Older Adults and HIV:
A Special Report and Action Plan
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November 2010
Aging and HIV: An Overview

By 2015 a majority of people with HIV in the United States will be over age 50.¹,²

This population is growing in both size and complexity. ACRIA’s landmark study, Research on Older Adults with HIV (ROAH)³ brings into sharp relief the emerging medical and psychosocial challenges confronting older adults as they age with HIV. Challenges arising from the early onset of age-related morbidities, high levels of depression, and low-functioning social networks are compounded by a service delivery system frequently hampered by the stigma and discrimination associated with homophobia, ageism, and HIV-phobia.⁴

To ensure that older adults with HIV are able to lead healthy and full lives and remain actively engaged in their communities, researchers, providers, service organizations, and policymakers must examine their assumptions about what will soon be the majority of Americans with HIV.

For example, how should health and service providers respond to a 58-year-old with HIV who presents physical or mental health conditions usually associated with people in their 70s? How should the Social Security Administration (SSA) treat the disability status of a 61-year-old with HIV whose health conditions permit only intermittent work? And how should providers coordinate the care of someone for whom HIV-related health challenges are less pressing than other conditions, such as cancer, cardiovascular disease, diabetes, osteoporosis, and depression?

For too long, the needs of older adults with HIV have been neglected or overlooked. The failure of the federal government to fund and mount a bold, large-scale national study of these older adults, many of whom are long-term survivors, leaves us without the data needed to inform effective policies and programming. Primary care providers routinely fail to test older adults for HIV or to screen for behavioral risk factors, leading to high rates of concurrent HIV and AIDS diagnoses.⁵ AIDS service and aging service organizations have often not recognized this change in the HIV epidemic, have little knowledge of each other, and have rarely if ever worked together. Moreover, they often do not have the competencies or capacities to build the kind of integrated service delivery model that can provide this population with the critical care, supportive services, and health information they need. And the National HIV/AIDS Strategy (the Strategy) makes little mention of prevention and treatment issues related to older adults.

At the same time, the Strategy is moving our collective efforts in the right direction. Its call for a more highly coordinated, integrated, and responsive HIV and AIDS service delivery

¹ Effros, 2008.
² Justice, 2010.
³ Karpiak, Shippy & Cantor, 2006.
⁴ Brennan, Karpiak, et al., 2009.
model signals a turning point. Its call for targeting resources toward the most highly affected communities is also welcome. Allocation of resources according to disease burden and level of risk is certain to advance the goals of reducing new infections, increasing access to care, improving outcomes, and reducing HIV-related disparities. But these goals can be achieved only after indicators of health and quality of life of the over-50 population are explicitly and consistently incorporated into the Strategy’s definition of the problem, its goals and objectives, and its implementation plan.

**Older Adults and HIV: Recent Findings**

This new approach should be informed by the growing body of literature that is defining the unique challenges faced by someone aging with HIV. Key findings include:

- Older adults with HIV experience an array of complex medical conditions. These include age-related morbidities, such as cardiovascular disease and osteoporosis, and drug-drug interactions. The advent of highly active anti-retroviral therapy (HAART) transformed HIV into a manageable chronic illness, with the result that HIV disease is now just one of many conditions that require medical attention. ROAH found that older adults with HIV and an average age of 55 have three times as many morbidities as HIV-negative adults over age 70.\(^6\) Often, however, fragmented care compounds their health challenges.

- Older adults with HIV often have smaller and lower functioning social networks than other older adults.\(^7\) ROAH found that 70% of study participants live alone—twice the rate of other similarly aged New Yorkers without HIV. Other research has produced similar findings. As a result, they have limited access to the traditional forms of informal support provided by a spouse, partner, children, or extended family.\(^8\) This large unmet need has profound implications for a formal care system that is arguably incapable of meeting even current demand.

- HIV-positive adults are five times as likely to experience depression when compared with HIV-negative adults of similar age.\(^9\) Depression arising from chronic stress, trauma, stigma, loneliness, and social isolation can suppress immune response and exacerbate the cognitive decline that is typical in the normal aging process.\(^10\) Moreover, depression has a negative impact on engagement in care and treatment adherence.

- Alcohol and substance use, including nicotine addiction, are significant challenges for older adults with HIV. ROAH found that more than one-third of participants

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6 Havlik, 2010.  
7 Cantor & Brennan, 2010.  
reported current use of recreational drugs (37%) or alcohol (38%) and 57% smoke. The persistently high levels and severity of mental health and substance use disorders suggests that current interventions are not leading to improved outcomes.

- Ageism, homophobia, racism, AIDS-phobia, sex-phobia, sexism, and poverty erect powerful barriers when an HIV-positive older adult seeks services, from primary care to long-term care or mental health and substance use services.

