

Research on **O**lder **A**dults with **H**IV

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ROAH is a comprehensive research study of 1000 people
over the age of 50 living with HIV in New York City.

Conducted and funded by the
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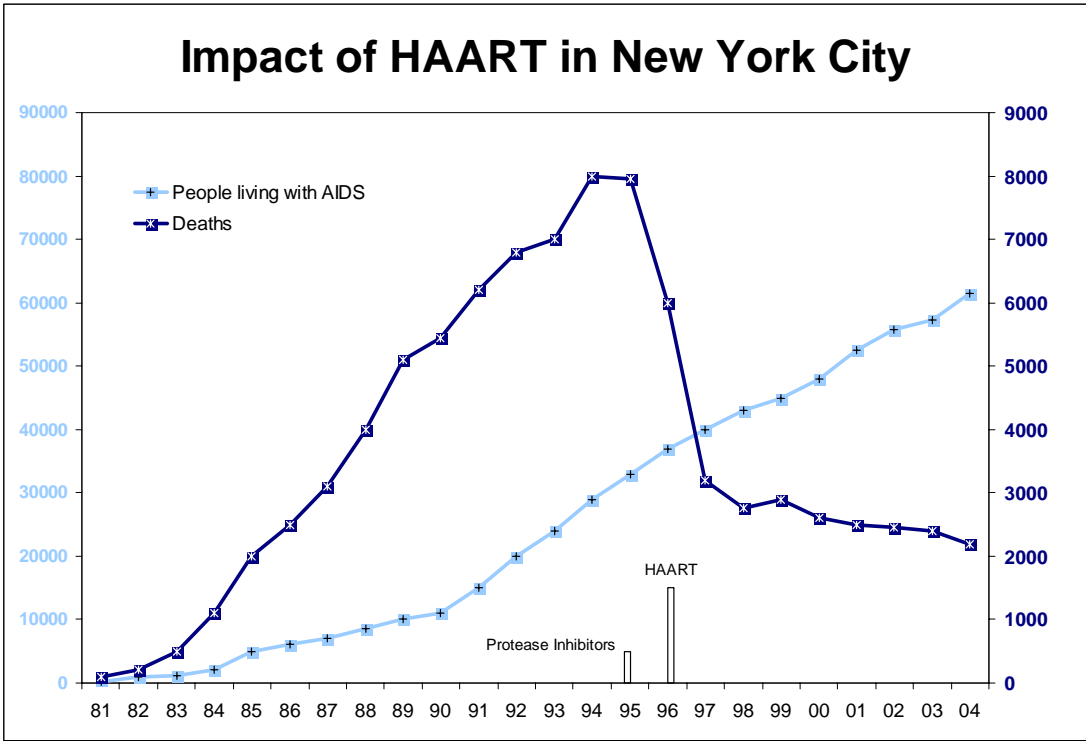
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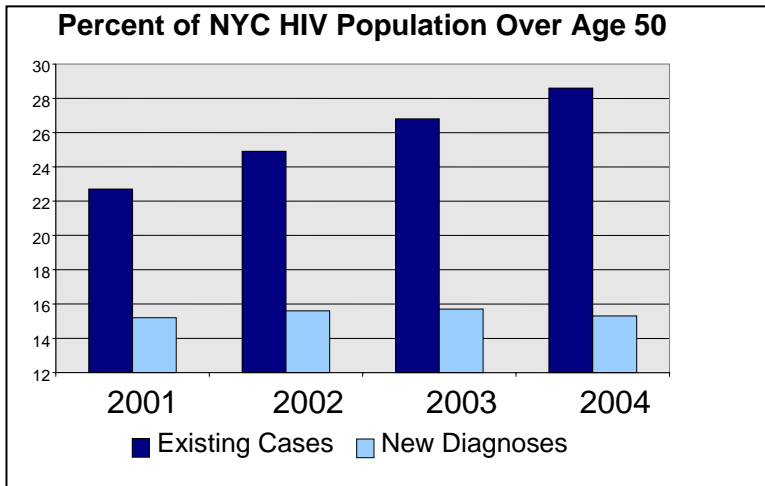
The Aging HIV Population: Growing and Invisible

One decade after the introduction of highly active antiretroviral therapy (HAART) we have witnessed a dramatic decrease in mortality rates and increased life expectancy among people living with HIV/AIDS. With new HIV infection rates remaining level, the net result is an HIV-positive population that is both graying and growing. Almost 27% of all people living with AIDS in the United States are aged over 50. In New York City, the HIV/AIDS epicenter in the United States, 30% of the almost 100,000 people living with HIV are over age 50 and 70% are over age

40.¹ Within the next decade it is probable that the majority of people with HIV in New York City will be over age 50. This pattern is seen throughout the US. Yet few have internalized this fact: there will soon be large numbers of senior citizens living with HIV and AIDS.



¹ New York City Department of Health and Mental Hygiene. (2006). HIV Epidemiology Program 1st Quarterly Report, Vol4(1). Available online: <http://www.nyc.gov/html/doh/downloads/pdf/dires/dires-2006-report-qtr1.pdf>

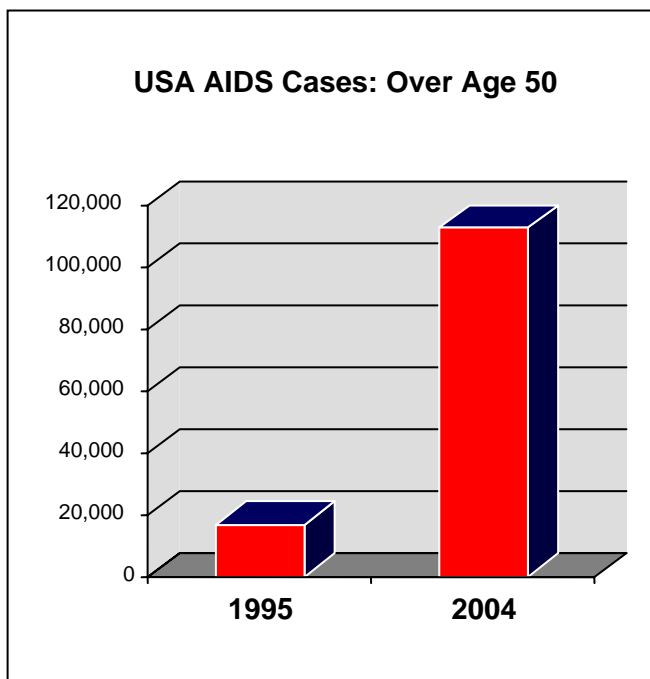


There is nothing equivocal in the New York City Department of Health (NYCDOH) HIV epidemiological data. The population of older adults with HIV is expanding. Misinformed media and public voices contend that these increases are the result of the use of erectile dysfunction drugs by older adults. Few report or know that the primary reason for the growth in the numbers of older adults with HIV is the

unparalleled success of anti-HIV drugs (HAART) that make it possible for people to live longer, healthier lives. The death sentence of AIDS has been transformed into life, albeit one with challenges.

The number of older adults infected with HIV may be even greater.² Since physicians do not perceive older adults to be at risk for HIV infection, they are less likely to test them for the virus. Consequently, underdiagnosis occurs, and HIV is detected later.³ One study of people between the ages of 60 and 79 who had died in a long-term healthcare facility found

that five percent were HIV antibody positive although none had been diagnosed with HIV.



AGING, THE IMMUNE SYSTEM, DELAYED TREATMENT

It is known that the immune system's function declines with aging. Since HIV degrades the immune system, many predicted that HIV disease would progress more rapidly in older adults. When an older person is infected with HIV, CD4 T-cell loss is more pronounced when compared with younger individuals. Studies have found that

² N C Casau. (2005). Perspective on HIV Infection and Aging: Emerging Research on the Horizon. *Clinical Infectious Diseases* 41(6): 855-863.

³ Inungu, J. N., Mokotoff, E. D., & Kent, J. B. (2001). Characteristics of HIV infection in patients fifty years or older in Michigan. *AIDS Patient Care & STDs*, 15(11), 567-573.

untreated, older HIV-positive individuals are twice as likely to die than their younger, untreated counterparts. It was thought that there would be a delayed immune response once HAART was begun in older adults. However, it is striking that three months after older adults initiate HAART, no significant differences in survival are seen as compared to younger patients. Studies have found similar rates of undetectable viral loads once HAART is initiated. This may in part be the result of older people being more adherent to drug therapy than younger individuals. Nonetheless, these data support the conclusion that older adults are at greater risk when there is a failure to diagnose HIV infection that results in delayed treatment.²

HIV AND THE COMORBIDITIES OF AGING: THE MEDICAL CARE SYSTEM IS UNPREPARED

The interaction of HIV with the aging process and common comorbidities of aging such as cardiovascular disease, osteoporosis and dementia are inevitable. Yet there is little research and even less acknowledgment or foresight anticipating this consequential commingling of HIV and aging comorbidities. Is this ageism? Is there such a need to place emphasis on youth to sustain AIDS health dollars? Or is this a failure to recognize that HIV is a manageable disease because the system does not want to engage the even more complex health and social issues that are needed to respond to a population that has been given a new lease on life?

Older adults have population-specific health challenges, such as adult-onset diabetes, Alzheimer's disease, cardiovascular disease and hypertension, menopause, osteoporosis and prostate cancer. Little is known about how these age-related diseases and conditions will manifest in the HIV-positive population. In addition, HIV is now overwhelmingly a disease affecting poorer populations, particularly people of color and women. Individuals from lower socioeconomic strata are at higher risk for many age-related diseases. For example, Blacks are disproportionately affected by cardiovascular disease, hypertension and diabetes. Will the onset of age-related

“...the agency has shifted from primarily serving the terminally ill to serving HIV-positive individuals who are living longer and presenting more *complex needs*.”

comorbidities be earlier? Will the disease course be more severe? How will aging HIV-positive individuals tolerate the mix of antiviral medications and the powerful medications that target age-related illnesses? Moreover, the racial and ethnic groups most affected by HIV are the same people who continue to encounter endemic disparities in access to healthcare.

The NYC DOH indicates in a recent Kaisernet report – “...the agency [DOH] has shifted from primarily serving the terminally ill to serving HIV-positive individuals who are living longer and presenting more *complex needs*.” Those *complex needs* are manifest in this aging group. They include the impact of the comorbidities of aging, increased isolation from social support networks, and the negative impact of HIV stigma and ageism.”

ACRIA AND THE AGING HIV POPULATION

The AIDS Community Research Initiative of America (ACRIA) is a 15-year-old, community-based HIV research and education agency in New York City. ACRIA has developed a network of partnerships with over 100 AIDS service organizations (ASOs) and community-based organizations (CBOs) and multiple medical and hospital facilities throughout the five boroughs of New York City. The agency also maintains a HIPAA-compliant database of over 1500 older adults living with HIV/AIDS who have expressed interest in participating in ACRIA’s clinical and behavioral research studies.

The highly visible emphasis on preventing HIV transmission in youth and younger adults suppresses the accurate picture of those who now live long lives with this virus.

Many studies of HIV/AIDS populations reflect a sampling bias based upon an organization’s catchment area, or are limited to rosters of patients who utilize a specific healthcare or service facility. The diversity of organizations with which ACRIA interacts ensured that participants in any large-scale study would to a large degree reflect the current demographic characteristics of those living with HIV/AIDS in New York City.

ACRIA has recognized the critical need to understand this emerging and often obscured HIV population better. The highly visible emphasis on preventing HIV transmission in youth and younger adults suppresses an accurate picture of

those who now live long lives with the virus. ACRIA initiated studies on this aging population in 2003.⁴ ACRIA's findings and those of others began to create a picture of a population that survives and manages HIV while facing the demands of aging with marginalized resources.

Enormous resources have contributed to changing the death sentence of an HIV/AIDS diagnosis to the reality of a longer life. It is disconcerting that those who now live with HIV will face a healthcare system and communities ill-prepared to care for them as they age with the disease.

