all with HIV. And we must act now to better understand and address the needs and challenges of what will soon be the majority of Americans with HIV -- those over age 50.

# The Aging HIV Population Who Are These Older Adults with HIV ?

Stephen Karpiak PhD  
Associate Director for Research

**AIDS Community Research Initiative of America (ACRIA)**

**ACRIA Center on HIV and Aging**

New York University College of Nursing  
NYU Medical Center for AIDS Research



## ACRIA : AIDS Community Research Initiative of America

founded in New York City in 1991

### Clinical Trials

- Antiretrovirals
- Side-effects management
- Comorbid treatments

### Research on Older Adults

- Social networks
- Depression management
- Comorbidities
- Service utilization
- Accessing caregivers
- Stigma
- Spirituality

### Education Health Literacy

- Staff/agency trainings on needs of aging HIV populations & those at-risk
- Local and national technical assistance & capacity building
- Continuing education credits
- Materials in several languages



## It Has Been 30 Years

By the end of 1990, just nine years from the start of the epidemic, approximately 160,000 Americans had been diagnosed with AIDS and 110,000 of them had already died

As of 2010 there are nearly 1.1 million Americans living with HIV

By 2015 the CDC estimates that one-half of Americans with HIV will be age 50 and older



September 2008: HHS Establishes  
September 18 as an annual  
National HIV/AIDS and Aging Awareness Day

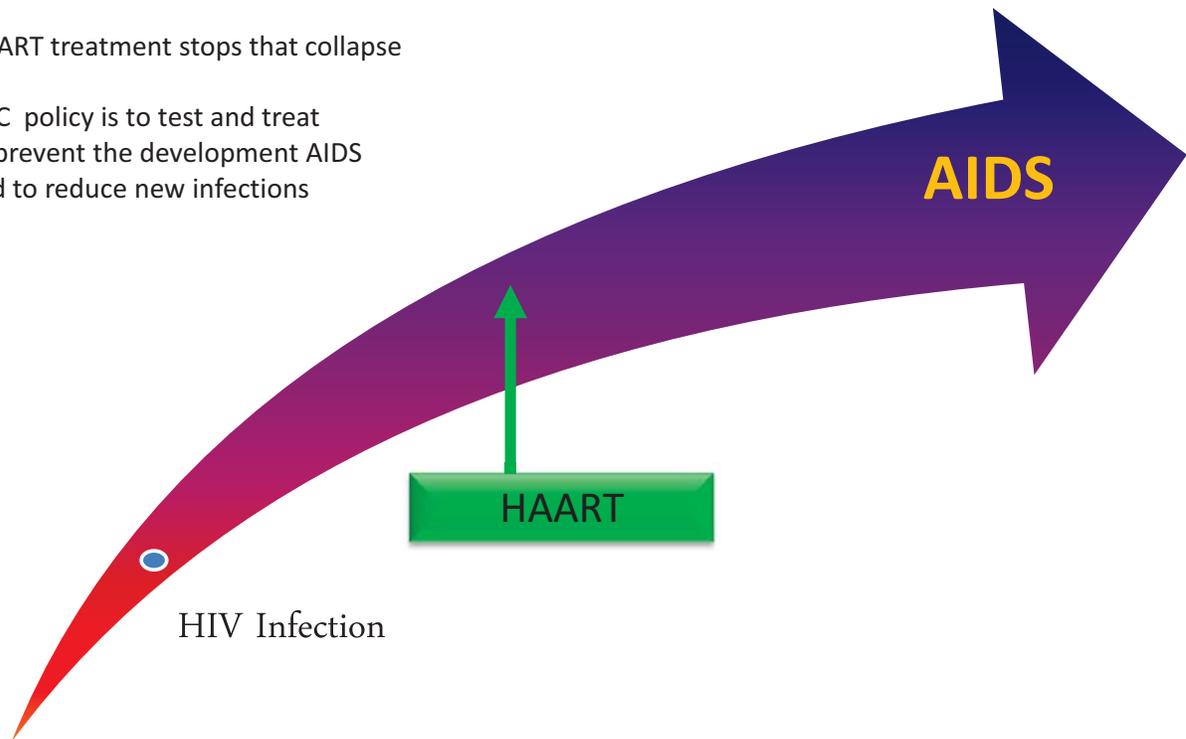
Oct 2010:  
White House Office of National AIDS Policy convenes  
a Special Meeting on HIV and Aging



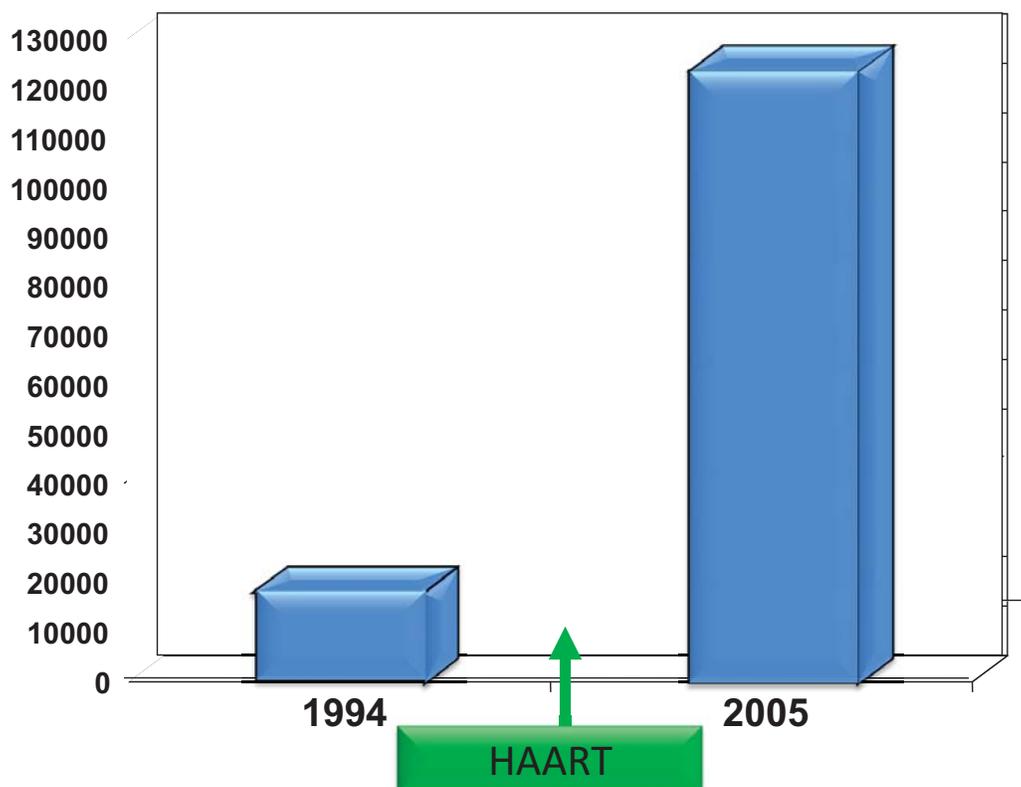
It takes 10 years for the virus to cause the collapse of the immune system resulting in AIDS

HAART treatment stops that collapse

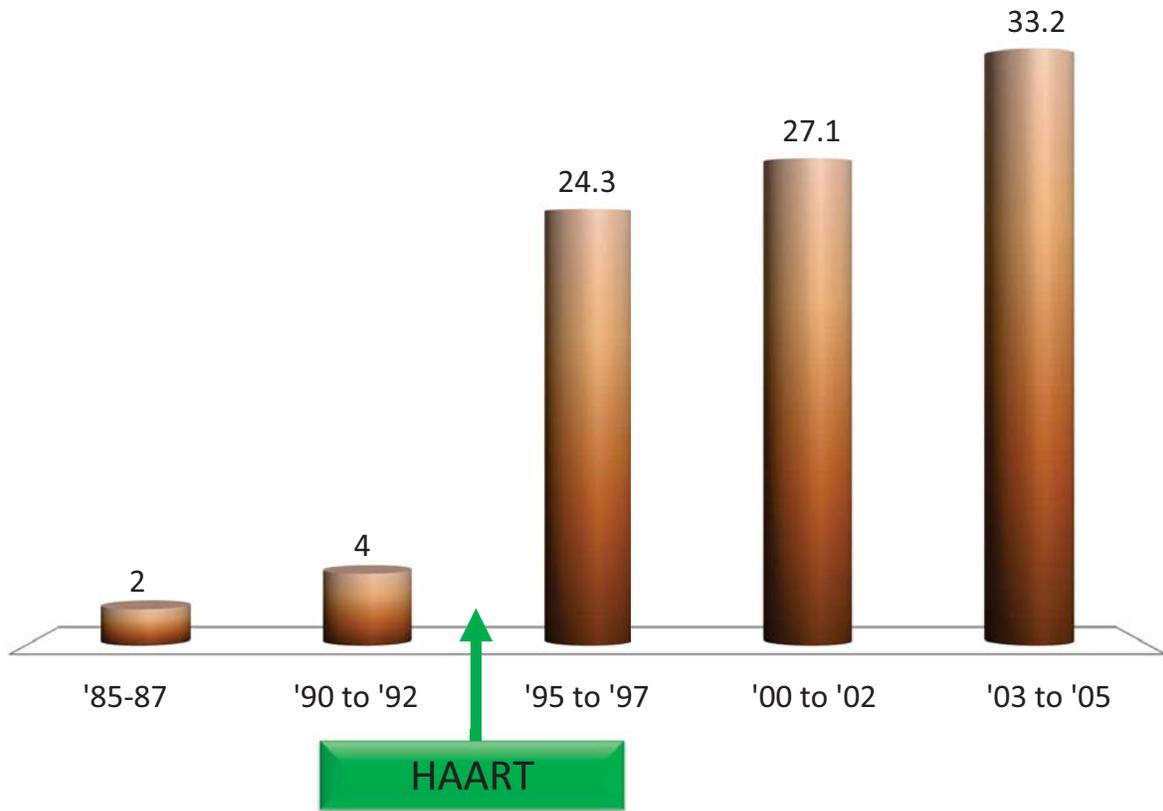
CDC policy is to test and treat to prevent the development AIDS and to reduce new infections