- Two-thirds of older adults over 50 do not use condoms, disproving assumptions that older people are not at risk for HIV. Still, ageism and sex-phobia often prevail, as providers, and even AIDS educators, are reluctant to discuss sexual risks, offer an HIV test, or provide prevention information. Older adults are therefore the least likely of all patient groups to get tested and to know their HIV status. Moreover, 42% of those over age 50 who test positive for HIV also receive an AIDS diagnosis, compared with 23% of those under 50. Status quo prevention efforts, which are not tailored to older adults, are failing this population and contributing to the increase in new infections.

**Priority Policy Recommendations**

Decisive, immediate, and simultaneous policy adaptations are required across multiple fronts:

**Medical and Behavioral Research**

The National Institutes of Health (NIH) should make HIV and aging a top research priority, utilizing new and existing resources to understand this population better. In so doing, the Office of AIDS Research should actively plan, budget, and guide trans-NIH efforts to focus efficiently and effectively on older adults with HIV, most notably (but not exclusively) with the National Institute of Allergy and Infectious Diseases, National Institute on Aging, National Institute on Drug Abuse, National Cancer Institute, National Institute of Neurological Diseases and Stroke, National Institute of Mental Health, and the Center for Scientific Review.

NIH should promote and fund research to:

- Investigate the extent to which the onset and course of age-related morbidities differs between HIV-positive and -negative older adults.

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13 Schick, 2010.
14 Golub, et al., 2010.
15 Golub et al., 2010
- Determine the association between barriers to access and health outcomes.
- Understand better the unique biological and psychosocial characteristics of older adults with HIV and determine how they affect health outcomes.
- Understand better how HAART interacts with aging bodies and treatments for other conditions.
- Determine the association among and between mental health disorders, substance use, low-functioning social networks, and unprotected sex among older adults.
- Determine whether the factors precipitating depression differ between HIV-positive and HIV-negative older adults, and whether the course and severity of depression is similar to that of the general population.
- Assess which lifespan factors (e.g., mental health issues, substance use, etc.) contribute to HIV risk and how best to address these factors.

*Integrated Service-Delivery Demonstration Projects and Structural Interventions*

The Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration, among others, should:

- Fund capacity building, technical assistance, and training for AIDS services organizations, faith-based organizations, community-based organizations, lesbian/gay/bisexual/transgender (LGBT) organizations, and aging services providers to integrate evidence-based over-50 HIV prevention, treatment, and care programs into larger organizational, cultural, and programmatic frameworks.
- Fund/conduct Special Projects of National Significance grants or other demonstration projects to develop effective evidence-based capacity building, technical assistance, and training, not only among health care workers but for all HIV and senior services providers, to reduce HIV and LGBT stigma and discrimination and to improve knowledge and understanding of the prevention and care needs of older persons living with or at risk for HIV.

The Department of Health and Human Services and the Department of Education, among others, should:

- Urge the development of gerontology, social work, and other curricula at colleges and universities, as well as medical schools, that train aging specialists and service providers in the particular characteristics and needs of the over-50 HIV-positive population and those who are at-risk.

The CDC should:

- Adjust its epidemiological surveillance systems and requirements to collect and deliver complete age and risk category data for both HIV incidence and prevalence/total cases.
- Fund research to develop new (or adapt existing) evidence-based HIV/STI behavioral interventions targeting older adults at risk for HIV and older adults with HIV, particularly for the most at-risk populations, such as women of color and, especially, older men who have sex with men.
The Administration on Aging should:

- Expand the definition of “vulnerable populations” to include those with HIV or a larger group of “specific health minorities” that could include seniors with HIV and other diseases.
- Encourage service systems to become more flexible and responsive to the needs of older adults with HIV, e.g., consider functional status and need in addition to chronological age in determining eligibility for services.

The SSA should:

- Amend its disability eligibility criteria to take into account improvements in treatment (the last revision was in 1993) and to allow for greater flexibility for those who are able to work only intermittently.

Conclusion

Older HIV-positive adults will soon be the majority of Americans with HIV, and more people over age 50 are being diagnosed every year. Yet the U.S. research agenda, the health care system, and aging and HIV service providers have only begun to respond to this reality, and our systems remain quite unprepared to deal with these emerging issues. In this report, ACRIA presents specific policy recommendations to address the needs of older adults with HIV and those at highest risk of contracting the virus. These recommendations are by no means exhaustive, but constitute vital first steps. We urge immediate adoption of these recommendations and stand ready to do our part to understand this population better and to ensure quality care and services for older adults with HIV and those at risk.

References


Havlik, R.J. “Health Status, Comorbidities, and Health-Related Quality of Life,” in Brennan, Karpiak, et al., op cit., 19-37.