The primary findings of ACRIA's preliminary research indicate that the aging HIV population does not have access to social support networks that provide support upon which the typical aging adult relies. Without these functional informal support networks these older adults find themselves relying on costly formal care services. Enormous resources have contributed to changing the death sentence of an HIV/AIDS diagnosis to the reality of a longer life. It is disconcerting that those who now live with HIV will face a healthcare system and communities ill-prepared to care for them as they age with the disease.

⁴ Shippy, R.A., & Karpiak, S.E. (2005). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health, 9*(3), 246-254.
Shippy, R.A., & Karpiak, S.E. (2005). Perceptions of support among older adults with HIV. *Research on Aging, 27*(3), 290-306.

ROAH: The Research Study

Developing the best strategy to sustain the health and quality of life for the aging population living with HIV/AIDS requires a rigorous assessment of this group's characteristics. ACRIA's Research on Older Adults with HIV (ROAH) is a first step in establishing a valid and comprehensive knowledge base of the unique characteristics and needs of this growing HIV/AIDS population.

This effort is guided by an experienced research team and to date has been wholly funded by ACRIA. The ROAH team has been joined by Marjorie Cantor, Professor Emerita and Brookdale Distinguished Scholar at Fordham University. Other researchers and community members have become collaborators with ACRIA, providing their expertise and perspectives to assist in directing the research project.

ROAH was designed to recruit a 1000-person cohort. As noted earlier, ACRIA is uniquely positioned to conduct a

A goal of ROAH is to give this large and growing group of older adults a needed voice and visibility. A key feature of the Ryan White CARE Act has been the inclusion of community members in decision-making processes. Unfortunately, older adults have not been integrated effectively into this process.

high-quality, community-initiated study on a large representative sample reflecting today's HIV epidemiology. It is our hope that the ROAH data will have a significant impact on the priorities for HIV/AIDS funding. For the first time there will be valid data that describe the physical and mental health, sexual behaviors, substance use, social networks, behavioral health, and quality of life in this largely unknown population. A goal

of ROAH is to give this large group a needed voice and visibility. A key feature of the Ryan White CARE Act, a key source of federal HIV/AIDS funding, has been the inclusion of community members in decision-

making processes. Unfortunately, older adults have not been integrated effectively into this process.

ROAH PARTICIPANTS AND THE SURVEY INSTRUMENT

Recruitment for ROAH did not target any specific geographic locality, neighborhood or infected group. Participants in ROAH were recruited by an ACRIA outreach coordinator utilizing ACRIA's established network of New York City-based AIDS service organizations (ASOs), public and private hospitals, and the agency's database of clients. In order to qualify for the study, participants must have been diagnosed with HIV/AIDS, be age 50 or older, be community-dwelling (i.e., not institutionalized), and be sufficiently fluent in English to complete the survey instrument. From a sample of 1000 completed surveys, a final sample of 914 was obtained.

The survey content was determined by the ROAH research team (Karpiak, Shippy, Cantor) with input from the Research Advisory Committee. The ROAH survey instrument was constructed using existing standardized tests and encompasses six primary areas (see appendix for details):

- Demographic Profile
- Health Status
- Sexual Behaviors
- Social Networks
- Stigma
- Psychological Resources

ROAH was reviewed and approved by an independent review board (IRB) to ensure ethical treatment of participants. Its components, methodology and data collection details can be found in the appendix. This report is a summary of the outstanding findings, which provide key defining characteristics of this aging population. These data were also used to formulate a limited set of general public policy recommendations.

Questions that ROAH was designed to address include:

- Will an already overburdened healthcare system be able to meet the increased demands of the aging HIV/AIDS population?
- How can communities and individuals be mobilized to reduce the impending burden on formal care networks?
- How best can limited resources be utilized to address the needs of this aging population with HIV/AIDS?
- Are there differences in the needs of males and females, or among racial/ethnic groups?
- To what extent will the aging HIV population have access to informal support from their family and friends?
- To what extent is the older HIV population isolated by stigma? How can the effects of stigma be reduced or reversed?

Demographic Profile: Who Are They?

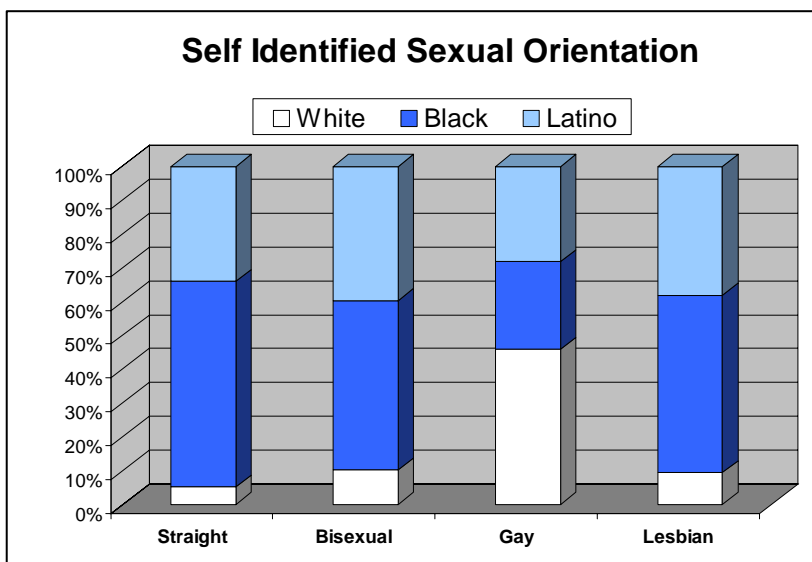
The demographic profile of the ROAH respondents largely reflects the current demographic characteristics provided by epidemiological HIV data for New York City.⁵ The demographic variables include age, race/ethnicity, gender, education, relationship status, living arrangement, income adequacy, language, nationality/immigration status, and religion.

Almost 67% of the participants self-identified as heterosexual.

The sample consisted of 640 men, 264 women, and 10 transgender persons.⁶ The average age was 55.5 years: 58% were 50–55, 26% were 56–60 and 16% were over

age 60. Half of the respondents were Black, a third Latino, and about 14% White. The remaining 4% identified as Asian/Pacific Islander, American Indian, or multi-ethnic⁷. The vast majority, (83%) of the participants were born in the USA. About half (47%) of participants regularly attend religious services. Christians (42% Protestant and 34% Catholic) comprised the majority, with 6% Muslim and 2% Jewish.

Regarding sexual orientation, 67% of the participants self-identified as



⁵ New York City Department of Health and Mental Hygiene. (2006). HIV Epidemiology Program 1st Quarterly Report, Vol4(1). Available online:

<http://www.nyc.gov/html/doh/downloads/pdf/dires/dires-2006-report-qtr1.pdf>

⁶ Because the number of transgender persons is low, gender comparisons will be made throughout the report on only those individuals who identified as either male or female. Where appropriate, the experiences of transgender individuals will be discussed separately.

⁷ Similarly, race/ethnicity analyses will include White, Black and Latino individuals. The number of Asian, Native American and multiethnic individuals precludes a fair and statistically meaningful comparison with other ethnicities. In all other analyses, these people are included and where appropriate, we will discuss the experience of these individuals separately.

heterosexual, 9% bisexual, and 24% homosexual. Nearly half (49%) of male participants and over a third (37%) of the females reported a history of incarceration.⁸

A substantial portion of the ROAH participants lived alone (70%). Of those who did not live alone, 15% lived with a partner, 9% lived with a relative, and the remaining 7% lived

In NYC, 70% of older adults with HIV live alone and only 15% live with a partner.

with a friend or other person. This is significantly higher than the percentage of HIV-negative people over the age of 50 who live alone (32% of people over 65 in NYC live alone).⁹ Men were more likely to live alone (75%) than women (58%); however there was

no significant difference among ethnic groups. The high proportion of people who live alone is likely to create significant implications on the need for assistance from the formal care and services system.

EDUCATION, DISABILITY AND INCOME

the education level of the study group is similar to that of the general population of NYC. Nearly 53% of the participants graduated high school, and 25% had some college experience. Over 13% of the participants were college graduates and 9% had graduate degrees.

The majority of the participants indicated that they were not working: 20% were unemployed, 54% were on disability, and 7% were retired. Nearly 8% were currently employed and an additional 3% were volunteers.

The majority indicated that they were not working: 20% were unemployed, 54% were on disability, and 7% were retired.

The responses to questions of income adequacy reflect the fact that most of this population is not working. When describing their current income, 53% reported having “just enough to get by” and 23% said

that they “do not have enough to make ends meet.” An examination of income adequacy, work status, and education concluded that the majority of the ROAH participants are on the lower end of the socioeconomic spectrum.

⁸ The survey question was unintentionally ambiguous, which may have resulted in overreporting.

⁹ U.S. Census, 2000. Older (55+) Population Data. U.S. Census Bureau, Washington, DC.

Health Status

The HIV population is most often defined by those parameters used to measure the delivery of medical care (e.g., office visits, lab tests, treatments received, ambulatory versus hospital care, etc.). Such analyses rarely include age as a key variable. In an effort to understand the complex health status of these older adults, ROAH assessed parameters that would provide a more complete view of this population's health. The health picture presented in ROAH is driven by the voices of the participants' self-reports.

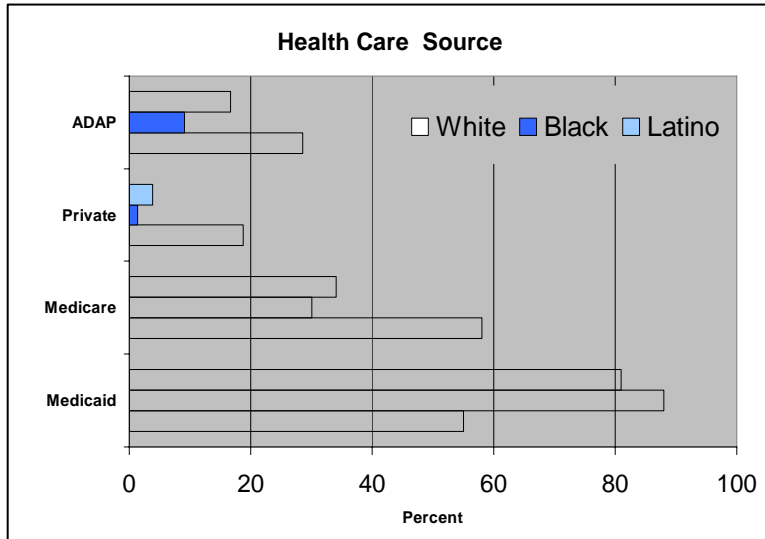
ROAH participants rated their current health on a possible scale of 0-10, with higher scores indicating better health.

Half of the older adults in ROAH have had an AIDS diagnosis. Currently only 13% report CD4 levels below 200.

Participants' scores ranged from 1 to 10, with a mean score of 6.8, slightly above the midpoint of the scale. This indicates that most consider their overall health to be at least fair or good. In many ways this measure is analogous to asking the question, "How are you feeling today?" The answer of ROAH's participants is "Not bad or pretty good." Given the tremendous challenges that these individuals face in managing HIV, as well as their own daily life activities, this suggests care, services and funding successes.

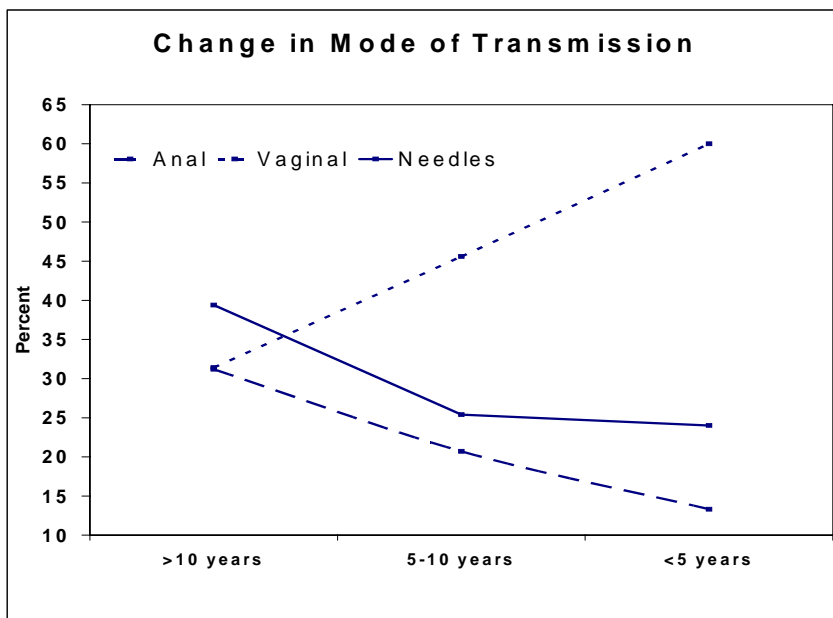
HIV-RELATED HEALTH

The older adults in ROAH have been living with HIV for an average of 12.6 years. The range from date of HIV diagnosis is 3 months to 26 years. Half have an AIDS diagnosis (51%), while only 13% currently have CD4 levels below 200. Again, the extraordinary success of antiretroviral (ARV) treatment is evident in the ROAH data set.