USA AIDS Cases Over Age 50 - CDC

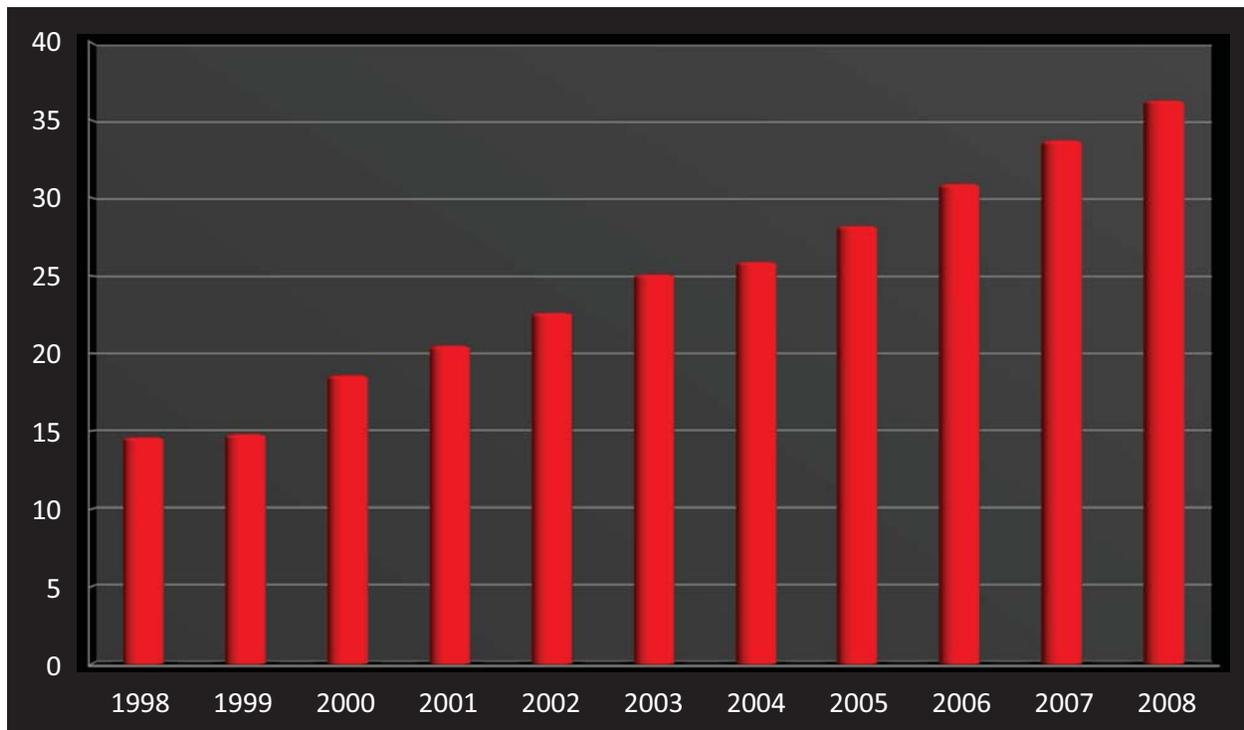


## Median Life Years at Age 20 with HIV and in Care



## % of People Living with AIDS Diagnosis Over Age 50 in US

CDC Surveillance Data



# New York City is the U.S. HIV Epicenter

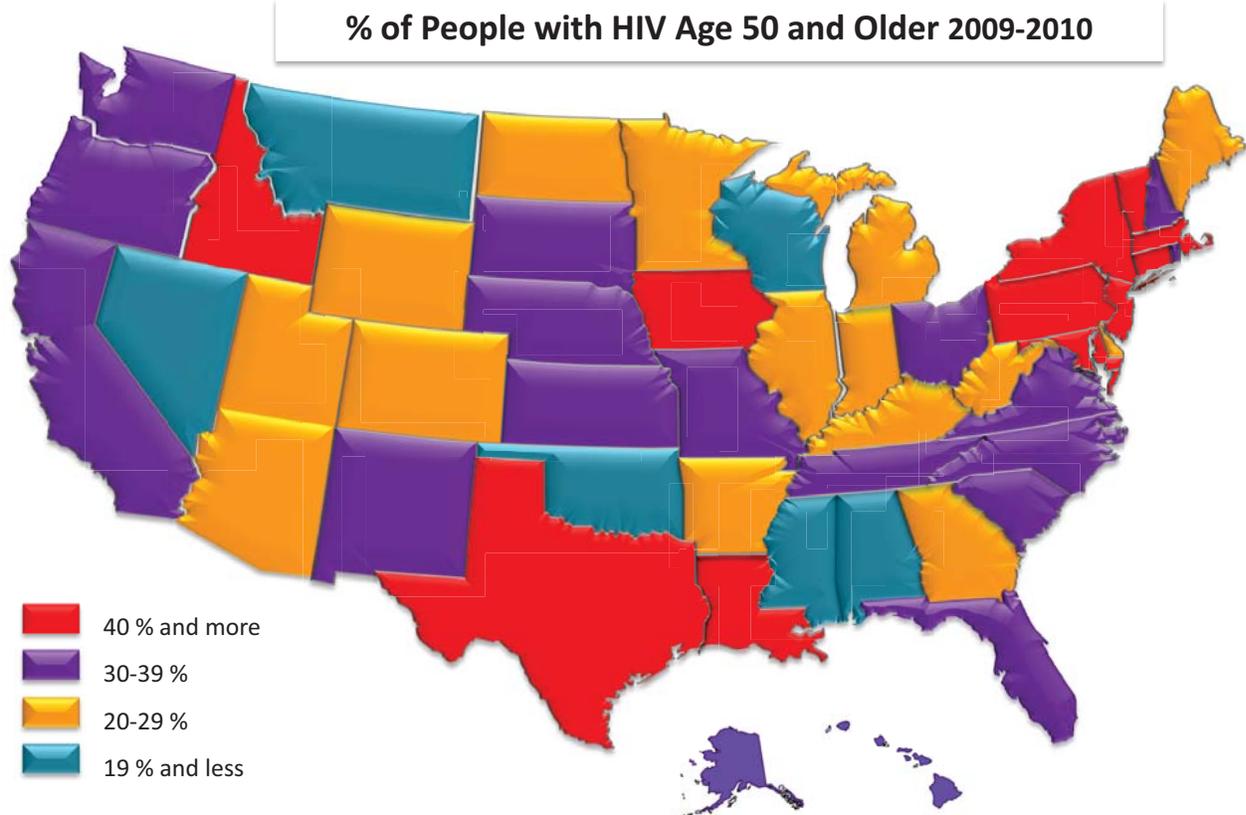
There are approximately

**120,000**

people living with HIV

**42%** are over age 50  
and

**75%** are over age 40



## Why is the HIV Population Growing and Graying?



- Drugs to treat HIV are effective thereby transforming a diagnosis from a death sentence to a long life span



- The overwhelming majority of older adults with HIV were infected before age 50



- Almost 1 in 6 new HIV infections occur in people 50 and older



- New HIV infections have been largely ignored HIV Prevention efforts have not targeted older adults

ACRIA Funded Initial Studies On HIV and Aging in 2004



# WHO

## Are These Older Adults Living with HIV?

Nearly 1,000 NYC Adults Over Age 50



# RESEARCH on OLDER ADULTS with HIV

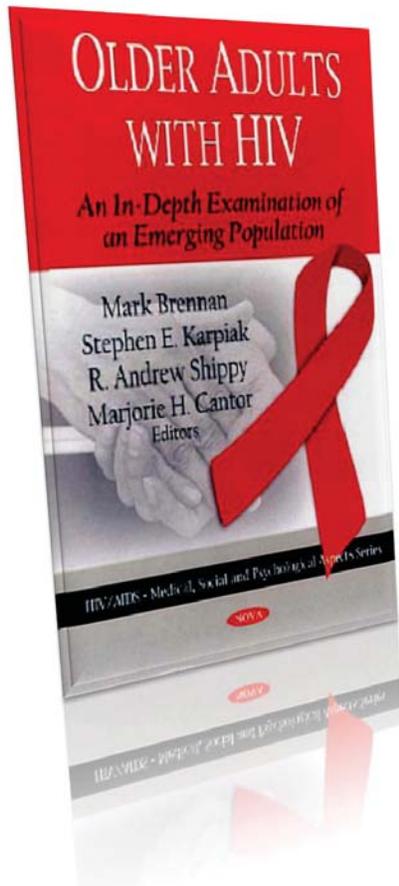
**Stephen E. Karpiak, PhD**

**Mark Brennan, PhD**

Principal Investigators

ACRIA Center on HIV and Aging

## ROAH is COMPREHENSIVE



**Demographics**

**Sexual Behavior / Substance Use**

**Social Networks**

**Psychological Well-Being**

**Distress – Depression**

**HIV Status/Health**

**Religiousness & Spirituality**

**Loneliness Among Older Adults**

**HIV Stigma and Disclosure**

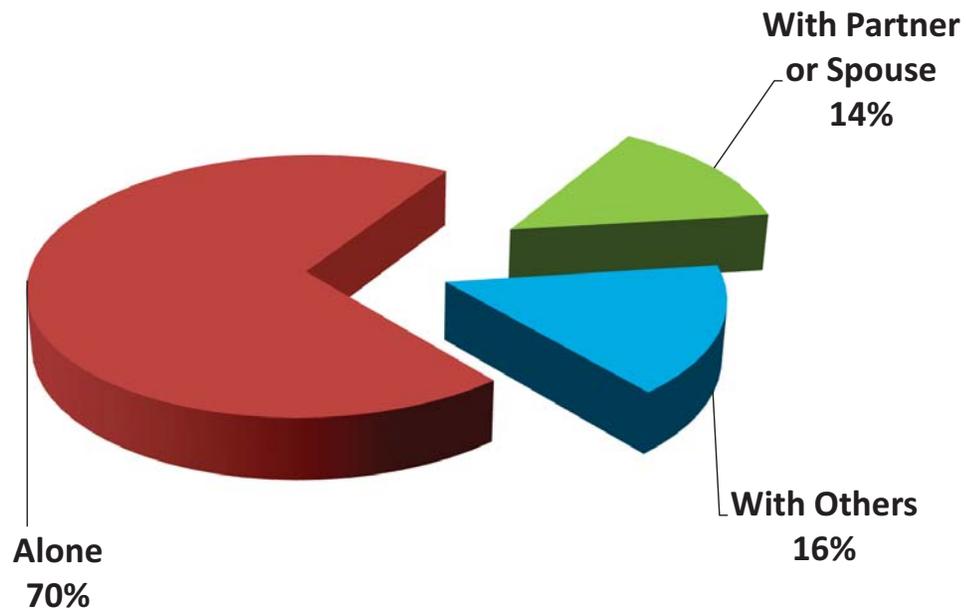
- **70% Live Alone**
- **Most are Socially Isolated**
- **Less than 15% have spouses/partners**
- **Less than 20% have children**
- **Fragile social networks – no informal caregivers**
- **A majority remain involved with their Congregations**
- **20% provide care giving to others**
- **Resiliancy**

