

# AGING TODAY

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## REFLECTIONS ON HOW HIV/AIDS EMERGED AS ISSUE IN AGING

By NATHAN L. LINSK

The first reports relating to HIV and AIDS surfaced in 1981—a quarter century ago. Increasingly, older professionals in aging can add this to our knowledge as community historians: We can remember a time before HIV and AIDS.

In the early 1980s, some of us began to hear about this disease and the patients who first presented with symptoms. Although early on we knew that mostly young men were infected, the reality has always been that HIV is age blind, that humans from birth to late life can be affected. For many, the first public figure they knew to succumb to AIDS was actor Rock Hudson, who died in late 1985, just shy of his 60th birthday.

Although 60 is not old age, it characterizes the elder stage of life. Among other celebrities whose deaths from AIDS raised public awareness of the disease in that period included Liberace, who died at age 67 in 1987; Amanda Blake (Miss Kitty from *Gunsmoke*), who passed away at 60 in 1989; and dancer Rudolf Nureyev, age 54 when he died in 1993.

One of the first acknowledgements of this emerging issue occurred in Philadelphia, where the Commission on AIDS included older adults in its 1988 “Report to the Community,” authored by Jeannette Bressler. The early 1990s saw the development of programs especially designed to serve older adults with HIV. The first, established in 1991, was the New York AIDS and Aging Task Force (now the New York Association on HIV Over Fifty). A year later, a national meeting on HIV and aging was held in New Orleans. Sponsored by the Delta AIDS Education and Training Center and the Geriatric Education Center at Louisiana State University in Baton Rouge, the event—at which I was privileged to be a keynote speaker—attracted about 100 participants.

Although all these early programs involved older adults living with the virus, few of the infected were inclined to publicly disclose their status, so the world of older people and HIV was heavily represented by social service and healthcare providers.

In many ways, the New York group put this issue on the map. In addition to forming the first task force, headed by Rose Dobrof and Kathleen Nokes at Hunter College, the first funded project was established with a half-time social worker, Marie Nazon, as organizer. The development of service and outreach networks for older adults with HIV/AIDS was also significant at that time. In Chicago, Cynthia Poindexter and I worked to establish a network. In Miami, Vincent Delgado took up this task. A few networks emerged then, such as the New England AIDS Education and Training Center, which held annual meetings on affected older adults.

By 1993, several of these advocates joined forces to discuss holding a national meeting on this issue. Even though the Centers for Disease Control and Prevention (CDC) rejected a request for funding, the group decided to go ahead and convene the first national conference in October 1995 in Manhattan. More than 100 people converged at Hunter’s Brookdale Center on Aging in New York to learn about the ABCs of AIDS and aging.

This two-day gathering resulted in the formation of a national network, which I agreed to lead and develop while I was on professorial sabbatical from the University of Illinois at Chicago. To serve as cochairperson with me, I asked Jane Fowler, then a 60-year-old conference participant from Kansas City who had retired from a newspaper career when she discovered she was HIV-positive. (See Fowler's personal reflections on this page.)

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#### WHOM TO TARGET?

One challenge for professionals and advocates was to determine whom to target and how old one had to be to qualify for this national organization. There ensued a lively debate about when aging begins: Of course age begins at birth, but it took some time to find an inclusive definition so that people who believed they belonged in the group would not be left out. We settled on the idea of "over fifty," so that midlife and older adults would no longer be overlooked as they had been by HIV/AIDS networks that existed for younger people. The result was the establishment of the National Association on HIV Over Fifty (NAHOF).

Today, HIV affects the elder community in multiple ways. Because some individuals become infected in their later years—yes, older people do engage in sexual or drug-related behaviors that can be risky—there is a critical need for visible prevention programs directed to this age group. Other older people are diagnosed in later years because, due to ignorance, denial or fear, they did not get tested earlier.

In addition, many noninfected older individuals are affected by HIV/AIDS. Some are caregivers for or otherwise assist people infected by HIV. Some help their adult children who are infected, and others raise their grandchildren who have lost parents to HIV. Still others volunteer with community groups providing education, care and support to the population with HIV/AIDS.

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#### LIVING LONGER

Current CDC recommendations—to test everyone between the ages of 14 and 64—indicate that the U.S. public health and healthcare system is still ignoring older people in HIV prevention and testing. Yet increasingly, the more than 1 million people in the United States living with the virus include those who both contracted and were diagnosed with HIV before age 50, but thanks to good medical care and treatment are now living longer, well into advanced years. One concern is that although most older HIV-positive individuals adhere to taking their medications regularly, the effects of aging and HIV are often difficult to distinguish.

Multiple groups now address issues of aging with HIV, such as Fowler's group, HIV Wisdom for Older Women; NAHOF; a number of local task forces and associations that provide support and information; and health and service programs offering care services, education and case management. The American Society on Aging's Lesbian and Gay Aging Issues Network has also been an important information source on this issue for professionals in aging.

The good news is that in 2007, people with HIV are living longer. More than ever, we in the field of aging need to plan together on how to bring people with HIV into our array of aging services and communities. ❖

*Nathan L. Linsk is a professor at the Jane Addams College of Social Work, University of Illinois at Chicago.*