Consistent with New York State standards of care, the majority of participants (88%) visited their primary healthcare provider every 3-4 months.¹⁰ Nearly 85% are currently on ARV treatment. Most patients receive care in public hospitals, clinics or at ASOs (76%). There are no apparent disparities in access to treatment among the major racial and ethnic groups or between males and females. Almost one-third (29%) utilize complementary or alternative medicine (CAM).

With respect to the level of CD4 cells (a measure of disease severity and immune system status), Whites appear to have similar CD4 counts compared to Blacks and Latinos, although they have a higher rate of AIDS diagnosis (69%). Whites also have a longer history of HIV (mean 15.0 years) which may explain the higher prevalence of AIDS diagnoses. Similarly, males have a higher frequency of an AIDS diagnosis and lower CD4 levels than females. Again, gender differences may reflect the longer HIV history of the White male cohort.



When asked how they were infected with HIV, 38% reported vaginal intercourse, followed by needle sharing (intravenous drug use, or IDU, 36%) and lastly anal sex (28%). Heterosexual sex is emerging as the current dominant mode of transmission. When comparing ROAH participants who tested HIV positive in the last five years to those who tested HIV positive more than 10 years ago, vaginal sex is given as a mode of transmission in 61% of those infected in the last five years as

¹⁰ New York State Department of Health AIDS Institute. (2005). *Criteria for the Medical Care of Adults with HIV Infection, Chapter 1: Primary Care Approach to the HIV-Infected Patient.*

compared to 32% in those who were infected more than ten years ago. During the same time frame, needle sharing (IDU) and anal sex declined as modes of transmission from 41% to 24% and from 32% to 13% respectively. This change is a function of the increase in females and heterosexuals becoming HIV infected. The lower rate of HIV infection due to IDU is probably a result of needle exchange programs and targeted education for users.

Vaginal transmission of HIV is higher among Blacks and Latinos due to the proportionally higher representation of women and heterosexuals in those groups, as compared to the White sample. Infection through sharing needles is higher in Blacks and Latinos, compared to Whites, irrespective of gender.

THE CHALLENGE: MANAGING HIV AND OTHER DISORDERS ASSOCIATED WITH AGING

People with HIV infection are now living long enough to experience HIV as a chronic illness. As they age they will engage the challenges of competing health risks from aging, drug toxicity and comorbid diseases and conditions. Absent the opportunistic infections associated with AIDS and the collapse of the immune system, there is a need to focus on non-HIV-associated health needs. HIV alone does not define the health status of these individuals. As HIV-infected persons are living longer, there will be at least one if not several disease processes that will challenge them and their healthcare providers.¹¹

One of the most important research goals in studies of HIV/AIDS and aging is to distinguish and understand the interactions among concomitant and overlapping conditions including HIV disease, comorbidities (HIV-related and non-HIV-related), normal aging and age-related medical changes and diseases.

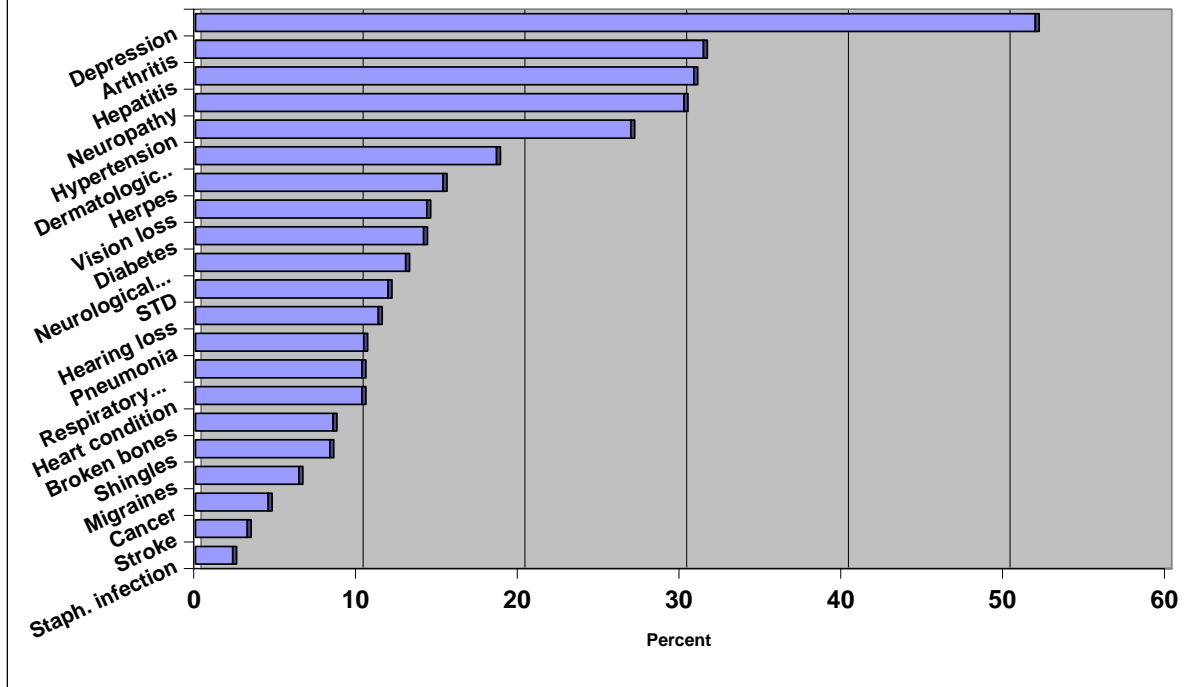
ROAH findings highlight several important issues that need to be considered and will be investigated in follow-up ROAH studies:

¹¹ Stoff, D. M., Khalso, J. H., & Portegies, P. (2004). Introduction: HIV/AIDS and aging. , 18(suppl 1):S1-S2

- Are the comorbidities that increase with age and with HIV infection different?
- Are these comorbidities related to aging alone or to the interaction of the aging process, HIV infection and the medications used by this population?
- What are the consequences of long-term ARV treatment?
- What is the impact of earlier and persistent substance use on the health outcomes of this population?
- What impact does treatment for comorbidities have on HIV treatment?
- Will the rate and severity of neurocognitive syndromes increase in these older adults and what impact will this have on managing care and treatment? HIV has an affinity for the brain and can lead to a host of neurocognitive problems, including HIV-associated dementia, which could be expected to have a negative impact on quality of life and adherence to HIV medications and other treatments.

Most participants experience one of the listed comorbidities (91.4%) and 77% have two or more comorbidities. The most common comorbidities were depression (52%), arthritis (31%), hepatitis (31%), neuropathy (30%) and hypertension (27%). Many medications commonly taken by older people can make the depression worse, among them steroids, anticancer drugs, tranquilizers, anti-anxiety agents, and drugs to treat Parkinson's disease, hypertension, heart disease, rheumatoid arthritis and pain.

Comorbid Health Problems



MENTAL HEALTH: DEPRESSION

Depression afflicts people of all ages, but it can be particularly destructive for older people, who are less likely to seek treatment. Caregivers often fail to recognize the symptoms of depression in the elderly. And frequently depression is thought to be a characteristic of aging rather than an illness. Further, people can be depressed without feeling sad. Rather, the depressive disorder is expressed more by agitation and irritability, and in physical terms, like vague complaints of aches and pains or gastrointestinal upset.

Older adults continue to regard depression as shameful or a sign of weakness that should not be acknowledged, even to physicians. Physicians, in turn, often fail to ask the questions that will identify and diagnose depression in their older patients. And there is too often the belief that little or nothing can be done for people with ample reason to be depressed.

Older adults continue to regard depression as shameful or a sign of weakness that should not be acknowledged. Physicians often fail to identify and diagnose depression in their older patients. And there may be the belief that little can be done for people with ample reason to be depressed.

By suppressing the immune system, depression may render people more vulnerable to infectious diseases. Stress and depression have harmful effects on cellular immunity,

ROAH data indicate that aging HIV-positive adults experience significantly high levels of depression, at a rate almost 13 times higher than the general New York City population.

including those aspects of the immune system affected by HIV. Body cell mass depletion is associated with significant increases in fatigue, global distress and depressive symptomatology, and reduced life satisfaction.¹² Elevated symptoms of depression are associated with a faster progression to AIDS and a higher risk of mortality.¹³ Depressive symptoms, especially

in the presence of severe stress, are related to decreases in CD4 cell count and declines in several lymphocytes.¹⁴

Older HIV-positive adults who are depressed are more likely to have financial problems, have fewer people to turn to for support, lack critical HIV-related information, live alone, have thoughts of suicide, and experience greater levels of stigma related to HIV and aging as compared to older adults who are not depressed. Depression may

By suppressing the immune system, depression may render people more vulnerable to infectious diseases... [D]epression has harmful effects on those aspects of the immune system affected by HIV.

interfere with adherence to treatment, doctor visits, participation in social activities, and personal relationships.¹⁵

In ROAH, depression symptoms were measured by the Center for Epidemiologic Studies Depression Scale (CES-D).¹⁶ This is one of the primary standardized tools used to assess depression. The CES-D includes 20 items that are summed to obtain a total symptom score

that can range from 0 to 60. Higher scores indicate greater depressive symptoms. People with scores below 16 are not depressed. Scores between 16 and 27 indicate moderate levels of depression and would typically correspond with a clinical depression diagnosis. Scores of 28 and above indicate severe levels of depression.

¹² Wagner, Ferrando and Rabkin (2000)

¹³ Leserman (2003)

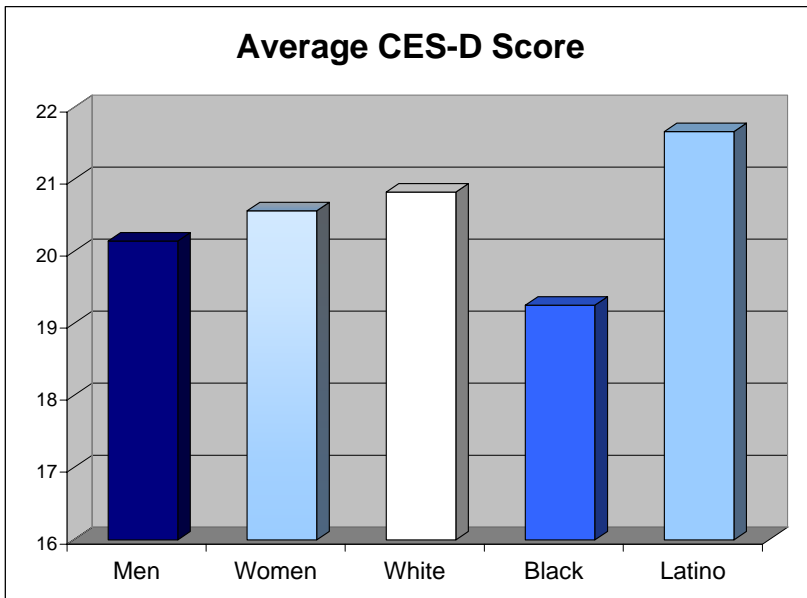
¹⁴ (Kopnisky, K., Stoff, D., & Rausch, D., 2004)

¹⁵ Heckman, T. G., Kochman, A., Sikkema, K. J. (2002). Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model. *Journal of Mental Health & Aging*, 8(4), 267-279.