## **ROAH:HIV Treatment and Care**

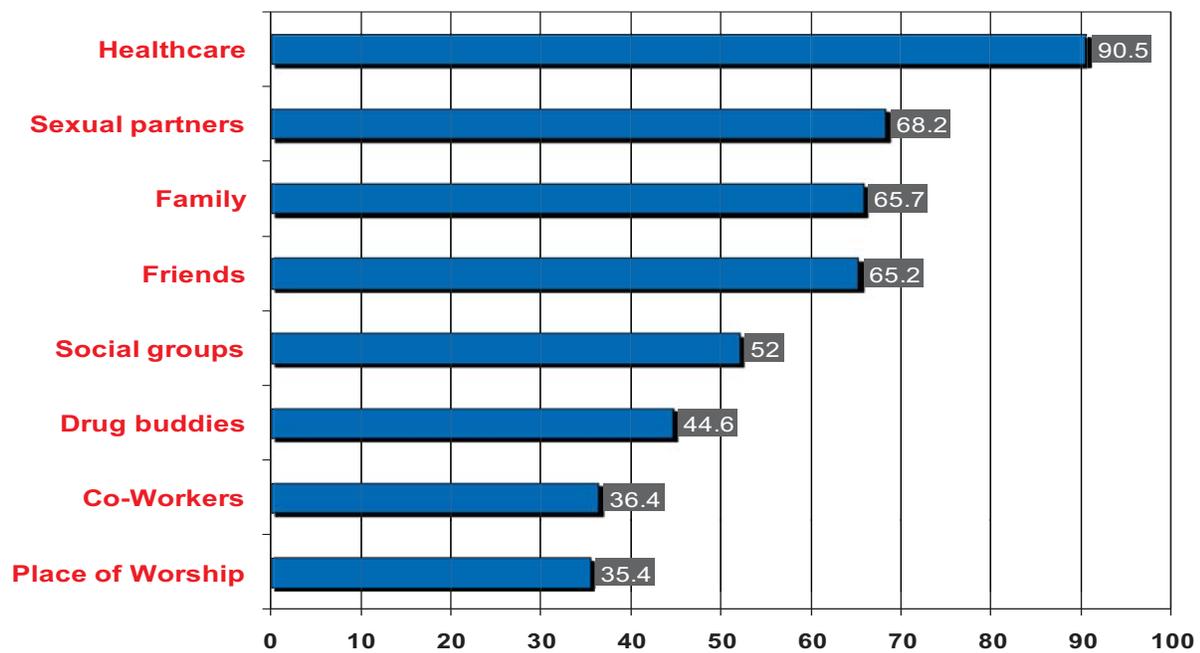
<b>Treatment facility</b>	<b>%</b>
– Private physician	<b>21.9</b>
– Public clinic / hospital	<b>58.7</b>
– VA Hospital	<b>4.9</b>
– AIDS Service Organizations	<b>17.0</b>

**83% of ROAH Participants Rely on Medicaid**

# ROAH: Living Arrangement



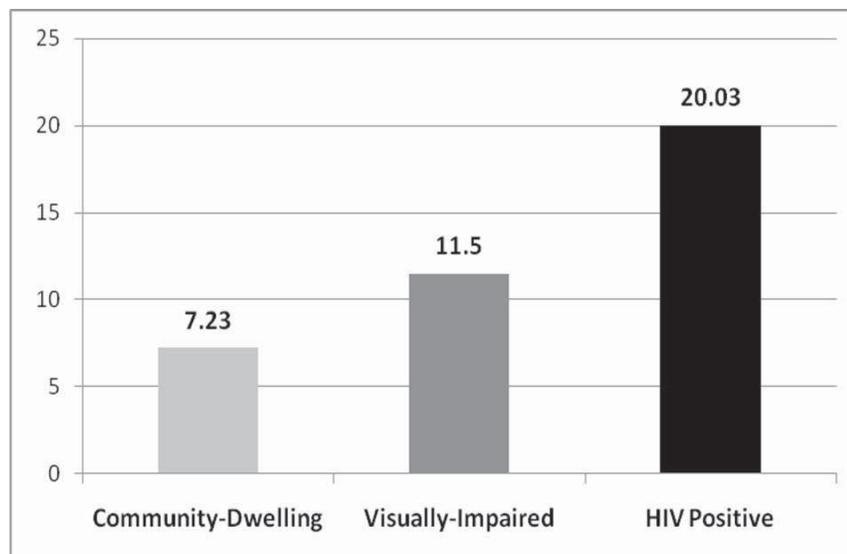
## ROAH: Stigma and Disclosure of HIV Status (%)



# ROAH: Substance Use Recovery

<u>Recovery Status</u>	<u>%</u>
■ Ever enrolled in 12-step	62
■ Currently in recovery	54
■ No substance use in past 3 months	48
■ In recovery for more than 1 year	44

## Depression in ROAH vs. Other Older Adults



**Figure 2** Comparison of Average CES-D Scores among Middle-age and Older Adults who are Community-dwelling, Visually-Impaired, or Living with HIV in ROAH. Data on Community-dwelling adults and visually impaired adults were obtained from Gump et al. (2005) and Horowitz et al. (2006), respectively.

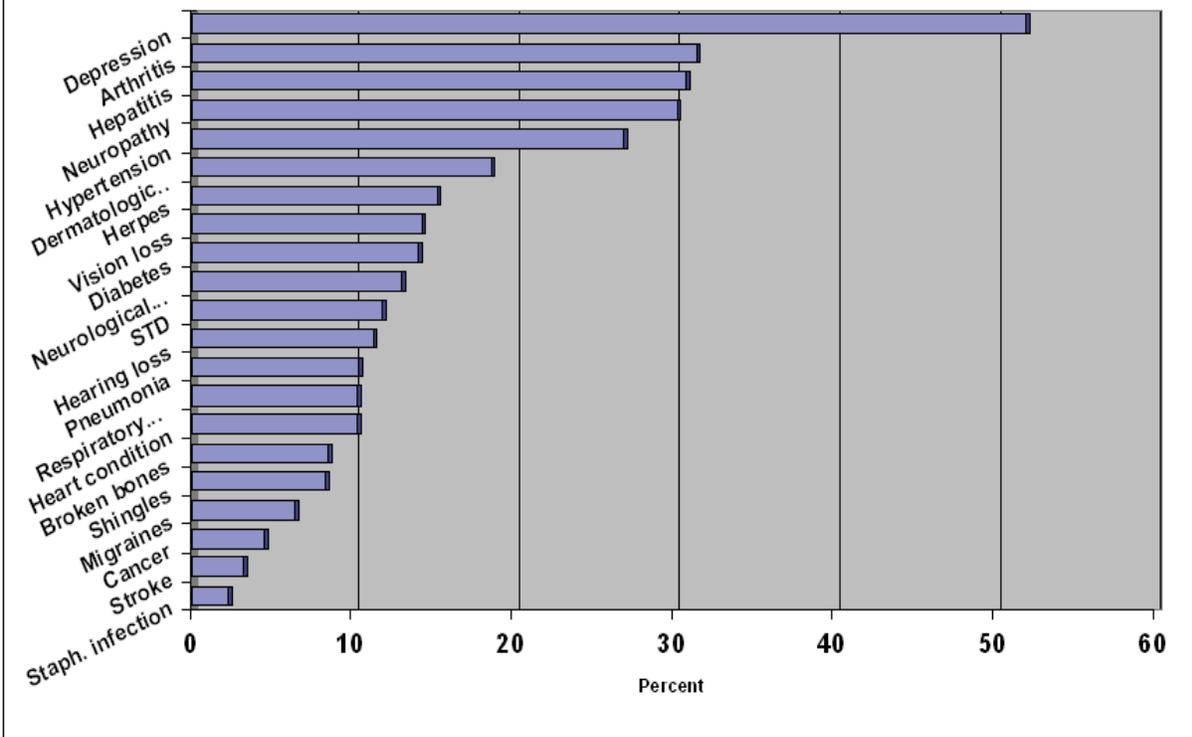
# The Complications of Success

## The NEXT Challenge

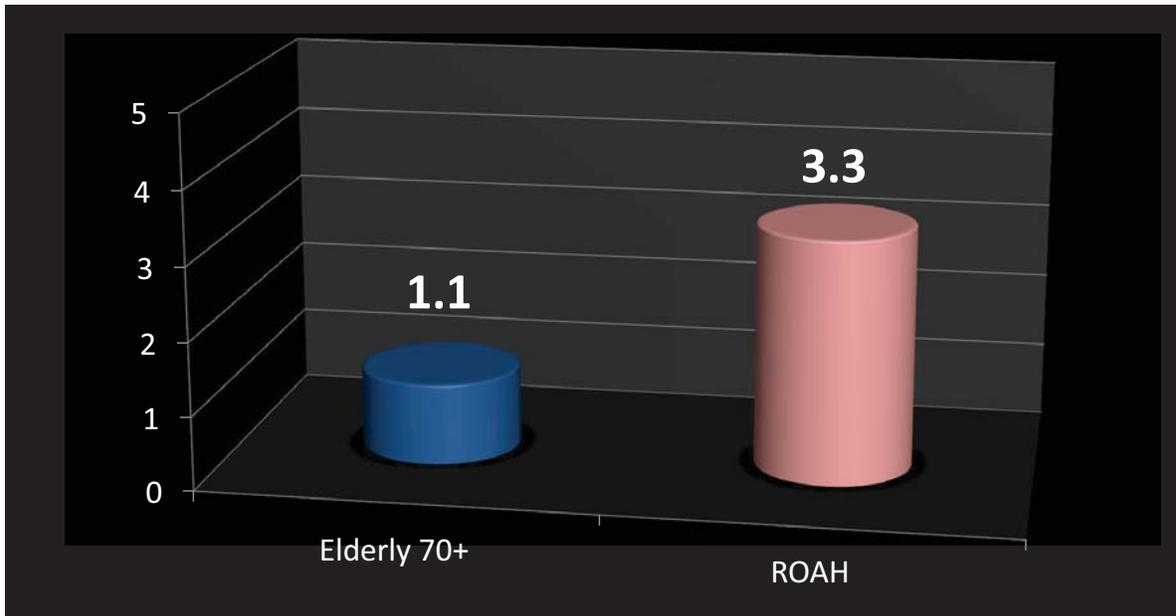
Older adults with HIV  
are developing at an early age  
illnesses that are more typically associated with  
later senior years.

