

The Policy Issues and Social Concerns Facing Older Adults with HIV

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Given what many Americans think they know about HIV, you might be wondering why an organization devoted to understanding and addressing the needs of aging Americans has turned its attention to HIV. Here's why: the nation's first ever National HIV/AIDS Strategy reported that by 2015, 1.2 million Americans will be living with HIV, and the Centers for Disease Control and Prevention estimates that fully half of them will be age 50 or older by 2015 (see Figure 1; Centers for Disease Control and Prevention, 2008).

Almost one-third of people with HIV in the U.S. are women and 80 percent are people of color. And just over half are men who have sex with men. Not long ago, few would have expected to see large numbers of older adults living with HIV. But in the major U.S. cities where most people with HIV live, 40 percent of them are over age 50. This graying of the AIDS epidemic is primarily the result of new classes of HIV medications, first introduced in the mid-1990s, that effectively suppress HIV and prevent the collapse of the immune system. Before 1995, a person diagnosed with HIV often had a life expectancy of a few years. Today that same person can expect to live an almost typical life span if diagnosed and treated early.

However, this burgeoning population is also the result of older people becoming infected with HIV. Just a decade ago only 10 percent of new HIV infections occurred in those over age 50. Today they account for 17 percent of new diagnoses and are increasing (see Figure 2).

Targeted prevention interventions and appropriate care are two key challenges in addressing the aging of the HIV epidemic. Due to the persistent myth that HIV only affects the young, a growing number of older adults are getting HIV because they don't believe that they are at risk. In fact, older adults are more vulnerable to HIV infection than younger people due to certain biological changes associated with aging, such as thinner mucosal membranes in the anus and vagina that tear more easily during sexual intercourse, thus creating easy access for the virus. More significantly, there have been virtually no widespread, federally funded HIV prevention efforts targeted to older adults. Research finds high rates of unprotected sex among all older adults and reports that as many as 18 percent of older adults with HIV engage in unsafe sex (Golub, Tomassilli, Pantalone, Brennan, Karpiak, & Parsons, 2010).

Just as with others, HIV treatment for older adults is quite effective as long as they adhere to their medication

regimens. But for reasons not yet well understood, older adults with HIV are exhibiting increased rates of age-related illnesses 20-to-30 years earlier than is typical among their peers without HIV. Some describe this as accelerated aging. Research by AIDS Community Research Initiative of America (ACRIA) and others has shown that there are increased rates of cardiovascular disease, hypertension, diabetes, and osteoporosis among older adults with HIV, as well as cancer. In fact, several studies indicate that adults with HIV age 50 and older report three comorbid conditions on average, as opposed to just one such condition among HIV-negative adults over age 70 (Brennan, Karpiak, Shippy & Cantor, 2009; Havlik, Brennan & Karpiak, 2011; Vance, Mugavero, Willig, Raper & Saag, 2011). This creates significant challenges for this population and their providers.

Moreover, older adults with HIV suffer from high rates of depression. Approximately 40 percent of the participants in ACRIA's Research on Older Adults with HIV (ROAH) study had high depression scores using a standard measure, which is exacerbated by persistent HIV stigma. Depression not only has a negative impact on quality of life, but may be the single best predictor of treatment non-adherence and poor outcomes. Furthermore, there is a consistent link between depression and physical comorbidities.

Finally, adherence to a complex regimen of pills is facilitated by having a spouse, partner, or nearby friend or neighbor who can provide the emotional support and instrumental assistance that is essential for successful aging. But ROAH found that older adults with HIV are more socially isolated from family and friends than are those without HIV. More than 70 percent of the older adults in ROAH lived alone, fewer than 15 percent had a spouse or partner, and they had little support from family or friends (see Figure 3; Brennan et al., 2009). Moreover, ROAH found fragile social networks that are

Figure 1

% of People Living with AIDS Diagnosis Over Age 50 in US – CDC Surveillance Data

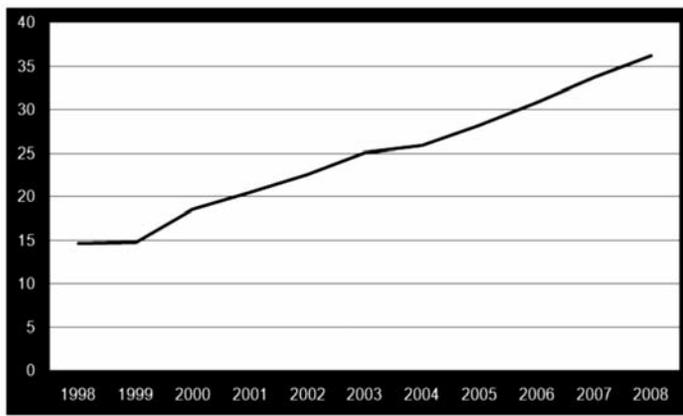
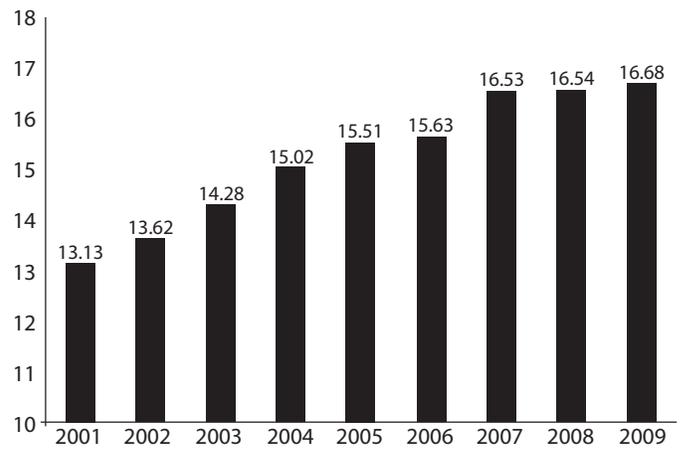