¹⁶ Radloff, L.S. (1977). The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

ROAH participants' scores ranged from 0 to 52. The mean CES-D score was 20.3: 36% of the participants were not depressed (scored less than 16), while 38% were moderately depressed (scored 16-27) and 26% could be categorized as severely depressed (scored 28+).

Even though women over age 50 are more likely to be diagnosed with depression than men, no differences between males and females were seen in ROAH. There were significant differences between the racial and ethnic groups:



Latinos reported levels of depression significantly higher than Blacks. The White group's score placed them between Latinos and Blacks. ROAH found that aging HIV-positive adults experience significant levels of depression, at a rate almost 13 times higher than the general New York City population.¹⁷

There is no single evident reason that these numbers are so high. The ROAH cohort is already in care and arguably has access to a myriad of support and treatment modalities for the management of

depressive disorders. One reason may be the difficulty in diagnosing depression when symptoms are not typical or are easily confused with a physical ailment. Too often, treating physicians are focused on HIV and see depressive symptomatology as an expected reaction to living with HIV. The mental health needs of this growing group of adults may be overlooked. In the era of effective antiretroviral medications, it is important for healthcare providers to be prepared to assess and treat the comorbid physical and mental health conditions that aging adults will present. In fact, the co-occurrence of HIV and depression is a formula for continued distress of the immune system. The effectiveness of ARV treatment might have also caused

¹⁷ Galea, S., Ahern, J., Resnick, H., Kilpatrick, D., Bucuvalas, M., Gold, J., & Vlahov, D. (2002). Psychological sequelae of the September 11 terrorist attacks in New York City. *New England Journal of Medicine*, 346(13), 982-987.

healthcare providers to view depression as a less significant comorbidity to aggressively treat.

SUBSTANCE USE

Substance use is a risk factor for HIV infection. Injection drug users who share needles are at high risk of infection with HIV. Substance users who do not inject are also at risk; if they are under the influence of psychoactive substances, they may engage in unsafe sex practices. The risk is not limited to substance users but also to their sexual partners.

Because of its impact on health and well-being, substance use can complicate the course of HIV disease. Consequently, ROAH included a careful inquiry into patterns of substance use in this older adult population. Physical, psychological, and social problems are indicators of comorbidities that must be identified and assessed. Thoughtful dependence and addiction treatment may reduce the risk of transmission of HIV and improve quality of life for people who are HIV positive. The best outcomes occur when alcohol and other drug rehabilitation efforts are coordinated with HIV care. The challenge for caregivers of people living with HIV disease and substance use disorders is to devise a pragmatic management plan that addresses a complicated set of problems with scarce resources.

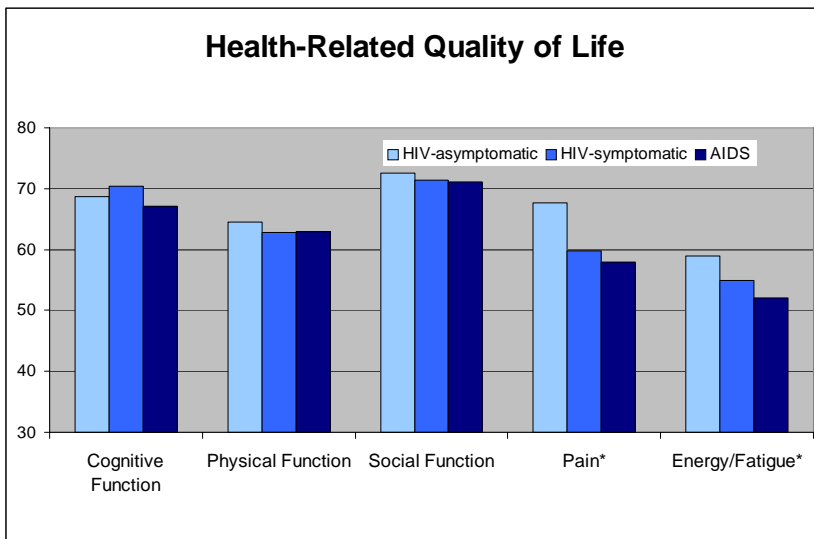
ROAH found that a majority of this older adult population used cigarettes (84%), alcohol (81%) or illicit drugs (84%) in their lifetime. Current use of illicit drugs was reported as follows: marijuana (23%), crack (16%), cocaine (15%), and heroin (7%).

Alcohol (54%) and crystal meth (5%) are used significantly more often by Whites. Crack use is significantly higher in Blacks and Latinos. Smoking is significantly higher among Blacks (63%) and Latinos (58%) compared to Whites (31%). Females have notably lower cigarette (28%), alcohol (31%) and illicit drug use (28%). More than half of those ROAH participants who were users of alcohol or illicit drugs are now in recovery (55%). Still, over one-third of the entire sample population continues to use illicit substances (37%) or alcohol (38%). More than half continue to smoke (57%).

HEALTH-RELATED QUALITY OF LIFE

Functional ability and overall health-related quality of life was evaluated using a modified version of the MOS-HIV.¹⁸ This measure was designed specifically for studies of HIV-positive individuals and has been used extensively by researchers. Five of the 10 dimensions of health (physical function, cognitive function, social function, pain and energy/fatigue) were selected for use in ROAH. Previous ACRIA research found these scales to be most relevant to older HIV-positive adults' self-rated health. Participants' scores ranged from 0 to 100 on each of the five scales, with higher scores representing better quality of life. The mean scores for each scale were: physical function 63; social function 72; cognitive function 69; pain 64; energy/fatigue 57. When we examined the differences in quality of life

among participants based on their HIV status, we found that people who had never received an AIDS diagnosis [HIV-asymptomatic] scored significantly better on the pain and energy/fatigue subscales than those who had received an AIDS diagnosis, regardless of their current CD4-count. Thus, although many people today have CD4 counts that have risen from previously low levels, having once reached a disease stage that warrants an AIDS



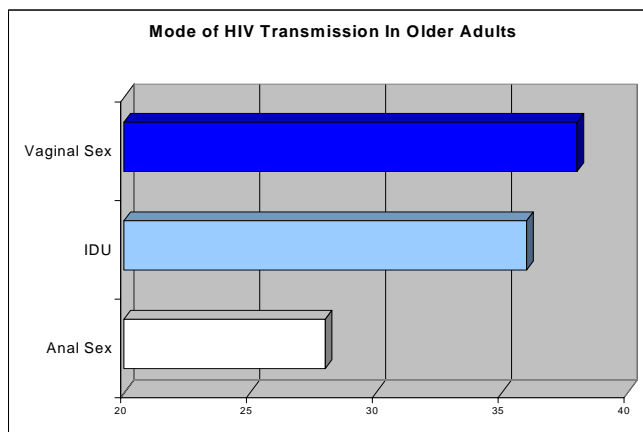
diagnosis appears to result in deleterious effects that continue to influence these individuals' health, particularly on certain domains of quality of life (e.g., pain and energy/fatigue) even if there is significant immune reconstitution.

¹⁸ Wu, A.W., Rubin, H.R., Mathews, W.C., et al. (1991). A health status questionnaire using 30 items from the Medical Outcomes Study. Preliminary validation in persons with early HIV infection. *Medical Care*, 29, 786-798.

Sexual Behavior

HIV is a sexually transmitted disease (STD). ROAH is the first study to assess the sexual behaviors of an older adult population living with HIV. The data illustrate one of the notable changes in the HIV epidemic in the US inasmuch as the primary mode of transmission of HIV is no longer a result of sex between two males. The shift from homosexual to heterosexual sex as the primary mode of transmission is significant. This finding is not surprising since, in ROAH's sample, which largely reflects the present HIV epidemiology, fewer than one in four identify as homosexual (gay 21%; lesbian 3%) and 9% as bisexual. ROAH's data include assessments of sexual activity in the last three months. Half of the subjects did not have sex. This may be related to ROAH's finding that 70% live alone. Only a minority of all participants (15%) live with their sexual partner.

The shift from homosexual to heterosexual sex as the primary mode of transmission is significant.



Those engaging in sexual activities reported having oral sex (83%), vaginal sex (60%) and anal sex (39%). The type of sexual activities reflects the subjects' gender and sexual orientation, oral sex being least prevalent in straight females (63%), vaginal sex being most prevalent in heterosexual men (89%) and anal sex being most prevalent in gay men (71%).

The ROAH data illustrate a trend seen in younger HIV groups toward selection of sexual partners based on HIV status (sero-selection). More than one-third of sexually active participants (39%) had sex exclusively with HIV-positive partners. Fewer had sex exclusively with partners who had a negative or unknown HIV status (29%) and 32% had sex with both HIV-positive and HIV-negative individuals or those of unknown serostatus.

Most of those who have sexual partner(s) report having one partner (77%), and one-quarter (23%) have more than one sexual partner. Women (93%) were more likely to have only one partner than men (70%). Blacks (82%) and Latinos (77%) were more likely to have one sexual partner as compared to Whites (57%). Heterosexual males (86%) were more likely to have only one sexual partner than homosexual and bisexual males (73%). Sexual behavior involving significant risk for HIV transmission (unprotected insertive or receptive anal or vaginal sex) occurred in 33% of the sexually active subjects in the last three months. Half of the time the risk behavior occurred with a partner who was not known to be infected (16%).

Sexual behavior involving significant risk for HIV transmission occurred in 33% of the sexually active subjects in the last three months.

ROAH subjects were asked the reasons they engage in unprotected sex. Almost one-third of the subjects who had had sex in the last three months indicated that they would not have unprotected sex under any circumstance (28%). Others indicated desire for sex and partner attractiveness (32%), partner's request (32%), being high on drugs (27%), depressive feelings or neediness (19%), and conviction of low risk of STD (14%) as reasons for unprotected sex.

Those who report current use of alcohol or drugs were more sexually active (58%) compared to those who did not use substances (42%). Almost half of sexually active people used alcohol or drugs with sex (47%). The substances most often used with sex were alcohol (32%), marijuana (20%), crack (17%), cocaine (15%) and poppers (11%). The use of illicit drugs with sex influenced the amount of risk taken. Unprotected anal or vaginal sex occurred more frequently when alcohol or illicit drugs were used with sex (40%) than when no substance was used (27%).

The use of illicit drugs during sex influenced the level of risk taken. Unprotected sex occurred more frequently when alcohol or drugs were used during sex.

As expected in this older population, almost half of the women are postmenopausal (44%). One in six men (17%) reported impotence.

Social Networks

The critical role of social networks is illustrated by the impact of informal caregiving on the healthcare system.

If the informal caregiving provided by the social networks of family, friends, and neighbors were replaced by formal (i.e., paid) caregivers, the cost would exceed \$300 billion annually.

Approximately 44 million Americans currently provide caregiving assistance to family members or friends. If the informal caregiving provided by family, friends, and neighbors were replaced by formal (i.e., paid) caregivers, the cost would exceed \$300 billion annually.¹⁹ While significant resources have been expended on understanding HIV/AIDS and its impact on individuals, groups, societies and healthcare delivery, little research

has examined how HIV/AIDS affects the ability of older adults to maintain their social networks. Few studies systematically examine the informal networks that provide critical support for the rapidly growing population of older adults living with HIV/AIDS. Therefore, we do not know who comprises their informal networks and whether those networks will be able to provide needed support for this at-risk group of older adults.

Little research has examined how HIV/AIDS affects the ability of older adults to maintain their social networks.

Life events such as retirement, illness, relocation and death of family and loved ones can result in shrinking social networks.²⁰ As one ages, a person's social network is transformed into a social care system comprised of family, friends, and formal support services (e.g., community and government agencies, hospitals, homecare services) that respond to the older adult's changing needs.²¹ Typically older adults want to receive help from those who are close to them. A common process by which older people adapt to infrequent or reduced contact with their families is to

¹⁹ National Alliance for Caregiving and AARP (April, 2004). *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving and AARP.