These include Cancers – Cardiovascular Disease - Osteoporosis  
Liver and Kidney Disease – Diabetes

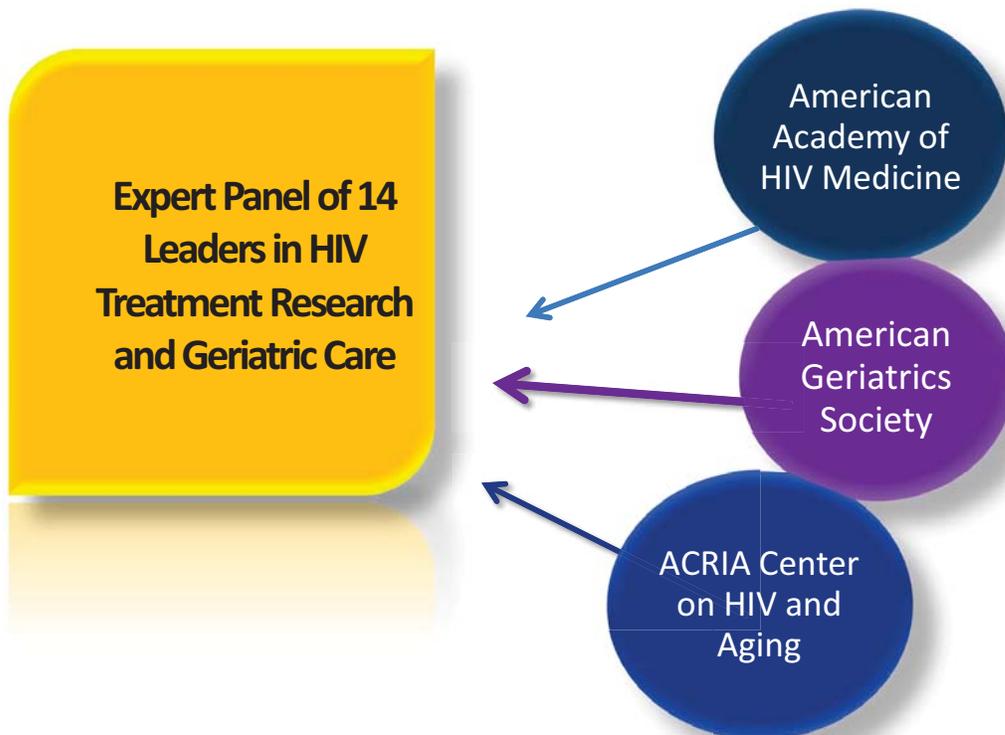
### ROAH: Comorbid Health Problems

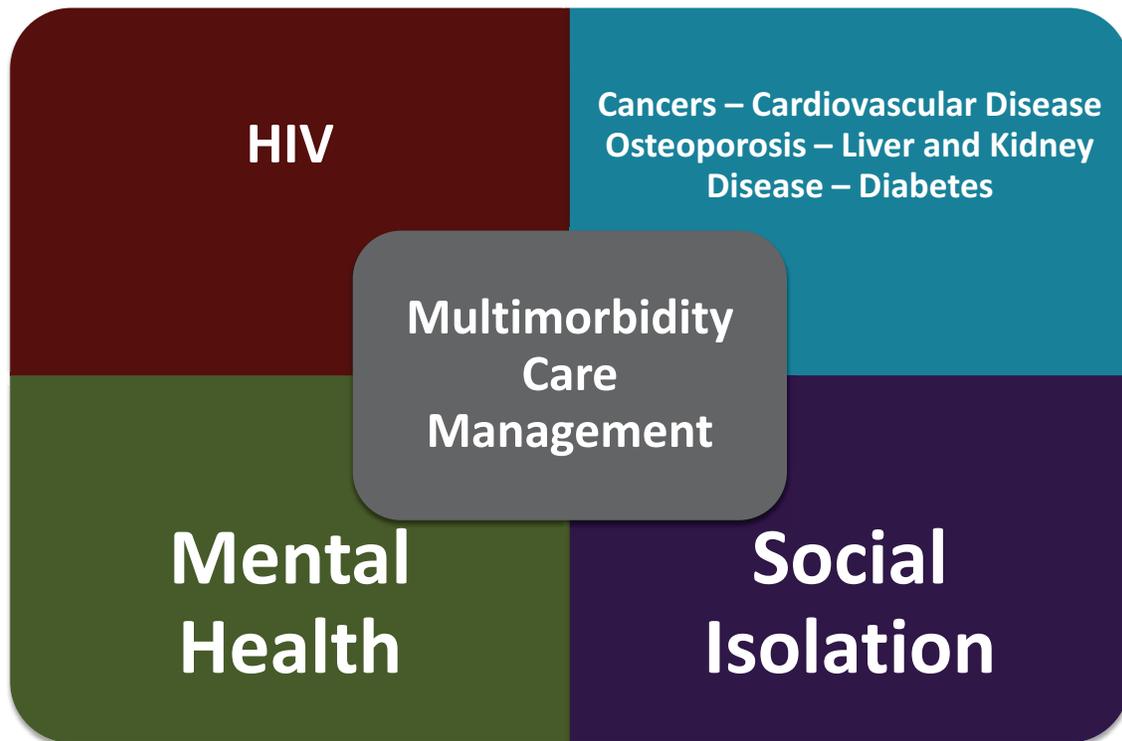


## Average Number of Comorbidities



## AAHIVM: Guides for the Management of Older Adults with HIV





**There is NO**

**Great sex  
After 50!**

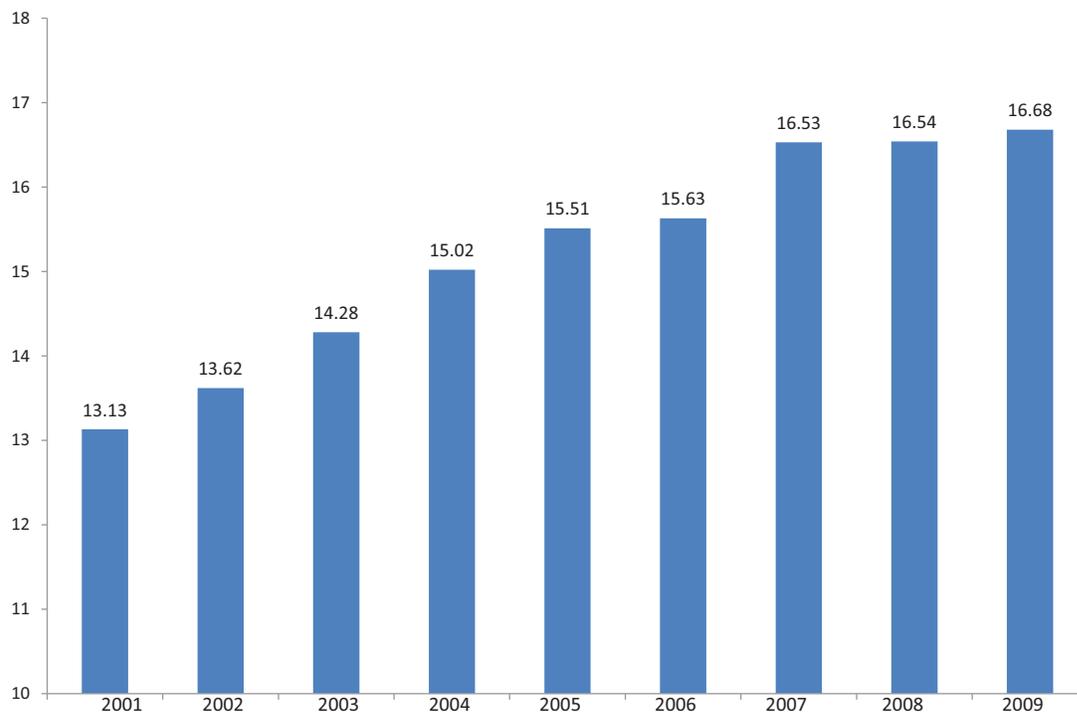
**And other outlandish lies about getting older**

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In 2009

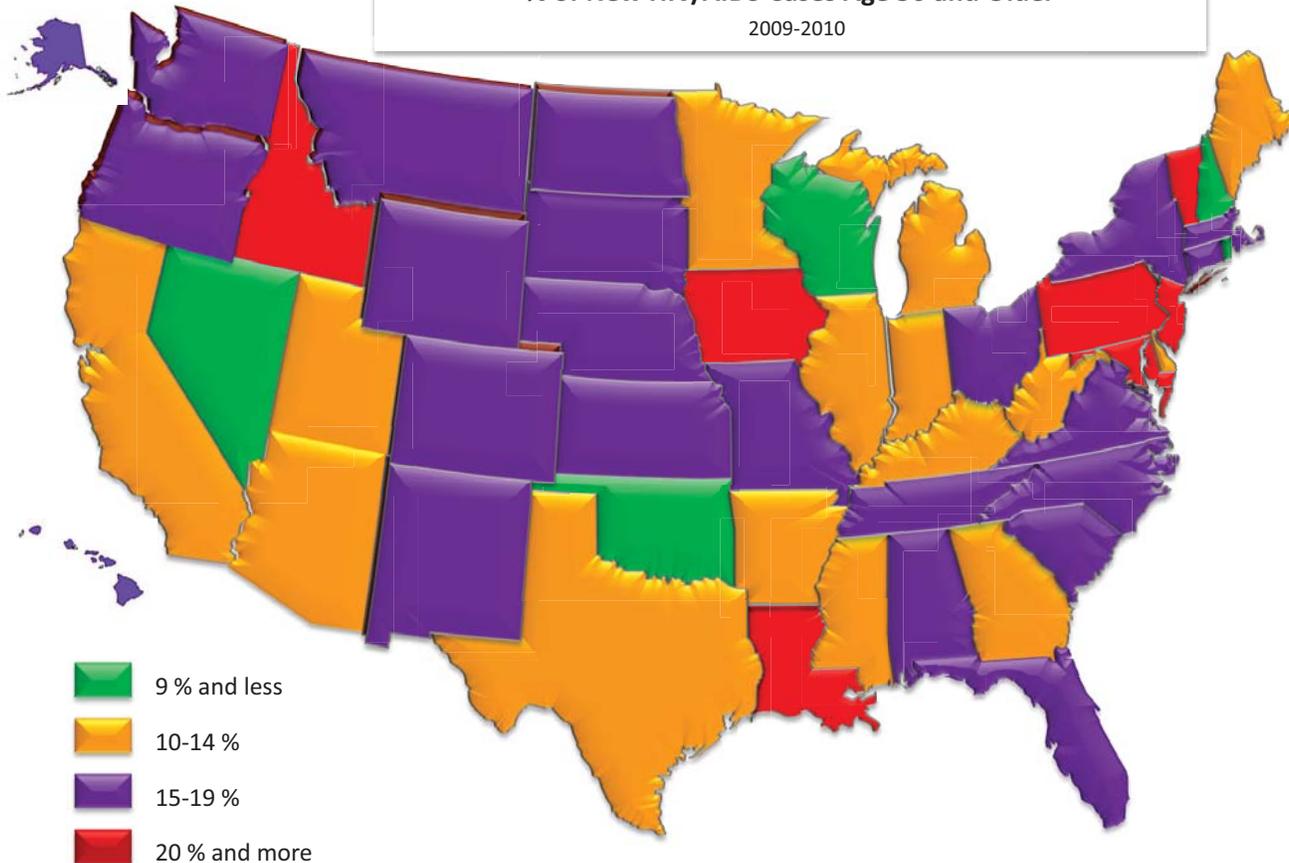
**1 of every 6**  
**New**  
**HIV Diagnoses**  
**in the U.S.**  
**Was in People Age 50**  
**and Older**