Figure 2

% of New HIV Infections in those 50 and Older



inadequate to deliver the caregiving and support these older adults with HIV need to age successfully. Without such support, they will not be able to manage their health effectively and will more likely be relegated to costly long-term care facilities.

Increasingly, HIV is taking its place as one of many treatable chronic conditions affecting older adults. But the evolution of people aging with HIV into long-term survivors demands a parallel evolution in HIV care and services. The challenges of managing the care of those with HIV into their 50s and beyond are often substantial and the present medical model is unlikely to be sufficient. In an effort to address this gap, ACRIA recently joined with the American Academy of HIV Medicine and the American Geriatrics Society to develop clinical guidelines for the management of the health of older adults with HIV, which are expected to be issued in October 2011.

For a host of reasons, AIDS service organizations (ASOs) and other community-based organizations (CBOs) serving people with HIV are not prepared alone to meet the needs of those aging with HIV. Likewise, the existing senior services network across the country is ill-prepared to address the needs of older adults with HIV, and those most at risk, not least because of a lack of HIV knowledge and continuing myths, stigma, and discrimination.

Given existing resource limitations and the likelihood of future funding reductions how can we best address the health, psychosocial, and other needs of aging adults with HIV and help to reduce the number of new infections among older adults? How do we draw on the strengths that already exist among these older adults and their communities?

Below are several policy recommendations that we believe could improve our understanding of older adults

with and at risk of HIV and make a genuine difference in how we deliver care and services.

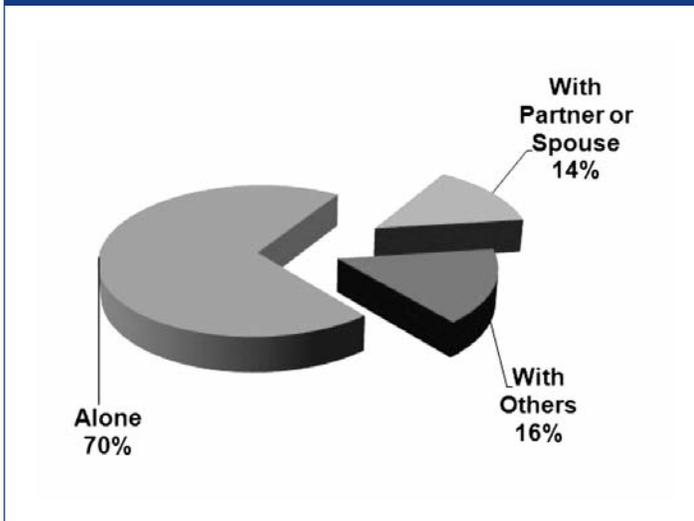
Department of Health and Human Services

There is very little research on older adults with HIV. They are often exempted from clinical studies and drug trials, leaving a dearth of information about the effects of HIV and its treatment on the aging body. As noted earlier, we must recognize the high incidence of multiple morbidities and the long-term effects of highly active antiretroviral treatment (HAART) and other drug therapies. The social context in which older adults with HIV live, including the damaging effects of stigma on their physical and emotional well-being, must also be considered in efforts to improve care. Greater understanding of the unique health circumstances that people with HIV experience as they age is necessary, and will require a coordinated and targeted response from federal agencies, most notably those within the Department of Health and Human Services (HHS).

HHS supports demonstration projects, such as Special Projects of National Significance (SPNS) grants through the Ryan White Treatment Modernization Act, and other resources that could specifically target this population. Research could help identify the unique treatment needs of older adults with HIV, particularly in the management of multiple morbidities. Structural interventions aimed at delivering targeted training and capacity building are needed if ASOs and CBOs are to improve program services and access for these older adults.

HHS could also support demonstration projects that address mental health interventions for the persistent problems of depression and other mental illness among older adults with HIV. Appropriate community-based care

Figure 3



can reduce costs associated with institutionalization and could greatly improve the quality of life for many older adults with HIV. Finally, HHS and the Office of AIDS Research at the National Institutes of Health (NIH) could support research to better understand the development, causes, and course of comorbid conditions and how they affect the management of HIV, as well as the effect HIV and its treatment have on comorbidities.