²⁰ Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M. M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences* (pp. 1-34). Cambridge, England: Cambridge University Press.

²¹ Cantor, M. H. 1979. "Neighbors and friends: An overlooked resource in the informal support system." *Research on Aging*, 1: 434-463.

augment their support networks by reliance on friends as primary sources of support. For example, research on the social networks of older gay men found that among men

Friends are the most important element of older adults' social network, more than parents, siblings and children.

who did not maintain close connections to their families of origin, friends became a chosen family, assuming many of the emotional ties and legal rights and responsibilities of biological family.²²

However, the number of people in an older adult's informal network of family and friends is not the only important factor. Research shows that a person's level of satisfaction with support from their informal social networks is more important than the actual number of individuals who are available to provide that support.²³

Previous research by the ROAH study investigators suggests that the capacity of the informal networks of older HIV-positive adults to provide needed support is inadequate.²⁴ Unlike the general population, who rely upon spouses, partners and family, many older adults with HIV rely on friends as the primary source of informal support. Many of these friends are also living with HIV and may not be able to function as caregivers. Aging adults with HIV who receive marginal social support report feelings of isolation and a decreased ability to cope with the rigors of disease management.²⁵

Social Network Composition

In order to assess the level of informal support that is available to older adults with HIV, ROAH participants were asked to complete a detailed assessment of their social networks. This assessment included the number of people, the relationship to the ROAH member and frequency of in-person and telephone contact with such persons. From these data, we designated those individuals who maintained frequent and regular contact as "functional" components

²² Shippy, R.A., Cantor, M.H., & Brennan, M. (2004). Social networks of aging gay men. *Journal of Men's Studies*, *Vol 13*(1), 45-66.

²³ Cantor, M. H., & Brennan, M. (2000). Social care of the elderly: The effects of ethnicity, class, and culture. New York: Springer.

²⁴ Shippy, R.A., & Karpiak, S.E. (2005a). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health*, *9*(3), 246-254.

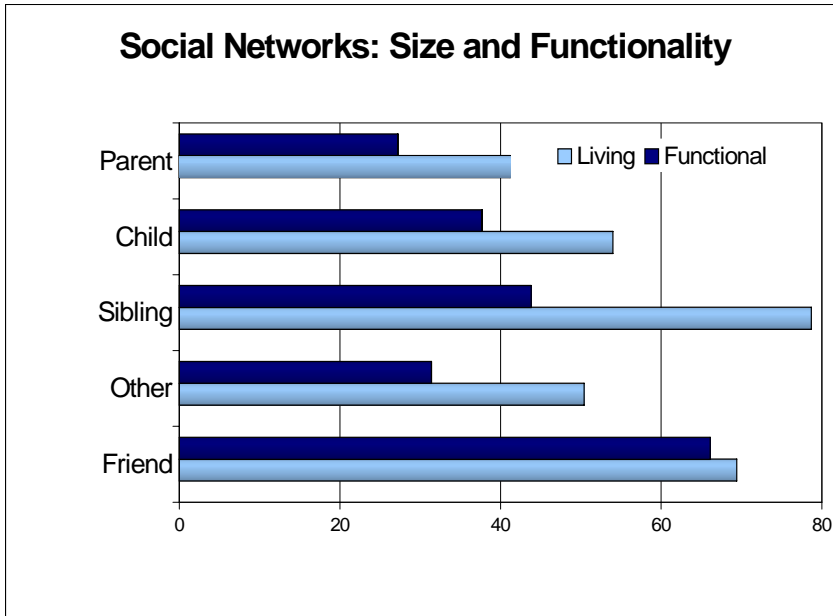
Shippy, R.A., & Karpiak, S.E. (2005b). Perceptions of support among older adults with HIV. *Research on Aging*, *27*(3), 290-306.

²⁵ Heckman, T. G., Kochman, A., Sikkema, K. J. (2002). Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model. *Journal of Mental Health & Aging*, *8*(4), 267-279.

(e.g., parents, children, siblings, other relatives and friends), according to criteria defined by Cantor.²⁶

Approximately 40% of ROAH members had a living parent, but only 27% reported that they had regular contact with their parent(s). Of the total group, 54% had at least one child

and 38% maintained regular contact with their child(ren). Women were more likely to have children than men. Similarly, Blacks and Latinos were more likely to have children than Whites. This is a result of the greater proportion of gay men in the White sample. Eight in ten participants had a sibling, but only 44% were in regular contact with their siblings. Half of the participants had another relative (e.g., cousin, aunt, niece, etc.); 33% of the group saw or spoke to their



relatives regularly. Most participants reported that they received infrequent assistance from family members. However, the incidence of family members showing negative reactions to requests for help was very low.

Friends are an important source of support for ROAH participants, as evidenced by the fact that 69% of the

Friends were more likely than family members to provide emotional support.... 20% had no friends that were HIV positive.

participants have a close friend with whom they share confidences. More than any other informal network component, 66% of the group saw or talked to their friends regularly. While there were no differences between men and women, White participants were more likely to

report having friends than Black or Latino participants. Most participants received infrequent assistance from friends for instrumental tasks of daily living (e.g., cooking, cleaning, transportation needs) but friends were more likely than family members to provide emotional support. As with

²⁶ Cantor, M. H. 1979. "Neighbors and friends: An overlooked resource in the informal support system." *Research on Aging*, 1: 434-463. The criteria set by Cantor require either weekly telephone or monthly in-person visits to be considered "functional."

family members, few participants experienced negative reactions to requests for support from friends. An important finding was that approximately 40% of participants had friendship networks comprised of a majority of HIV-positive individuals, but almost 20% said that none of their friends were people living with HIV.

42% said the support they had received was inadequate to their needs in the past year. An increasing number of participants (25%) reported receiving assistance from paid helpers (e.g., home health aide) and 15% were assisted by volunteers.

Family members and friends were the most common sources of support for these older adults with HIV. Partners were an important resource for about 25% of the participants.

However, a noticeable number of participants (25%) reported receiving assistance from paid helpers (e.g., home health aide) and 15% were assisted by volunteers.

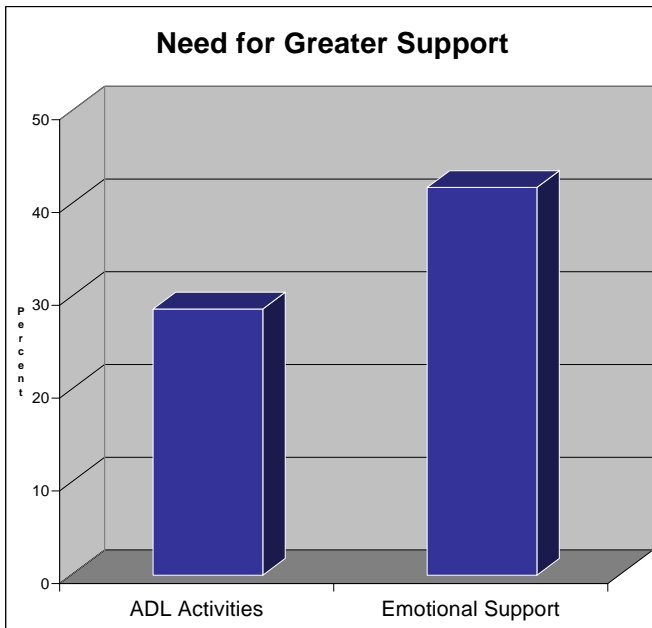
ADEQUACY OF SUPPORT

To understand the extent to which participants had readily available and adequate informal support networks, we asked four questions. The first item asked, “Do you have someone you can count on to help you with activities of daily living (ADL, e.g., shopping, cleaning, getting to the doctor)?” Slightly more than half (56%) had someone they

could rely on, but 44% had no one at all or someone only occasionally to assist with ADL tasks. Next, participants were asked, “In the past year, how much more assistance with instrumental activities of daily living did you need?” Most (71%) said they were satisfied with the level of ADL support they received, but a significant group (29%) needed more assistance during the previous year with these tasks.

When asked if they had someone to provide emotional support (e.g., someone to talk to or from whom they could get advice), a majority (74%) identified a readily available source of emotional

support. However, when participants responded to the question about how much more emotional support they needed in the past year, 42% said the support they had received was inadequate to their needs. This pattern of



unmet need is similar to studies that examined diverse groups of older adults.²⁷ However, the magnitude of need, particularly emotional support need, is higher for older adults with HIV than other older New Yorkers.

LONELINESS

In other studies of older adults, researchers found that loneliness scores are not related to frequency of contact or the social network size. But they do measure the quality of that support. Levels of loneliness have been shown to be negatively related to self-rated health and life satisfaction and positively correlated with depression in older adults.

The UCLA Loneliness Scale is designed to assess perceptions of inadequate support from a person's social network.²⁸ The scale contains both positive and negative statements about feelings of loneliness. Scores range from 20 to 80, with higher scores indicating a greater degree of loneliness.

ROAH participant responses covered the entire range of scores from 20 to 80, with an average score of 53. Thus, among older adults with HIV, loneliness is a significant issue. This level of loneliness is significantly higher than the levels found in a study of seniors (65 and older) who had a range of scores from 20-59 and an average score of 32.

Taken together, the findings from the assessment of the ROAH participants' social networks describe a population at risk. Older adults may not have access to the support they need to age in place successfully. The high levels of unmet need for emotional and instrumental support as well as significant evidence of loneliness reflect a certain distance from loved ones, either physically or emotionally. One of the possible causes for this estrangement, the stigma related to HIV/AIDS, will be discussed in detail in the following section, which examines stigma.

Among older adults with HIV, loneliness is a significant issue. This level of loneliness is significantly higher than the levels found in seniors (65 and older).

²⁷ Cantor, M. H., & Brennan, M. (2000). *Social care of the elderly: The effects of ethnicity, class, and culture*. New York: Springer.

Schrimshaw, E. W., and K. Siegel. (2003). "Perceived Barriers to Social Support from Family and Friends among Older Adults with HIV/AIDS." *Journal of Health Psychology*, 8: 738-752.

Shippy, R.A., Cantor, M.H., & Brennan, M. (2004). Social networks of aging gay men. *Journal of Men's Studies*, Vol 13(1), 45-66.

Shippy, R.A., & Karpiak, S.E. (2005b). Perceptions of support among older adults with HIV. *Research on Aging*, 27(3), 290-306.

²⁸ Russell, D.W. (1996). UCLA Loneliness Scale (Version 3): Reliability, validity and factor structure. *Journal of Personality Assessment*, 66(1), 20-40.

Stigma

Although HIV is treatable and manageable, the disease is chronic and incurable. HIV remains an infection surrounded by fear and myths. Many people in the US remain unaware or poorly informed about the modes of transmission and risk factors for HIV. Many people fear the mere presence of the illness. Many believe an HIV-positive person's lifestyle led to the infection. These myths contribute to the continued stigma directed against people living with HIV. HIV-related stigma exacerbates other types of stigmas faced by many older adults living with HIV, such as racism, sexism and ageism. The presence of HIV-related stigma is well documented, and appears to have increased. In 1991, 21% of the US population reported negative feelings toward HIV-positive persons, or stigma. In a similar study in 1997, HIV-related stigma increased to 28%.²⁹

Silence Equals Death...

ROAH finds that stigma causes older adults to hide from half of their friends the fact that they live with HIV.

The stigma associated with HIV is more pervasive than in most other stigmatizing health conditions. The fear of HIV is so powerful and pervasive that stigma can extend beyond those living with HIV/AIDS to their families and friends, as well as

the professionals who provide health and social care to them. HIV-related stigma can have a significant impact on the health and well-being of people living with the disease.

Individuals may experience discrimination that leads to loss of employment, estrangement from friends and family, and violence. Although some people can be supportive and accepting, others reject the HIV-positive individual or distance themselves in more subtle ways.³⁰ HIV stigma fuels the risk of spreading the virus to others because it creates a barrier to testing for HIV. Stigma can

²⁹ Herek GM, Capitano JP, Widaman KF. (2002). HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *Am J Public Health*. 92(3):371-7.