CDC Surveillance Data: New HIV Infections in 50 and Older Group  
% of Total

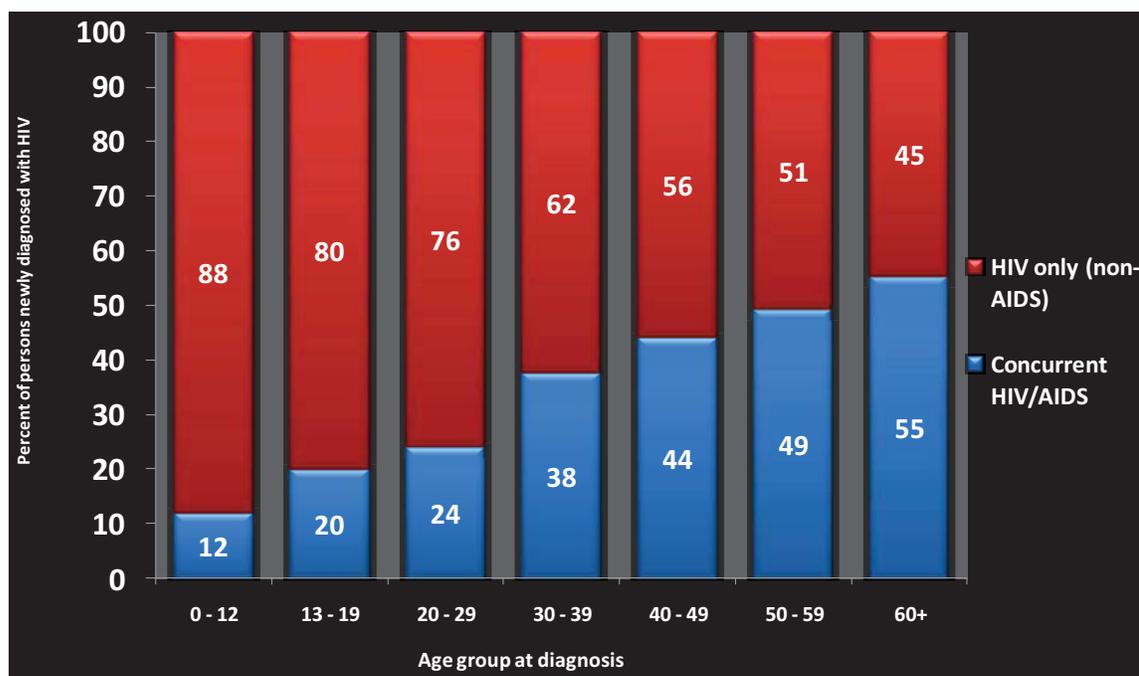


**% of New HIV/AIDS Cases Age 50 and Older**

2009-2010



**Concurrent HIV/AIDS among persons diagnosed with HIV in 2006 by age group, United States**



Source: CDC HIV/AIDS Surveillance Report, 2006. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm>

# The New York Council Funded HIV and Older Adults Initiative

2007-2011



## Sample of ACRIA's Older Adults Materials

**older adults and HIV**

**HIV In Older Adults: Engaged**

**Conózcalo. Combátalo. Derrótelo.**

**Detenga el SIDA.**

**Felipe**  
My name is Felipe, but people call me "Negrito." I'm 59 years old and was born in Venezuela. I managed to get across the U.S. border with help from friends. I was

**Para Detener el SIDA**

**Las personas mayores también pueden tener VIH....**

**En la Ciudad de Nueva York, dos de cada tres personas VIH positivas tienen 40 ó más años de edad, y una de cada tres tiene más de 50.**

**Brenda**  
My name is Brenda. I'm a 59-year-old grandmother living in Harlem. Some years ago, I met a man who I thought was wonderful. We were both doing drugs - in fact that's how we met.

**Pedro**  
My name is Pedro, but my friends call me Pete. I was born and raised in the South Bronx by very religious parents. They thought all homosexuals were going to hell, so I never told them I was gay.

**Funded in whole by the New York City Department of Health and Mental Hygiene**



ACRIA launched the first-ever wide spread social messaging campaign on HIV specifically targeting older adults

In June 2011



Thank You

Stephen Karpiak, PhD

Skarpiak@acria.org

AIDS Community Research Initiative of America

Training, Technical Assistance, Capacity Building,  
Materials and Consulting

Contact: Luis Scaccabarozzi

LScaccabarozzi@acria.org

ACRIA Center on HIV and Aging

www.acria.org



<http://www.lgbtaggingcenter.org/resources/resource.cfm?r=324>

## HIV & Aging Research: A Roadmap for the Future

*Recommendations on future research priorities for older people living with HIV/AIDS.*

We are beginning the fourth decade of the HIV epidemic. In the beginning few would have imagined that HIV/AIDS would evolve into a chronic, manageable disease due to the success of highly-active anti-retroviral therapy (HAART) within our lifetimes. This success has led to increasingly large numbers of long-term survivors, which has changed the face of HIV/AIDS. By 2015 the CDC estimates that half of those living with HIV in the U.S. will be 50 years and older.

However, this success is not without its challenges. Many of those aging with HIV are also living with a considerable burden of disease as a result of the early onset (often in their 50s) of multiple comorbid conditions (e.g., heart disease, cancers, osteoporosis, diabetes) as well as continued elevated levels of mental health issues like depression, active substance use, stigma-driven social isolation and concomitant loneliness. Unlike the general population, these older adults with HIV do not have the social supports they will need to age successfully. Nonetheless, there are significant levels of resilience among these long-term survivors that should not go unnoticed.

Understandably, there is an increased research focus on the medical management of HIV in the older patient. Few have assessed how psychosocial factors can contribute to better health outcomes and quality-of-life issues. ACRIA's seminal study on this population, *Research on Older Adults with HIV (ROAH)*,<sup>[1]</sup> was a detailed comprehensive needs-assessment of adults aging with HIV. ROAH, and past studies conducted by ACRIA and other scientists, serves as the basis for the following recommendations on research priorities for older people living with HIV/AIDS (OPLWHA), as well as some caveats as we move forward with this work.

### **State of the Research on OPLWHA**

With few exceptions, most research on HIV relies on convenience samples, making it difficult to generalize findings. Like GLBT studies, researchers have difficulty in constructing a representative sample for the simple fact that we do not have good population-based data to know whether or not any given sample is representative. While the ROAH study enrolled a 1,000 person cohort, most of these participants were Medicaid-dependent and recruited from AIDS service organizations (ASOs) so that persons of higher socio-economic statuses, Caucasians, and those receiving assistance from non-Medicaid providers were probably not well-represented.

Research on OPLWHA is also limited because the vast majority is cross-sectional, hampering our ability to understand the effects of aging and development. That is, we get a snapshot of participants at one time point, which limits our ability to examine cause and effect relationships or examine a particular phenomenon, such as substance use, over time. In the few longitudinal studies that exist, age is rarely considered a variable of interest even when older adults are included in the sample.

The longitudinal studies that are currently being conducted (e.g., Veterans Aging Cohort Study [VACS], Women's HIV Interagency Study [WHIS], Multicenter AIDS Cohort Study [MACS]), have provided detailed information on the progression and treatment outcomes of HIV, but have not related their data to many of the psychosocial issues we raise below. Thus, we need to establish population-based data on this population that would allow us to construct representative samples, and use longitudinal research designs that will allow us to track the course of aging with HIV over time.

### **Behavioral Research Priorities for an Aging Population with HIV**

In ROAH, a picture emerges of three major and inter-connected threats to successful aging with HIV: stigma, mental health and social isolation. Stigma remains a powerful and toxic factor for those living with HIV, and contributes to poor mental health outcomes and greater degrees of social isolation.

**Mental Health.** Our research has consistently found elevated levels of depressive symptoms among OPLWHA, approaching five times the rates of depression found in community-dwelling middle-age and older adults. OPLWHA have even higher levels of depression than others with serious, stigmatized conditions, such as visual impairment. What is even more remarkable about the high rates of depression is that these older adults are fully engaged with the health care system, seeing their providers several times per year. This suggests that current standards of care for behavioral health services are inadequate and must be reassessed.

At the same time, we see high levels of past and current alcohol and other drug use (marijuana, cocaine, crack, and heroin) that exacerbate mental health issues. By not adequately addressing the mental health needs of OPLWHA treatment and health outcomes are jeopardized. Depression is the single best predictor of not adhering to HIV and other medical treatments. Alcohol and other drug use can also interfere with adherence to and the effectiveness of medication. We need to know much more about the etiology of depression among OPLWHA through longitudinal research. In addition, more attention must be paid to developing effective interventions to better resolve these conditions. Lastly, we need more research that examines resilience factors, such as coping mechanisms, including spirituality, to understand the positive factors that shape the lives of OPLWHA and how they can be used to optimize their health status. For example, a recent paper based on the ROAH study found that OPLWHA who had higher levels of psychological well-being were more likely to use condoms.<sup>[2]</sup>

**Social Isolation, Loneliness and Support.** Social isolation and resultant loneliness are endemic among OPLWHA. Fewer than 20% have a partner or spouse, and they are about half as likely to have a living child as adults 65 and older. Approximately 70% live alone, which is nearly twice the rate of other older adults. OPLWHA tend to have friend-centered networks that we have typically associated with the LGBT community, yet two-thirds of these adults identify as heterosexual. And while friends do provide needed support, many also have HIV. Also, OPLWHA do not disclose their serostatus to many friends.