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) can greatly improve its epidemiological surveillance systems and data collection to track and understand older adults with HIV better. For example, it is currently difficult to glean from CDC data who is being diagnosed late in the course of HIV disease (those found to have AIDS upon an initial HIV diagnosis) or the demographic characteristics and number of older adults newly infected. Specifically, the CDC could provide data by age (in five-year increments) and risk category for adults over age 50 in the same manner in which trends are monitored for those under age 50. The availability of such data would inform HIV prevention programs, and educate public health and medical professionals on the specific routes of HIV transmission among older adults, thus improving tailored prevention interventions.

At present the CDC recommends an annual HIV test for all Americans aged between 16 and 64—an age cap which should be extended, since many adults over age 64 are sexually active. Improved HIV incidence data and screening recommendations would help ensure early HIV diagnoses. Early diagnosis is incredibly important, as delays compromise an individual's prognosis. Also, those

who are unaware of their HIV infection are more likely to transmit the virus to others.

Another area needing significant improvement is prevention programming. At present there are no CDC-approved HIV prevention models aimed specifically at older adults. The distinct experiences and risk behaviors of older adults warrant a new prevention model. The CDC has historically designed and targeted such programs to populations deemed at high risk. With approximately one in six new HIV diagnoses among those over age 50, the trend clearly indicates an urgent need. Any CDC prevention model should also include a social messaging component in order to end the rampant HIV and anti-gay stigma often seen in nursing homes, senior centers, and other senior programs.

Older Americans Act

The Older Americans Act (OAA) funds Area Agencies on Aging (AAAs) nationwide that support programming for older adults in senior centers, home delivered meals and other nutrition programs, long-term care and caregiver support, the prevention of abuse and neglect, and other social services. The legislation is due for a reauthorization this year, and clear opportunities for making the legislation more responsive to older adults living with and at risk for HIV are rising to the forefront.

Earlier this year, for the first time, a large coalition of aging organizations included specific recommendations that would better address older adults with HIV in the OAA. The Leadership Council of Aging Organizations, a coalition of 65 national aging organizations, recommended the inclusion of older adults with HIV as a population with greatest social need, recognizing their growing number and the related health disparities, discrimination, and stigma.

Defining older adults with HIV as a population of greatest social need within the OAA will allow the U.S. Administration on Aging (AoA) to dedicate critical resources to states for community planning and social services, research and development projects, and personnel training in the field of aging. This is a key step in helping senior centers, nursing homes, and other senior programs address the unique HIV prevention and treatment needs of older adults.

The authors have made additional recommendations to improve the OAA's response to the HIV epidemic. Included in these recommendations is an amendment to improve training of health care workers to help them provide culturally competent care for older people with HIV. This amendment would require state area plans, submitted to the AoA, to provide specific

assurances with respect to services and support for older adults with HIV.

A final recommendation for the OAA addresses HIV prevention programs across the broad range of aging services provider settings. An amendment could include HIV within the definition of disease prevention and health promotion. This amendment would specifically identify HIV as within the scope of the OAA's activities on health promotion and disease prevention.

Since it is expected that half of all Americans with HIV will be over age 50 by 2015, it is critical that we consider how all programs and policies that affect older Americans will respond to the epidemic (Centers for Disease Control and Prevention, 2008; Effros et al., 2008). Reauthorization of the OAA is a significant and precedent-setting opportunity to do just that.

In sum, existing resources and service networks must be integrated to ensure more seamless and comprehensive care and services for older adults with HIV. Working to create effective referral and services relationships among the existing array of aging support services and the ASO/CBO networks will do much to improve provider knowledge and reduce barriers. Until we address these barriers, older adults with HIV are unlikely to have equal access to the health and social support systems available to other aging adults in the U.S. In addition, we must work to empower and educate older adults with and at risk of HIV to engage their health and services providers with their unique and specific needs.

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References

- Brennan, M., Karpiak, S. E., Shippy, A. R., Cantor, M. H. (Eds). (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York: Nova Science.
- Centers for Disease Control and Prevention. (2008). *Persons aged 50 and older*. Retrieved October 3, 2011, from <http://www.cdc.gov/hiv/topics/over50/>
- Effros, R., Fletcher, C., Gebo, K., Halter, J., Hazzard, W., Horne, F. M., Huebner, R., et al. (2008). Aging and infectious diseases: Workshop on HIV infection and aging: What is known and future research directions. *Clinical Infectious Diseases, 47*(4), 542-553.
- Golub, S. A., Tomassilli, J. C., Pantalone, D. W., Brennan, M., Karpiak, Stephen E, & Parsons, J. T. (2010). Prevalence and correlates of sexual behavior and risk management among HIV-positive adults over 50. *Sexually transmitted diseases, 37*(10), 615-620.
- Havlik, R. J., Brennan, M., & Karpiak, S.E. (2011). Comorbidities and depression in older adults with HIV. *Sexual Health*. CSIRO.
- Vance, D. E., Mugavero, M., Willig, J., Raper, J. L., & Saag, M. S. (2011). Aging with HIV: A cross-sectional study of comorbidity prevalence and clinical characteristics across decades of life. *The Journal of the Association of Nurses in AIDS Care: JANAC, 22*(1), 17-25.