³⁰ Heckman, T. G., Kochman, A., Sikkema, K. J. (2002). Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model. *Journal of Mental Health & Aging*, 8(4), 267-279.

Herek, G.M., Mitnick, L., Burris, S., Chesney, M., Devine, P., Thompson, M., et al. (1998). AIDS and stigma: A conceptual framework and research agenda. *AIDS and Public Policy Journal*, 13(1), 36-47.

influence a person's choice not to disclose her or his HIV-positive status to sexual and needle-sharing partners.

HIV AND STIGMA

ROAH data from the Berger HIV Stigma Scale³¹ provide evidence for the existence of high levels of stigma among older adults with HIV. The average total score (with a possible range of 40 to 160) was 88, well above the midpoint of 60, indicating high levels of stigma. After more detailed analyses, the data reveal that the participants scored higher on items that describe negative reactions from others (e.g., "Some people avoid touching me once they know I have HIV") as opposed to items describing internalized negative feelings (e.g., "I feel guilty because I have HIV"). This finding suggests that the impact of stigma on this population emanates from external sources, rather than negative self-appraisals. These older adults clearly see stigma as an impediment or barrier in engaging their community, family and friends. These results are similar to those of other recent studies of stigma among older adults with HIV.³²

Another indication of stigma is whether people disclose to others the fact that they have HIV. Most people with HIV have disclosed their HIV status to someone, often with negative results. ROAH participants were asked to indicate whether they had disclosed to *All*, *Some*, or *None* of the people belonging to eight specific groups. While most ROAH members felt comfortable discussing their HIV status with others, they made careful and specific decisions about whom they told. Not surprisingly, 91% of all respondents disclosed their HIV status to healthcare providers. ROAH respondents were more likely to disclose their HIV status to people who were closer to them than casual acquaintances. Thus, ROAH participants were most likely to disclose their HIV status to sex partners, family members, friends and drug buddies.

Nevertheless, many ROAH members were reluctant to discuss their HIV status, even with the people closest to

Fewer than half (46%) told all of their family members and only one-third (35%) told all of their friends that they were HIV positive. Overall, Whites were significantly more likely to disclose their HIV status than either Blacks or Latinos.

³¹ Berger, B.E., Ferrans, C.E., & Lashley, F.R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV Stigma Scale, *Research in Nursing & Health*, 24, 518-529.

³² Emler, C.A. (2006). Extending the use of the 40-item HIV stigma scale to older adults: An examination of reliability and validity. Manuscript submitted for publication to AIDS Care.

them. Over half (57%) of the participants disclosed their HIV status to all of their sexual partners. It is a startling fact that 16% did not disclose to any of their sexual partners.

Fewer than half (46%) told all of their biological family members and only one-third (35%) told all of their friends. Similarly, (30%) told all their drug buddies. Overall, Whites were significantly more likely to disclose their HIV status than either Blacks or Latinos.

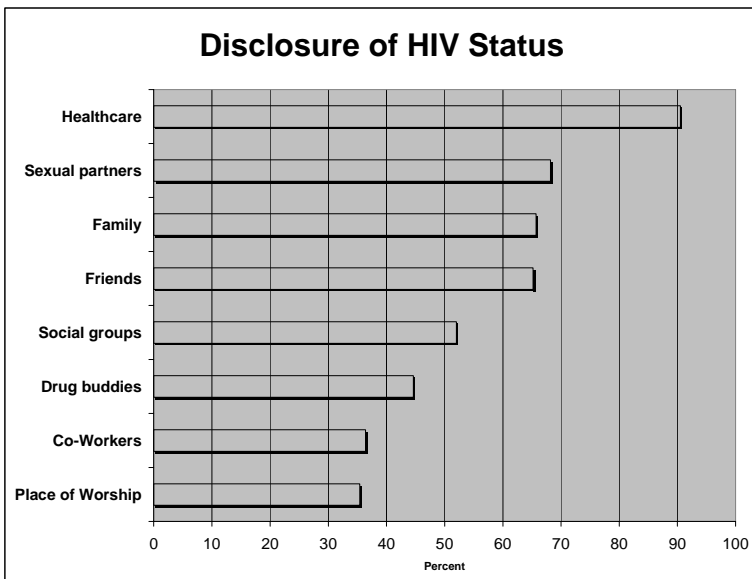
Older adults with HIV have many reasons for not disclosing their HIV serostatus to others. Responses varied from “I don’t want to worry them” to “The person might kill me.”

Members of social or political organizations, co-workers and people at places of worship were the least likely to have been told of a respondent’s HIV serostatus. About three-quarters (74%) of participants did not disclose to everyone they know in social or political organizations. Fewer than one-quarter (21%) disclosed their HIV status to all of their co-workers. Four in five (82%) did not talk to people about their HIV status at their place of worship.

REASONS FOR NONDISCLOSURE

Participants were asked if there were people who they would like to tell about their HIV status, but have not yet

done so. Two-fifths of participants reported not disclosing to people they would like to tell about their HIV status. Older adults with HIV have many reasons for not disclosing their HIV serostatus to others. Responses varied from “I don’t want to worry them” to “The person might kill me.” An examination of the responses revealed two major categories: Concern for Self and Concern for Others. The majority of respondents (61%) endorsed statements that demonstrated more concern for those individuals they did not tell rather than concern about themselves (45%).



Stigma is particularly complex as it operates at many different levels and has both social and psychological aspects. Stigma has been talked about since the beginning of the HIV/AIDS epidemic but has not been adequately

investigated or addressed in programs or policies. There are many factors surrounding stigma including denial, shame, blame, fear, rejection and discrimination.

Personal Resources

While life satisfaction and depression are often used to assess a person's quality of life, these indicators do not present a complete picture of an individual's psychological well-being. The absence of mental illness does not imply wellness.³³ Many of the ROAH participants evidenced signs of depression, but they may have psychological strengths that enable them to adapt to their illness.

PSYCHOLOGICAL WELL-BEING

Ryff's psychological well-being scales were used to understand the personal resources and assess the psychological functioning of older adults with HIV.³⁴ These scales (autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance) have a range of 9 to 54, with higher scores indicating greater well-being. ROAH is the first HIV study in which these scales have been used. Each scale is examined below:

Autonomy: Autonomous individuals are self-determining and independent, able to resist social pressures to think and act in certain ways. They judge themselves by their own set of standards and regulate their behavior based upon these standards. Most of the ROAH participants scored higher than the midpoint of the scale (M=40.4), indicating that most of these older adults have a strong sense of identity and independence.

Environmental Mastery: An individual who scores high on this scale is able to adapt to or create a comfortable environment that is suitable to personal needs and values. This particular domain of well-being is integral to an older HIV-positive adult's ability to live in a society that

³³ Jahoda, M. (1958). *Current concepts of positive mental health*. New York: Basic Books.

Lawton, M. P. (1984). The varieties of well-being. In C. Z. Malatesta & C. E. Izard (Eds.), *Emotion in adult development*. Beverly Hills, CA: Sage.

³⁴ Ryff, C.D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069-1081.

discriminates against people with HIV. Although ROAH participants had a slightly lower average score (M=38.1) than other Ryff scales, it was above the scale's median score.

Personal Growth: Older adults with HIV who are open to new experiences and see improvement in their attitudes and behaviors over time will be more likely to adhere to treatment regimens and actively seek new information about their illness. Those people can become more self-aware and realize their potential, further reinforcing positive psychosocial and physiological health. The mean score for Personal Growth was one of the highest (M=40.0). There were no significant differences between men and women.

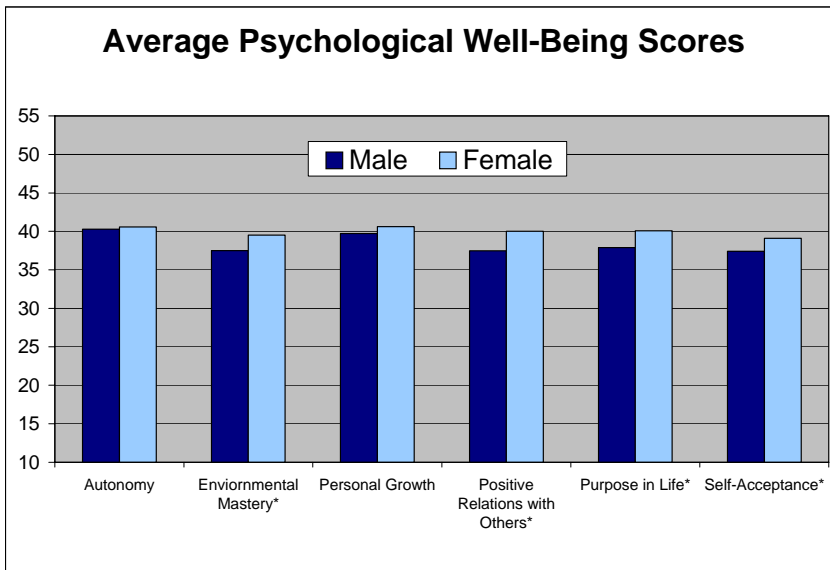
Positive Relations with Others: An older HIV-positive adult who has strong relationships with others is concerned with others' welfare and is capable of empathy, affection and intimacy. That person can develop mutually beneficial

relationships, which provide needed instrumental and emotional support. Participants' mean score in this scale was 38.2.

Purpose in Life: A sense of meaning for one's past and present life experiences assists an older adult with HIV create personal goals and objectives for living that result in positive adaptation to their illness. The person may be less likely to feel victimized and, therefore,

more proactive in seeking information and assistance with their illness. The average score was 38.5.

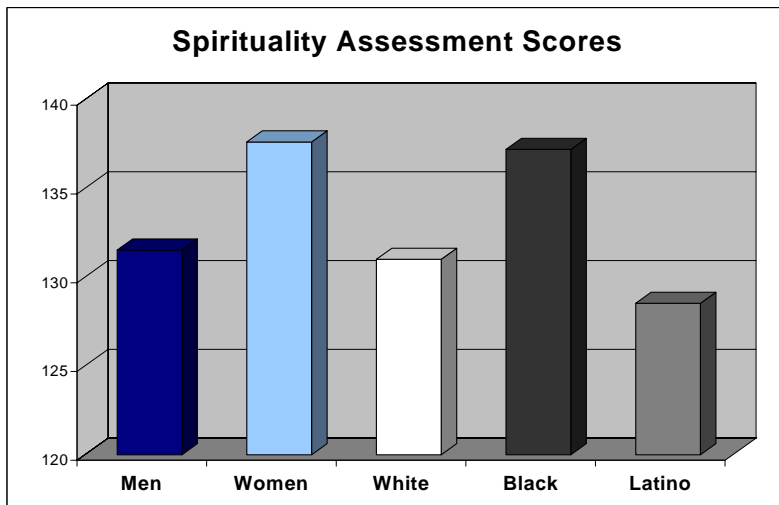
Self-Acceptance: A self-accepting person possesses a positive attitude; acknowledges and accepts both good and bad aspects of him- or herself; and feels positive about his or her past life. Although this scale had the lowest average score of the six scales (M=37.9), most respondents scored above the median for the scale. Given the frequently hostile attitude of society toward people living with HIV, it is important for them to achieve a high level of self-acceptance,



so that even when facing powerful stigma, they can maintain a positive outlook on life.

Average scores on each of the six scales were above the midpoint of the range, indicating that the participants have relatively high levels of well-being in each of the domains. Women reported significantly higher levels of well-being on four of the six scales (environmental mastery, positive relations with others, purpose in life and self-acceptance), suggesting that women may be better able to adapt to their illness than men and that men may need additional support to build stronger relationships with family and friends.

In addition to the Ryff scales, we used a single item to assess a global perspective of life satisfaction. The mean score was 7.3, with a possible range of 0 – 10. Women scored significantly higher than men (7.7 v. 7.1) and Whites scored lower than Blacks and Latinos (6.4 v. 7.5 and 7.3, respectively). Taken together, these measures provide a positive picture of a group of aging adults living with a chronic illness in the context of a society that is far from welcoming toward people with HIV.