Beyond the high rates of loneliness and poorer quality-of-life, social isolation also points to an impending shortfall of the support these older adults will need now and as they grow older and confront multiple health issues. Caregivers are derived from these social networks. Without caregivers, OPLWHA will need to increasingly turn to supports that are medically based, as well as formal community-based social services that address their treatment and care needs. However, ASOs and other HIV service providers are not experienced in the domain of aging. Conversely, most aging service providers have little knowledge of HIV.

Research is needed to better understand the causes of social isolation among OPLWHA, as well as studies that examine dynamics of social support among this population to better understand their needs and how they are met. We need to develop and test interventions that can serve to reduce social isolation and increase available levels of support. Furthermore, we need research on the service utilization patterns and associated factors (i.e., needs, service barriers) that can provide an

evidence base for policy makers and program planners to address the growing needs of this aging HIV population. Lastly, we need to better understand how to better integrate HIV and aging services with research targeted at understanding how we can best leverage the resources available from these providers.

### **HIV Education and Prevention**

The myth that older adults do not have sex or use drugs leads to a lack of HIV testing among this population. Lack of public education about HIV/AIDS targeted at older adults results in a poorly informed group of older adults who are not knowledgeable about how to protect themselves against HIV and other STI infections. The CDC currently estimates that 17% of all new HIV infections occur in people over the age of 50. Physicians are often reluctant to address sexual health and sexual risk issues with their older patients, since they do not consider them to be at risk and are afraid of offending them by delving into these issues. However, adults over 50 who receive an HIV diagnosis are significantly more likely to receive a concurrent AIDS diagnosis compared to their younger peers (51% vs. 33%). Thus, not only are older adults referred for testing much later in the course of their illness, but many may be passing on the virus because they are unaware of their serostatus.

We need more research on the sexual health of older adults, including sexual minorities (i.e., GLBT individuals) to be able to better educate medical providers in the care of their older patients. It is also important to note that OPLWHA remain sexually active, and some continue to engage in high-risk sexual and substance use behaviors. Thus it is important to test the effectiveness of both primary and secondary prevention programs for older adults living with or at risk for HIV, in order to maintain and/or reduce the incidence of HIV infection among our older citizens. While test and treat has emerged as a powerful primary HIV prevention initiative, this approach has not been validated in older adult groups. In addition, there are no evidenced-based interventions that have been designed specifically for older adults, and little effort is expended in evaluating existing interventions that have been adapted to the older population.

### **Conclusions**

Research can be a powerful tool in empowering OPLWHA to live healthy, happy and productive lives. Health care providers are becoming aware of the importance of addressing the psychosocial issues and needs of this population, not only because it will improve treatment outcomes, but because it will help adults with HIV age successfully. HIV is no longer a disease that affects primarily young men and women, and our research must mature as this population itself matures. Gathering evidence through research that addresses the challenges facing OPLWHA will help to improve their circumstances, and in turn, contribute to our aging society as a whole.

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**Stephen E. Karpiak, Ph.D.**, is Associate Director for Research at the AIDS Community Research Initiative of America (ACRIA). Dr. Karpiak launched ACRIA's behavioral research efforts in 2002, with a focus on older adults with HIV. He was principal investigator on the seminal large-scale study, Research on Older Adults with HIV (ROAH), a comprehensive needs-assessment of 1,000 individuals which greatly increased the visibility of the issue of aging with HIV. He is the author of over 250 articles in scientific journals, and is frequently invited to lecture on the topic of HIV and

aging at national and international venues. Prior to his work on HIV and LGBT issues, Dr. Karpiak had a distinguished research career as a research scientist in neurobiology and immunology at Columbia University.

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# Religion, spirituality, and older adults with HIV: critical personal and social resources for an aging epidemic

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**Abstract:** By 2015, approximately half of adults with HIV in the United States will be 50 and older. The demographic changes in this population due to successful treatment represent a unique challenge, not only in assisting these individuals to cope with their illness, but also in helping them to age successfully with this disease. Religious involvement and spirituality have been observed to promote successful aging in the general population and help those with HIV cope with their disease, yet little is known about how these resources may affect aging with HIV. Also, inherent barriers such as HIV stigma and ageism may prevent people from benefitting from religious and spiritual sources of solace as they age with HIV. In this paper, we present a model of barriers to successful aging with HIV, along with a discussion of how spirituality and religiousness may help people overcome these barriers. From this synthesis, implications for practice and research to improve the quality of life of this aging population are provided.

**Keywords:** HIV, aging, spirituality, religion, stigma, coping, successful aging

## Introduction

Thanks largely to the effectiveness of highly active antiretroviral therapy (HAART), people with HIV are aging.<sup>1,2</sup> In 2005 in the United States, those 50 and older comprised 15% of all new HIV/AIDS cases, 24% of existing HIV cases, 29% of existing AIDS cases, and 35% of all HIV/AIDS-related deaths.<sup>3</sup> By 2015, adults 50 and older will make up half of the HIV population in the United States; this number is expected to continue to grow because of the aging of younger cohorts with HIV as well as new infections among persons over 50.<sup>4</sup>

With this upward shift in the age of people living with HIV, it is important to consider ways to promote successful aging in this growing population. Building upon the work of Rowe and Kahn,<sup>5</sup> Crowther and colleagues proposed four components of successful aging: 1) active engagement in life; 2) maximizing cognitive and physical functioning; 3) minimizing disability and disease progression; and 4) positive spirituality within a developmental context.<sup>5,6</sup> It is proposed that all of these components work together to promote successful aging; if one area is neglected, then the other components are negatively affected, ultimately reducing one's ability to age successfully. This model's inclusion of spirituality parallels Pargament's thematic switch from a biopsychosocial model to a biopsychosociospiritual model in understanding holistic therapeutic change.<sup>7,8</sup>

The purpose of this article is to summarize knowledge of spirituality as it is used to confront many of the barriers associated with successful aging with HIV. For this

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review, a model of successful aging with HIV is presented as a guide. A particular focus on spiritual benefits of coping will be provided during this review and in the implications for clinical practice and research. In discussing spirituality and religion, these two concepts are related but sometimes mutually exclusive. In this article, spirituality refers to “a person’s attempt to make sense of his world beyond the tangible and temporal. It strives to connect the individual with the transcendent and transpersonal elements of human existence. It might, but need not, include religion”.<sup>9</sup> While religion may contribute to spirituality, it refers to an outward expression of beliefs as exhibited by behaviors, practices, and rituals which focus on a core system of doctrines, morals, and norms.<sup>9,10</sup>

### Barriers to successful aging with HIV

Using the four components of successful aging with HIV mentioned above,<sup>5,6</sup> barriers to each of these components are identified in the model in Figure 1. Although not exhaustive,

these represent major barriers that have been articulated in the HIV and aging literature.<sup>2,4,11,12</sup> Underlying this model are three assumptions. First, the four components necessary for successful aging in the general population also apply to those aging with a chronic disease such as HIV. Second, this model assumes that barriers to each of these components act as stressors, activating the physical, cognitive, social, and spiritual resources of successful aging available to the individual, in accordance with Folkman and Lazarus’s Stress Process Model.<sup>13</sup> And third, all of these barriers are dynamic and interrelated, just as are the four components of successful aging. For example, age-related stigma and HIV-related stigma, although independent concepts themselves are also intertwined, in that older adults with HIV may be experiencing a combination of the two.

Starting in the left hand corner of the model in Figure 1 and going clockwise, medication side effects from HAART (eg, diabetes, high cholesterol, heart disease); unhealthy lifestyle choices (eg, smoking, substance abuse); and increased multi-morbidity with HIV compromise the

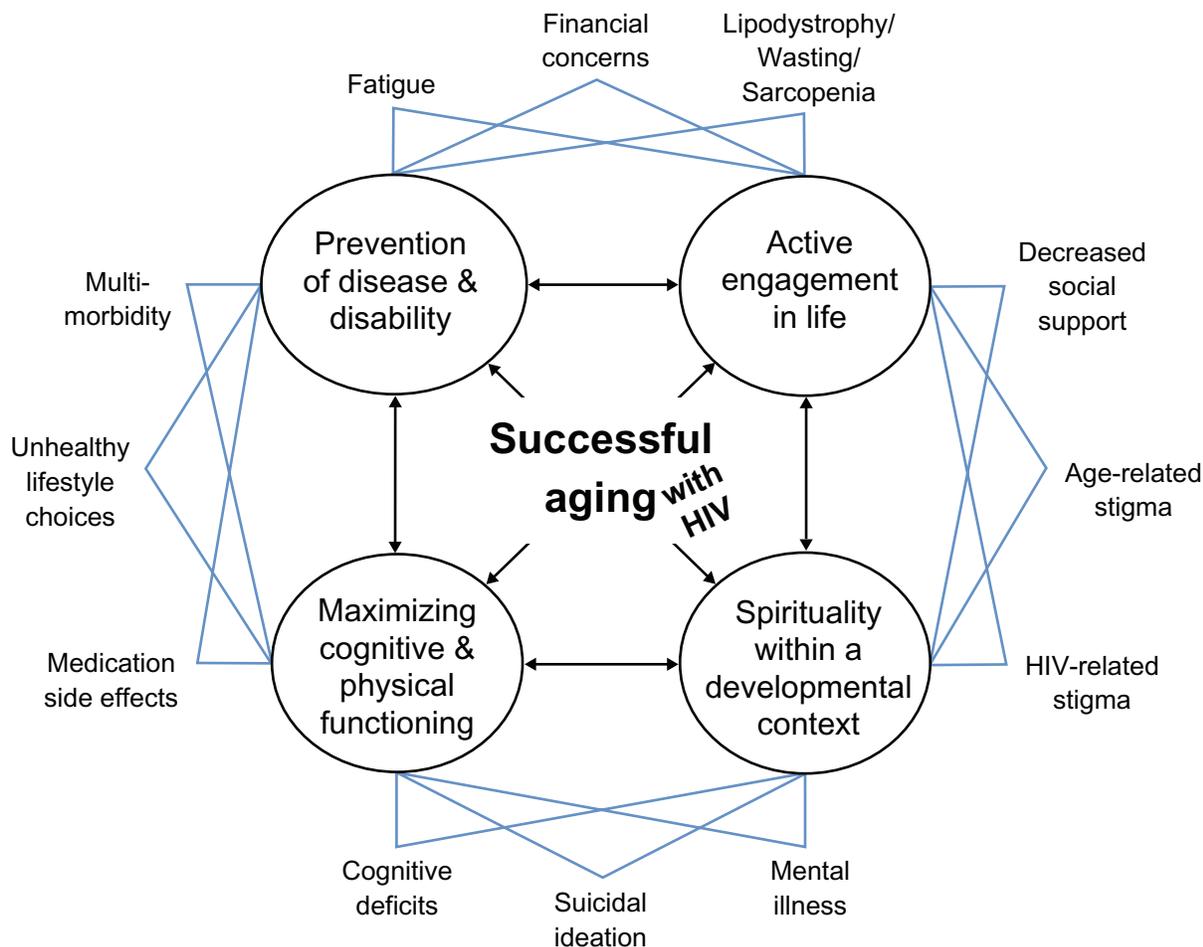


Figure 1 Barriers to and components of successful aging with HIV.