SPIRITUALITY

Spirituality can be an important personal resource for some older adults, especially when adapting to a chronic illness and the demands of aging. Because churches are both a source of practical support and a significant part of the social culture for many people, an assessment of religious participation and spirituality was included in ROAH. ROAH data show that 47% attend church

services on a regular basis, yet over half (56%) say they do not receive support from their place of worship. Spirituality has been conceptualized as a different phenomenon from religiousness, or frequency of attendance at religious services.

A sense of spirituality is a positive connection in which a Higher Power is seen as a source of help in any effort to improve health. Spirituality is perceived as an inner source of

strength, power, peace, and comfort needed to live life in a healthy way. Many reports show that spirituality increases self-awareness and positive view of self. One study found that HIV-positive African-Americans' experience of HIV symptoms decreased as their level of spirituality increased.³⁵ The pivotal role of a higher being or spirituality is also a vital part of 12-step programs. ROAH finds that 51% of older adults with HIV are in recovery programs/interventions.

The ROAH instrument included The Spirituality Assessment Scale (SAS), which provides scores that range from 28 to 168 and measures various aspects of spirituality (i.e., purpose and meaning in life, inner resources, unifying interconnectedness and transcendence).³⁶ The average score among ROAH participants was 133, indicating that spirituality is a critical element for them.

There was a small minority that did not report spirituality as a source of positive support. Intergroup comparisons, however, revealed some noteworthy results. Spirituality may be a more important resource for Blacks than Whites and Latinos. Women may gain more from a sense of spirituality than men.

A constructive association is reported to exist between spirituality and health. This work affirms the need for further research into the relationship between spirituality and religion and the ability to manage health and treatment.³⁷

³⁵ Holzemer, WI., Spicer, JG, Wilson, HS, Kempainen, JK, Coleman, C. (1998). Validation of the quality of life scale: living with HIV. *Journal of Advanced Nursing*, Vol. 28(3), p. 622-630.

³⁶ Howden, J. (1992). *Development and psychometric characteristics of the Spirituality Assessment Scale*. Unpublished doctoral dissertation. Texas Women's University.

³⁷ Popkess-Vawter, S., Yoder, E. and Gajewski, B. "The role of spirituality in holistic weight management." *Clinical Nursing Research* 14, no. 2 (May 2005): 158-174.

Policy and Practice Recommendations

Healthcare

- Conduct public education outreach campaigns to reduce and end HIV stigma, including homophobia and ageism, in healthcare, including mental healthcare services, and social care agencies that provide services to older adults.
- Increase funding for public health and mental health research into the particular needs and experiences of older adults with HIV.
- As older people live longer with HIV, reexamine and modify the HIV Standards of Care to include routine assessments for the myriad comorbid illnesses that are common among aging adults.
- Tailor and target HIV prevention messages to older adults.
- Include older men and women in clinical trials for new and current anti-HIV medications, and conduct clinical trials with older adults taking medications used to treat comorbid illnesses.

Social Policy

- The Older Americans Act (OAA) should be amended explicitly to include services, outreach, training, and research on issues of concern to older HIV-positive adults and to prohibit discrimination in services on the basis of sexual orientation and HIV status.
- Amend Title III of the Older Americans Act, which authorizes and funds the core programs of the OAA. Targeting language should be added that specifically authorizes outreach to older adults with HIV, along

with other underrepresented and underserved populations. However, new targeting should be accompanied by new funding to pay for the services, so that funds are not simply redirected away from other at-risk groups.

- Community-based organizations (CBOs) and AIDS service organizations (ASOs) should apply for demonstration funding under OAA, Part F, which provides for State and Local Innovation and Programs of National Significance, to train those who provide services to older adults with HIV. Training should lead to programs and services that are sensitive to this aging population and responsive to its needs.
- Training and education can decrease HIV stigma and create a safe environment in which HIV-positive older adults can partake fully of services offered to other elders. HIV-positive adults (peer educators) should be included as both trainers and advisors.
- Maintain the inclusive language in Part E of the National Family Caregiver Support Program that defines family caregiver as “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.”
- Appropriate ASO staff should work with their Area Agencies on Aging (AAAs) to assess the needs of older adults with HIV, evaluate whether those needs are being met by community-based services, and influence their area plans to ensure that older adults with HIV have the services they need and deserve.
- To improve the ability of AAAs in effectively serving older adults with HIV, we recommend:
 - in-service training on issues involving aging and HIV, conducted by ASOs, to the staff of member agencies.
 - developing effective outreach strategies, including marketing strategies targeting older HIV-positive adults.

- developing collaborations between senior centers and CBOs/ ASOs already providing services to older adults with HIV.
- better outreach coordination by ASOs and senior centers to HIV-positive older adults to join in the socialization activities in senior centers.
- Training for home healthcare staff on the needs of older HIV-positive people, including education aimed at eliminating stigma or other forms of prejudice.

Research

- Provide funding for targeted research aimed at treating depression and other mental health problems, including substance use and sexual risk-taking in older adults with HIV.
- Increase knowledge, through research, about how stigma continues to prevent people from disclosing their serostatus to others, thus limiting the amount and frequency of support they receive from family, friends and others.
- Funding should be made available from the National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH) for:
 - research on the needs and concerns of older HIV-positive adults.
 - evaluation of existing health and social services and their use by older adults with HIV.
 - development of gerontology and social work curricula at colleges and universities that train aging specialists and service providers in the particular needs of the over-50 HIV-positive population.
- Increase funding for basic research on the interaction between HIV and the common diseases of older adults, especially pertaining to drug interactions, needed to more accurately document the experiences and issues facing older adults as they become

susceptible to other common age-related illnesses. These illnesses may have an impact on both the medical and social care of older adults who are living and aging with HIV.

- Ensure that older people are included as an identifiable group at every stage of the HIV research process.

ROAH SURVEY INSTRUMENT COMPONENTS

Module 1: Demographic Profile

- Sociodemographic/background characteristics of individuals.

Module 2: Health Status

- Detailed HIV history including CD4, viral load, when diagnosed, HAART, etc.
- Past and current substance use, recovery, etc.
- Selected scales from the MOS-HIV will also be used for this module.
- The module contains the 20-item CES-D.

Module 3: Sexual Behaviors

- Sexual behavior checklist includes sexual activities, number of partners, safer sex practices, serostatus of partners, etc.

Module 4: Social Networks

- Perceived network size, functional network size, support satisfaction and support need.
- Independent measures of availability and adequacy of instrumental and emotional support.

Module 5: Stigma

- The Berger HIV Stigma Scale included in this module.
- Level of disclosure, reasons for not disclosing, and level of stigma experienced during interactions with six (biological family, friends, co-workers, social organizations, place of worship, and healthcare providers) groups of people.
- Reasons for nondisclosure

Module 6: Psychological Resources

- Psychological well-being - The absence of physical or mental symptomatology does not imply optimal health. Ryff's scales of psychological well-being encompass six domains (self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth) that measure positive aspects of well-being.
- Spirituality - Howden Spirituality Assessment Scale is a 28 item instrument with four subscales: 1) Purpose and Meaning in Life, 2) Inner Resources, 3) Unifying Interconnectedness, 4) Transcendence.

ROAH Methodology

Specific Aims

The primary goal of this research was to establish empirically valid normative data describing this population and to allow for the analyses of subgroups within the larger population. For example, comparisons of gender, education, health and race/ethnicity can identify potential disparities among these older adults, which will need to be addressed by healthcare providers and policy makers. New York City's HIV population, the largest and most diverse in the United States, is a gauge for changes in the HIV epidemic nationwide. This cohort of aging New Yorkers will be a benchmark against which other studies of aging adults with HIV will be compared. Pending future funding, this cohort will become the baseline data sample of a longitudinal cohort study of older adults with HIV. Before the ROAH study was undertaken, no other group representing the current demographic profile of older adults with HIV existed. Existing cohorts have limited utility because they contain highly selective groups of older adults (e.g., veterans, gay men).

Project Site

ACRIA is a well-established research entity that has completed over 80 clinical and behavioral studies on HIV, its related diseases, and side effects associated with antiviral medications. ACRIA's research program has existed since

1991, with proven procedures in place to monitor and evaluate progress of individual protocols. These procedures concern multiple aspects of a research project from timeliness and accuracy with regard to completing all study phases to compliance with HIPAA standards and other practices to protect study participants. The agency has consistently been among the most successful enrolling sites for national multicenter trials of new HIV medications, and has always been in full compliance with FDA regulatory requirements for trials of experimental therapies utilizing human subjects. In fact, a hallmark of ACRIA's work has been a strong focus on ensuring that all populations impacted by HIV have an opportunity to participate in our studies, including vulnerable populations traditionally underserved by HIV research, most prominently ethnic minorities and women.

ACRIA has one of the most extensive networks of partnerships with community-based organizations and AIDS service organizations of any not-for-profit organization in New York City. This network was used extensively in the recruitment of study participants for the proposed protocol. The agency maintains a database of over 1500 people living with HIV who are interested in receiving information about clinical and behavioral studies at ACRIA. These individuals received IRB-approved recruitment materials for this study.

Sample Selection and Recruitment

As of March 31, 2005, the last date for which data are available, there were approximately 95,707 known cases of HIV in New York City. Of this number, 28,433 (30%) were over age 50. Study participants ($N = 1,000$) were selected from this population. The ROAH study team utilized ACRIA's existing relationships with organizations in New York City to recruit individuals for the study. Recruitment occurred through on-site trainings, presentations and staff visits, as well as mail, telephone and email contacts.

Eligibility Criteria

- confirmed HIV diagnosis.
- age 50 years or older.

- reside in or receive HIV-related healthcare in New York City.
- sufficiently fluent in English to complete the measures.
- community-dwelling (non-institutionalized).
- have no significant cognitive impairment that would preclude completing the study instrument.

Instrument

The ROAH Program utilized a quantitative, self-administered instrument designed by the study investigators, composed of several standardized research measures in addition to items drawn from the investigators' previous. The instrument is designed to collect detailed information from five general conceptual areas (e.g., physical health, mental health, social support, formal care utilization, and HIV-related stigma and disclosure of HIV serostatus). The instrument has been constructed to yield empirically valid data that can be compared to population norms as well as other studies of HIV-positive individuals. These comparisons will provide a wealth of information about a group of older adults that has been heretofore invisible.

Conceptual Model

The conceptual model for the study is based on the stress and coping model (Lazarus, 1966) in combination with past empirical work by the Principal Investigator and others on the relationship between social support and well-being. The stress and coping model includes exogenous variables that are expected to affect living with to HIV and well-being, which are mediated by social support factors. Exogenous (independent) variables include sociodemographic characteristics (e.g., age, race, sex), HIV status (e.g., CD4 count, viral load, perceived stigma), and other health indicators (e.g., health-related quality of life, strain). Mediating variables in this model are measures of functional support resources, support availability and support adequacy. Outcome (dependent) variables will be quality of life (e.g., psychological well-being, life satisfaction, depression). Investigators will use innovative and sophisticated data analysis techniques such as hierarchical regression, structural equation modeling and qualitative

analysis to analyze study data. These statistical methods allow the research team to document the complex interconnections of multiple variables that affect the lives of older adults with HIV in addition to developing a model of how individuals adapt to chronic illness.

Measures

Demographic profile. Single items assessed participants' age, race/ethnicity, sex, education, health status, living arrangement, employment status, religious affiliation and participation, sexual orientation, income adequacy, history of incarceration, health coverage, and life satisfaction.

HIV status. Single items assessed date of HIV diagnosis, receipt of an AIDS diagnosis, prior history of HIV testing, CD4 count, HIV infection risk factors, use of HAART and complementary and alternative medicine use, and type of healthcare provider.

Depression. Depressive symptomatology was measured by the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a 20-item self-report scale designed to assess depressive symptomatology in the general population. The CES-D includes few somatic indicators, thus reducing the likelihood of elevated depression scores due to the physical symptoms common among people living with HIV. This measure has demonstrated high internal consistency (Cronbach's α s = .85 to .90) across diverse community and clinical samples (Radloff, 1977; Ryff & Essex, 1992). Responses are summed to obtain a total symptom score with a range of 0 to 60; higher scores indicate greater depressive symptomatology. Scores below 16 suggest that a person is not depressed. Scores between 16 and 27 indicate moderate levels of depression that would likely correspond with a clinical depression diagnosis, while scores of 28 and above indicate severe levels of depression.