components of maintaining and maximizing cognitive and physical functioning and the prevention of disease and disability.<sup>2,14</sup> Fatigue due to medication side effects; not possessing financial means to pay for medications and other self-care needs; and lipodystrophy and decreased muscle mass (eg, wasting, sarcopenia) compromise the components of prevention of disease and disability and active engagement in life. For example, lipodystrophy in more pronounced cases can result in severe loss of subcutaneous fat in the face producing profound disfigurement, which may reduce one's inclination to socialize and actively engage in life.

Decreased social support (and increased social isolation), age-related stigma, and HIV-related stigma compromise the components of active engagement in life and spirituality within a developmental context. Studies show that 71% of older adults with HIV live alone and few (15%) reported living with a partner or spouse.<sup>15</sup> Many older adults with HIV consider emotional and instrumental support from their social networks is either unavailable or inadequate.<sup>16,17</sup> Decreased social support is closely tied to HIV stigma. HIV stigma can intensify other types of stigmas faced by many older adults, such as ageism, sexism, and racism. This may involve rejection, stereotyping, fear of contagion, violations of confidentiality, and protective silence (ie, concealing one's HIV status to avoid negative reactions from others).<sup>18</sup> Thus, many older adults with HIV withdraw socially due to HIV stigma,<sup>19,20</sup> further decreasing active engagement in life. Stigma also serve to challenge successful aging with HIV with regard to spirituality. Cotton and colleagues reported that 25% of people with HIV/AIDS are alienated from their place of worship because of HIV stigma, and 10% changed congregations because of their HIV status,<sup>21</sup> which can also contribute to poorer active engagement in life. Findings are similar among older adults with HIV, with 15% reporting attending services less frequently following their HIV diagnosis. Furthermore, less than half of these older adults disclose their HIV status to their congregations.<sup>22</sup>

Finally, mental illness (often depression and anxiety), suicidal ideation, and cognitive deficits compromise the successful aging components of "spirituality within a developmental context" and "maximizing cognitive and physical functioning". These barriers have a greater prevalence in adults with HIV.<sup>23-25</sup> In a large sample ( $N = 1,478$ ) of adults with HIV, approximately 40% were found to be depressed and approximately 20% were found to have an anxiety disorder.<sup>14</sup> Grov and colleagues found similar rates of major depression among older adults with HIV (39%), which was strongly related to HIV stigma

and loneliness.<sup>26</sup> In one study of 113 older adults (>45 years) with HIV/AIDS, 27% experienced suicidal ideation within the past week.<sup>27</sup> With regard to cognitive functioning among older adults with HIV, the evidence to date is mixed; however, there are strong indications of neuropsychological impairments in this population in certain cognitive areas such as memory, executive function, attention, and speed of processing.<sup>2,28</sup>

Certainly, such cognitive deficits, suicidal ideation, and mental health issues can exert direct negative effects on physical health as well as interfering with adherence to HIV medications (such as not remembering or being apathetic about taking medications).<sup>29,30</sup> These cognitive deficits, suicidal ideation, and mental health concerns may be aggravated by financial concerns, multi-morbidity, and other such stressors. These stressful situations may also increase cortisol levels, exacerbate other health problems such as substance use, and compromise self-care behaviors such as sleep hygiene; all of which can lead to poor cognitive and physical functioning.<sup>24</sup>

All of these barriers represent unique yet inter-related stressors that can contribute to poor functioning in each of the four major components of successful aging. With such stressors, it is understandable why someone aging with HIV may feel particularly overwhelmed, hopeless, and abandoned – not only by society, but perhaps from their beliefs, faith, religious communities, and even by God.<sup>31</sup> Yet, despite such barriers to successful aging, many people with HIV still benefit from their religious and spiritual beliefs and actually thrive under such circumstances.

## Spirituality of aging

Involvement in religious and spiritual practice has been found to correspond to better health-related outcomes regardless of age.<sup>32-35</sup> Such involvement may provide one with social support, norms for healthy behaviors, and a sense of well-being which promotes better overall mood.<sup>36</sup> But with advanced age, older adults have unique stressors that may compromise successful aging and are exacerbated when they are aging with HIV. Such stressors include multi-morbidity, diminished social supports, limited financial capacity, limited functional ability, and end-of-life concerns. Spirituality and religiousness can serve as buffers to life stress, by allowing individuals to interpret their life experiences in the context of their beliefs, which provide purpose and meaning in life, as well as promoting transcendence over circumstances, and bolstering feelings of inner resources and connections to others.<sup>10,36-39</sup>

As an example of such benefits, Lowry and Conco examined the role of spirituality in the lives of older adults in Appalachia.<sup>40</sup> Using a qualitative study design, they asked participants a variety of open-ended questions about health, spirituality, and religiosity, as well as social supports. In general, these researchers found that spirituality protected these older adults from negative attitudes and declines in physical health. The primary themes that emerged included the belief that God is actively involved in their lives, God calls them to action, and God supports them at times of loss. In this study, it was clear that the participants' personal relationship with God buffered them from the negative aspects of aging by providing them solace and a sense of purpose

## Spirituality and coping with chronic disease

Just as in the gerontological literature, the chronic disease literature shows the biopsychosocial benefits of spirituality and religiosity in buffering one from the stressors of such diseases. Such benefits have been observed in numerous diseases including bipolar disorder,<sup>41</sup> cancer,<sup>42</sup> diabetes,<sup>34</sup> and heart disease,<sup>35</sup> as well as other stigmatizing diseases such as visual impairment.<sup>33</sup> Such benefits have also been observed with HIV.<sup>21,43–48</sup>

Despite a history of HIV being particularly stigmatized by some religious communities,<sup>22,49</sup> Lorenz and colleagues found adults with this disease had a high level (80%) of religious participation;<sup>50</sup> of those, most reported that their religion (80%) and spirituality (65%) were “somewhat” or “very” important. Brennan and colleagues found that older adults with HIV had similar rates of religious participation to other groups of older adults. Participation remained high even among those who did not disclose their HIV status to their congregation, and 47% reported receiving support from their congregations.<sup>22</sup> In a sample of 279 adults with HIV, Ironson and colleagues found religiosity and spirituality corresponded to lower cortisol levels, increased positive health behaviors, larger social supports, hope, and improved long-term survival among older adults with HIV.<sup>51</sup> Similarly, in a sample of 450 HIV/AIDS outpatients, Szaflarski and colleagues found that nearly a third indicated feeling that their life was better now than before they were diagnosed with HIV.<sup>52</sup> Specifically, they found that a 1 SD increase in the Duke Religion Index was related to a 68.5% increase in the odds ratio that life was better. Clearly, from these studies, spirituality and religious involvement is associated with better health outcomes in adults with HIV.

Yet, religion can hinder positive biopsychosocial outcomes. In a qualitative study, Miller interviewed African American gay men with AIDS about their religious involvement.<sup>53</sup> Some reported rejection by their church for being gay or HIV positive. In fact, some who maintained a relationship with their church reported lower self-esteem. Clearly, although religiosity and spirituality can have positive biopsychosocial outcomes, it can also be a source of stress and may negatively impact self-care behavior. In a sample of 306 adults with HIV in the southern United States, those who considered that their disease was a punishment from God were more likely to miss taking their medication and had trouble keeping their medical appointments.<sup>54</sup>

## Spirituality of aging with HIV

HIV presents several unique barriers to successful aging. As Figure 1 shows, older adults with HIV may be more vulnerable to a number of issues including stigma both for being older and having HIV. Yet, just as in the HIV and gerontological literatures, adults aging with HIV have also been shown to benefit from religiosity and spirituality.<sup>22,45,55</sup> Having coped with stressful experiences over the course of their lives, older adults with HIV may have the capacity to negotiate difficult situations such as barriers to successful aging due to HIV by drawing upon their repertoire of coping strategies.<sup>56</sup>

Being diagnosed with HIV is a life event that may serve as a catalyst for growth and maturity. Many adults aging with HIV report that they grew spiritually from being diagnosed with HIV. In a sample of 50 adults with HIV, Vance found that 72% of older adults with HIV indicated that their spirituality changed as a result of being diagnosed;<sup>31</sup> likewise, 44% considered HIV to be a blessing in that it helped them to dig into their spirituality and forced them to confront issues of health, self-care, and God's purpose for their lives. Others have found that spirituality and religiosity do increase with a diagnosis of a disease. Sodestrom and Martinson found a similar effect to Vance's finding, with 88% of cancer patients finding meaning in their illness through their beliefs and faith.<sup>57</sup> Other studies examining spirituality in adults with HIV have found that spirituality levels are higher in older adults with HIV than younger adults with HIV;<sup>50,58</sup> however, some studies do not detect such differences.<sup>45</sup> Other research finds that levels of spirituality among older adults with HIV were the same or higher compared to other adults coping with chronic illness.<sup>44</sup> These findings regarding the importance of spiritual and religious resources among older

adults with HIV suggest that one could facilitate successful aging with HIV through spiritually-based interventions and practice modalities.