Informal support networks. Detailed information regarding network size and composition, as well as frequency of contact and level of affiliation with network members was collected with an assessment used in previous studies of social networks (Cantor & Brennan, 1993; Shippy, Cantor, & Brennan, 2004; Shippy & Karpiak, in press A, B). Five groups (e.g., parents, children, siblings, other relatives, and friends), or network elements, that typically comprise

informal networks will be examined. Participants indicate if they have any living members of a network element. Three additional items assess frequency of contact with the element (e.g., in-person visits, telephone conversations, and written correspondence), using a five-level, Likert-type scale (daily, weekly, monthly, several times a year, once a year or less). A final item assesses the level of affiliation with the network element (e.g., very close, somewhat close, not too close, not close at all). Assessments of contact frequency are necessary to calculate the functional status of each network element, based on criteria established by Cantor (Cantor, 1979). These criteria define the minimum level of contact as either monthly in-person visits or weekly telephone conversations.

Support availability and adequacy. Four items assessed availability and adequacy of informal network support. Two identical items provided separate ratings of emotional and instrumental support availability, “Do you have someone you can count on to help you with [type of support]?” Respondents indicated availability on a four-level scale (e.g., most of the time, some of the time, occasionally, or not at all). Adequacy of support was assessed similarly to yield independent ratings for emotional and instrumental support needs. Participants responded to the item, “In the past year, how much more help or assistance with [type of support] did you need,” by indicating one of four choices (e.g., needed a lot more, needed some more, needed a little more, or I got all the help I needed).

Frequency of ADL support. Participants indicated the frequency and types of assistance provided by family members and friends (e.g., two sets of eight positive and three negative types of support that were provided by family and friends in the past month). Each of these responses was scored on a six-point Likert-type scale anchored with ‘everyday’ and ‘not at all’. Responses were summed for each section separately to create a frequency of ADL help provided by family members and friends.

Loneliness. The UCLA Loneliness Scale (Russell, 1996) is a 20-item measure with high internal consistency (coefficient α = .89 to .94) and acceptable test-retest reliability after one year (r = .73). There are 11 negatively worded items and nine positively worded items in the third version of the

scale. Participants responded to items with a four level scale (never, rarely, sometimes, always). The nine positively worded items are reverse coded and scores from all 20 items are summed. Higher scores indicate greater degrees of loneliness.

Substance Use. A substance use checklist assessed both past and current use of 15 different substances (e.g., tobacco, alcohol, cocaine, heroin, etc.). In addition, respondents indicated if, during the past 90 days, they engaged in sexual activities while under the influence of each of these substances.

Sexual Behaviors. Participants answered a series of gender-specific questions regarding their sexual behaviors in the past 90 days. The questions are designed to determine if respondents are involved in seroconcordant relationships or if they engage in sexual activities with HIV-negative partners and individuals who do not disclose their HIV status. In addition, participants will record the number of times they engaged in several behaviors with and without barrier protection (e.g., condoms or dental dams).

Health-related quality of life. Selected subscales (e.g., energy/fatigue, cognitive function, pain, physical function) from the MOS-HIV (Wu et al, 1991) will be used to assess health-related quality of life (HRQoL). These subscales were chosen because they assess unique domains not assessed by other measures in the instrument. In particular, the energy/fatigue subscale has been a significant indicator of functional ability in a previous study of older adults with HIV, conducted by the investigators (Shippy & Berman, 2004).

Psychological well-being. Ryff's (1989) theoretically-derived scales were used to assess psychological well-being. Each of the six 9-item scales (e.g., autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance) utilize a 6-point scale ranging from 'strongly agree' to 'strongly disagree' to assess well-being. Internal consistency for the scales is high, ranging from .93 (self-acceptance) to .86 (autonomy). These scales provide positive indicators of mental health and quality of life, as opposed to only assessing deficits.

Spirituality. The Spirituality Assessment Scale (SAS; Howden, 2000) is a 28-item self-report instrument constructed to measure four critical attributes of spirituality

(e.g., purpose and meaning in life, inner resources, unifying interconnectedness and transcendence). The SAS employs a 6-point response format ranging from Strongly Disagree to Strongly Agree (with no neutral option). The SAS is scored by summing the responses to all 28 items; each of the four subscale scores may also be obtained by summing the responses of the subscale items. The instrument was found to have high internal consistency $\alpha = .92$. The four subscales were found to have acceptably high internal consistency, $\alpha = .71$ to $\alpha = .91$.

HIV-related stigma. The HIV Stigma Scale (Berger, 2001) is a 40-item instrument to measure the stigma perceived by people with HIV. Analyses from previous studies of diverse samples of people living with HIV have identified four factors (e.g., personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV) and an overall summary score. Coefficient alphas between .90 and .93 for the subscales and .96 for the 40-item instrument indicate a high level of internal consistency.

Disclosure of HIV serostatus. Disclosure was assessed with an 8-item scale used in previous studies of older adults with HIV (Shippy & Karpiak, 2005a, 2005b). Respondents indicate how many people from various groups of individuals (e.g., family, friends, co-workers, sex partners, drug buddies, social/political organizations, healthcare providers, people at place of worship) are aware of their HIV status by marking one of four (i.e., none, a few, some or all) levels of disclosure. Participants indicated reasons for non-disclosure on a checklist of common reasons for withholding information about one's HIV status from important others. Responses ranged from "I'm afraid they might kill me" to "They have too many other things to worry about now."

Biographies

Stephen Karpiak, PhD

Stephen Karpiak has a distinguished career as a research scientist. After obtaining his PhD in 1972 he joined the

faculty of Columbia University Medical School with an appointment in Neurology and Psychiatry.

At Columbia for over two decades he conducted cutting-edge NIH and NSF funded research on the Immunological Bases of Seizures and Behavioral Disorders. His work showed that antibodies were capable of entering the brain and causing epileptic activity as well as significant behavioral alterations. In 1976 he published a seminal work in *Science* in the field of neuroimmunology.

In his last decade at Columbia he achieved international recognition as a researcher by demonstrating that the brain could adapt and repair after injury. His research contributed to changing the widely held belief that in the CNS there was only limited capacity to recover after injury. His work has contributed to the development of treatments and therapies for the management of peripheral neuropathies, stroke and spinal injury.

He has given over 300 invited lectures nationally and internationally and has been a scientific adviser for the United Nations WHO as well as serving on NIH peer review committees. He has published over 100 peer-reviewed articles.

After retiring from Columbia in 1993, Karpiak did his first HIV/AIDS community work in Phoenix. He was a Program Director at *AIDS Project Arizona*, directed its buyers club, and founded the *Arizona AIDS Project Wellness Center*.

He later was the Executive Director for *A Place Called Home*, which provided congregate group housing for the homeless with HIV/AIDS using HUD/HOPWA funding.

He returned to NYC to become Executive Director for *Pride Senior Network* and for the last three years has been the Associate Director for Research at ACRIA. With ACRIA support he initiated seminal studies on HIV and the aging population, and most recently saw ACRIA launch an historic research effort to study 1000 people over the age of fifty living with HIV/AIDS in NYC.

R. Andrew Shippy, MA, PhD (c)

Shippy is a doctoral candidate in Applied Developmental Psychology at Fordham University and has conducted gerontological research since 1997. His primary research interests include social support, psychological well-being, caregiving, and personal development in middle age and older adulthood. He has studied the effects of chronic illness and stigma among many vulnerable populations.

His work with Dr. Caryn Goodman at *Lighthouse International* examined the impact of vision impairment on the marital relationship and the mental health of disabled elders and their nondisabled spouses, and his research with Dr. Mark Brennan examined the roles of spirituality and religiousness in coping with vision impairment and personal development among middle-aged and older adults. In 2000, he (with Prof. Cantor and Dr. Brennan) began work on the first large-scale study of the caregiving experiences and needs of LGBT seniors in New York City, a joint research effort of Pride Senior Network, the National Gay and Lesbian Task Force Policy Institute and Fordham University Graduate School of Social Service.

Presently, he is an Associate Research Scientist at ACRIA, where he conducts behavioral research focusing on the growing population of older adults living with HIV. This research examines the impact of personal and social support resources on the quality of life aging adults living with HIV. He has published several articles and presented his research at major national and international scientific and advocacy conferences.

Marjorie Cantor, Emerita

Professor Marjorie Cantor is Professor Emerita and Brookdale Distinguished Scholar of Fordham University Graduate School of Social Service and the Scholar in Residence of Lighthouse International. Professor Cantor is a nationally and internationally recognized leader in the field of aging. A past President of the Gerontological Society of America,

she was the first Director of Research for the New York City Department for the Aging. Professor Cantor most recently served as a Principal Investigator on the major cross-ethnic study of New York's elderly, *Growing Older in New York in the 1990's*, and has been the Principal Investigator of over nine other large scale studies during her twenty-five years in the field of aging. She is the recipient of numerous awards including a Certificate of Appreciation from the City of New York for Outstanding Service to the City and it's Elderly; the Kent Award annually given by the Gerontological Society to a member who exemplifies the highest standards of professional leadership through teaching, service, and interpretation of gerontology to the larger society; and the Walter M. Beattie, Jr. Award for Distinguished Service in Aging from the State Society on Aging. She is a member of the Hunter College Hall of Fame. While at Fordham, Professor Cantor served as the Associate Director of the Third Age Center and Director of the Brookdale Research Center and Doctoral Training Program, in addition to being a faculty member of the Graduate School of Social Service. She currently continues to teach in the School and is responsible for the Doctoral Seminar in Aging as well as mentoring students involved in dissertations.

She has served as a consultant to numerous Federal, State and local agencies and boards; was a Senior Fellow of the Brookdale Foundation; and was a participant in both the 1980 and 1995 White House Conference on Aging and an Invited Participant at the International Forum on Aging hosted by the Chinese Government in Beijing. Her particular areas of research expertise include elderly in the urban setting, the effect of ethnicity and culture on elderly life styles, and the role of family and other informal supports in providing care for older people. She is the author of over 70 articles, books, chapters and papers presented here and abroad.

Giving a Voice to Those Who Are Invisible

As a research initiative, ROAH is ambitious in its size and scope. ROAH represents the voices of almost 1000 New York City older adults living with HIV who completed the study instrument. We thank them first! Listen to their voices.

The ROAH research endeavor attracted no government, foundation, or private financing. The trusting support of ACRIA's Board of Directors, and especially its former Executive Director, J Daniel Stricker, allowed this pioneering effort to move forward. They supplied both the financial support and the confidence this scientist needed to advance the effort.

ROAH is massive and comprehensive. It represents the labors of a large team of researchers and community members who unselfishly provided the insight and guidance needed to construct and execute ROAH. Their expertise, enthusiasm, and effort continue to guide the ongoing complex analyses of almost one million data points. They have been remarkable proponents of this research effort. Our continued dialogue advances the findings of ROAH. We thank them for being friends of ACRIA and those whom we serve.

ROAH has followed the rigorous demands of scientific inquiry. This adherence to established scientific process is shared by both Co-Principal Investigators. We believe that it was ACRIA's mission to use valid methodologies to begin to identify the emerging needs of these older adults living with HIV.

ROAH is a vision made real. Moving from idea to reality has been a process watched with caring eyes and a demanding intellect. Those elements best characterize the role of Professor Emerita Marjorie H. Cantor. Her firm hand has guided ROAH from inception to the ongoing publication of its findings. She has been a mentor, teacher, and friend who has influenced these investigators profoundly. ACRIA is fortunate to have counted Professor Cantor as a member of the ROAH team. She reminds us that "...teachers affect eternity". Thank you Marge.

Our personal gratitude and that of ACRIA goes to the family of professionals, community members, and study participants for making ROAH possible.

Stephen E. Karpiak, PhD, and Andrew Shippy PhD (c)
ROAH Co-Principal Investigators
ACRIA

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