## Implications for practice

Health professionals working with older adults with HIV need to assess the role of spirituality and religiosity and make an effort to include their findings in the management of the disease. Given the evidence that spirituality is a major component of successful aging with HIV (Figure 1), ignoring this important aspect of successful aging could contribute to poorer health outcomes. Older adults with HIV could benefit from a more comprehensive approach to disease management that incorporates their level of spirituality and religiosity, as well as appropriate referrals for those who need counseling in these and related areas of their lives. Such counseling may be of value to many with HIV as they confront and cope with issues of intimacy, fear, guilt, anger, and confusion over the disease.<sup>59</sup> During counseling, religious and spiritual issues will undoubtedly emerge. Some issues may stem from anger at religious institutions for their particular views on HIV or homosexuality. Others may focus on broader spiritual issues including end-of-life concerns such as “Will I go to heaven?”; while others may be concerned about more basic questions such as “Does God still love me?”

Traditionally, secular counseling has steered away from incorporating matters of faith and spirituality into the psychodynamic setting; too often this is considered the sole domain of clergy and spiritual counselors.<sup>60</sup> In the secular domain, Freud and others often considered the concept of God as a father image to be a form of wish fulfillment; in such a capacity, patients may not be able to work through deep personal issues due to adherence to strict religious doctrines or mores that limit personal growth. However, Freud and others also noted that religion and spirituality can serve as a catalyst for working through issues and promote coping, growth, and transcendence.<sup>61,62</sup> Yet religion and spirituality can be treacherous psychological waters to navigate with some therapists suggesting that instead of drowning in such unpredictable and uncharted rapids, it is better to walk on the banks of reason and logic.

Likewise, spiritual and religious counseling has traditionally steered away from secular techniques, leaving the treatment of severe mental illnesses such as schizophrenia, bipolar disorder, and other more serious conditions to the medical community and maintaining their focus on faith-based approaches. But over the past few decades,

spiritual and religious counseling has adopted more secular counseling techniques; this can be observed in training programs for clergy that incorporate more psychology classes and greater emphasis on the medical model.<sup>60</sup> Similarly, secular counseling has acknowledged the importance of the spiritual and religious lives of patients and has recognized that spiritual and religious thoughts and imagery are a rich source of personal information.<sup>60,63</sup>

Given that 85%–90% of those in the United States report believing in God or a higher power and that some 71.5% actually pray once a week,<sup>64</sup> ignoring matters of faith and spirituality is tantamount to ignoring the proverbial “elephant in the living room”. Clearly, religious and spiritual experiences are just as important to people as the objective circumstances of their lives. In fact, Gallup poll (cited by Foster)<sup>65</sup> found that 66% of those in the United States reported that they would prefer to go to a counselor with spiritual beliefs and values if they were seeking a mental health professional. Others have also come to the realization that it is valuable to incorporate the spiritual in counseling.

For example, the well-known 12-step program, originally developed to address alcoholism, incorporates several concepts of God or a higher power to help resolve personal conflicts and provide a guide for living. In the first step of the 12 steps, it states “We admitted we were powerless over alcohol – that our lives had become unmanageable”.<sup>66</sup> In this statement, alcohol can be substituted with any other recurrent problem whether it is unforgiveness, depression, a life-changing mistake, or even HIV. In fact, Potik suggested translating the 12-step program, normally used in alcohol and other addiction counseling, to other life situations such as adapting to a chronic disease.<sup>62</sup> As Potik explains, these 12 steps can be used flexibly to help recover from a number of issues. The principles of the 12-step program can be used to help with a number of spiritual issues and emotions that are consistent and debilitating, whether the problem is fear of HIV, guilt over how one acquired HIV, regret over the life one could have had without HIV, or anger over how one has been treated due to one’s HIV status.

As seen in the literature on the spirituality of aging and HIV, issues of fear, guilt, regret, and anger are recurrent themes; such emotions can be powerful, crippling, and stymie one’s ability to move forward and live one’s life fully. Clinging to such toxic emotions can be likened to addiction in that it can destroy relationships, prevent one from maintaining or forming relationships, and even lead to other addictions such as alcohol to escape such feelings of despair.

Such emotions also represent feelings of powerlessness as addressed in step one of the 12-step program – and could be articulated as “we are powerless over HIV”. In acknowledging this powerlessness, Potik explains that this is not “giving up” but rather it is a form of “acceptance”. By admitting such powerlessness, one opens up to a greater power beyond one’s own capability – whatever one’s nomenclature. This subsequently leads to step 2 – “Came to believe that a Power greater than ourselves could restore us to sanity”. By such a fundamental reliance on this power, one opens up to the possibility that one can be made whole again. Although it is beyond the scope of this article to explore the other 10 steps, it is clear that the steps gradually build on each other to help one to acknowledge weaknesses, take inventory of strengths, and to maximize one’s ability to live the best one can, one day at a time. Such steps would appear to be valid mechanisms for coping with the powerlessness and unpredictability of being diagnosed and aging with a life-threatening chronic illness such as HIV.

## Implications for research

For researchers studying the management of chronic illnesses like HIV, religious and spiritual resources represent a fascinating, meaningful, and beneficial way of optimizing health-related outcomes. The few research areas presented in this article focus on the development of hardiness and resilience, spirituality across groups, and the change of attitudes about HIV among communities of faith.

Since the concept of hardiness parallels aspects of spirituality, Vance, Struzick, and Masten proposed a daily cognitive-behavioral approach that employs exercises for developing characteristics of hardiness.<sup>55</sup> In this cognitive-behavioral program, a client aging with HIV may be experiencing anxiety and depression. So the therapist would help the client identify sources and icons of optimism and strength. Such sources could be inspirational songs, television shows, movies, books, poems, mantras, prayers, and art. The key to identifying such sources is that they must be personally and intensely meaningful to the client; often, these are very spiritual in nature. By identifying such salient sources, they can be woven into a cognitive-behavioral program to be used by the client on a daily basis. Examples of such structured features of the program may include the following instructions: 1) “Before getting out of bed each day, meditate for at least a few minutes about how you are going to take care of yourself so you can take care of your friends and family”, 2) “Repeat the following mantra every time you ride the elevator at work – ‘It is fine to fall, and even better to rise

again,’” 3) “Enjoy positive media such as Star Trek, Robin Williams, and gospel music”, and 4) “When you go to bed, write in your journal the two most positive things that have happened to you today”. Obviously, such an approach would include spiritual and/or religious activities, be more detailed and descriptive, and contain behaviorally-objective goals to ensure that the target behaviors occur in order to change thoughts and behaviors to facilitate a hardy attitude. By developing a more hardy and proactive attitude, one should be better adjusted psychologically and spiritually to deal with some of the barriers to successful aging with HIV.

A similar approach has also been studied in a group intervention to help adults with HIV. Tarakeshwar, Pearce, and Sikkema created an eight-session group intervention to address issues specific to HIV;<sup>67</sup> a focus on spirituality was included. Using a pre-post experimental design in this pilot study, researchers found that after completing this intervention, participants reported having more positive spiritual coping skills and feeling less depressed.

Spirituality may also support cognitive functioning in older adults with HIV. Many adults with HIV have been observed to suffer from subclinical cognitive deficits; there are concerns that with advancing age that such deficits will become more profound.<sup>2</sup> Since HIV is also associated with depression and anxiety, such negative affect has also been shown to negatively impact cognitive functioning.<sup>2</sup> Thus, interventions that reduce such negative affect may actually improve cognitive functioning.<sup>24</sup> Promoting spirituality as a coping resource may help reduce such negative affect and subsequently help promote successful cognitive aging in this population. Also, certain spiritual practices, such as meditation or attending religious meetings, have been shown to be stimulating cognitive exercises in their own right. In this sense, spiritual practices support the cognitive component of successful aging as well.<sup>68</sup> Despite these connections in the literature, a more systematic evaluation of how spirituality can affect successful cognitive aging with HIV needs to be evaluated.

Despite such interventions that employ aspects of spirituality and religious coping, evidence suggests that different groups of people may derive differential benefits from spirituality and religious involvement. In a series of studies, Vance and colleagues<sup>69</sup> surveyed 421 adults with HIV from across Alabama. A structural equation model was constructed that examined the effects of years since diagnosis with HIV, age, and education on the mediating role of religious activity on three biopsychosocial outcomes (ie, health status, social support, and mood). In the overall sample, older participants engaged in more religious activities, and

engagement in such activities was predictive of greater perceived social support. However, when the same structural equation model was examined for different subgroups in the sample (ie, men, women, African Americans, Caucasians, homosexuals, heterosexuals); women, African Americans, and homosexuals seemed to benefit more from such religious activities.<sup>70–73</sup> However, these results are in contrast with other findings. In a study of older adults without HIV, McFarland<sup>73</sup> found that men tended to receive more mental health benefits from religious involvement than women. Why such differential benefits occur is not clear. More research into this area is needed.

Finally, as already mentioned, religion and spirituality has not always been a source of solace or strength for many with HIV. Historically, at the beginning of the epidemic especially, several religious enclaves denounced those with HIV, offering recrimination to “immoral” behaviors such as intravenous drug use, homosexuality, and sex outside of marriage. These bombastic views were internalized for some with the disease. In their sample of 90 adults with AIDS, Kaldjian, Jekel, and Friedland found that 17% of adults with AIDS reported that their disease was a punishment from God.<sup>74</sup> Such guilt and self-denigration can obviously hinder mental health.<sup>75</sup> Brennan and colleagues report that stigma is a major factor in the failure of older adults with HIV to access support from their religious congregations, noting that many fear rejection due to moral judgments because of their seropositive status.<sup>22</sup> Over time, with more education and knowledge about HIV, such harsh views may have softened in some religious communities as well as in society overall. Whether this change in societal attitudes has increased access to religious and spiritual sources of solace and support among older adults with HIV remains unknown.

## Conclusion

Successful aging with HIV is possible; however, studies indicate several potential obstacles such as decreased social support, with many lacking intimate relationships; increased multi-morbidity; and potential financial difficulties from years of being unable to work and prepare for retirement.<sup>2</sup> These factors can be a source of regret, depression, and anger. Fortunately, religious and spiritual resources represent a source of coping for many, with the caveat of being able to access such resources without the barriers of stigma and moral recrimination. It is important for mental health professionals, both religious and secular, to recognize that many of their clients with HIV are aging within a spiritual context; a context that may be turbulent or serene based

upon their personal history and spiritual interpretation of their lives. Social support from a religious or spiritual body of like-minded people could certainly help some older adults with HIV. Still, mental health professionals will need to be creative in helping the older client with HIV to embrace their powerlessness over the disease itself in order to tap into inner strengths, become hardy, and age successfully.

## Disclosure

The authors report no conflicts of interest in this work.

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