HIV in People Over 50
Jane Pecinovsky Fowler

After my HIV diagnosis in 1991, my family and the few friends I told were as shocked as I was because I didn’t fit an AIDS stereotype: I was not a gay man, I had never been an injection drug user, nor had I ever had a blood transfusion. I was, at the time of my diagnosis, a 55-year-old career woman.

I had lived a conventional, traditional life. I had been a virgin on my wedding night in early 1959, and I remained monogamous during 23 years of marriage. But, in the early 1980s, I was divorced and, for the first time in a quarter century, I was dating again. I didn’t consider myself to be promiscuous. I didn’t frequent singles bars. I went out with men my age, men I had known socially for some years and who, like me, had been married and were divorced.

In those days, I knew little about HIV, only that a mysterious, fatal ailment was affecting the gay community. It didn’t occur to me that I would put myself at risk by engaging in unprotected sex with an attractive, intelligent, amusing man of many interests, who had been a close friend my entire adult life. But at the end of 1985, at age 50, I became infected with HIV.

Following my diagnosis in 1991, I withdrew. I did not have the courage to put myself in situations that might be painful—in which I might experience discrimination, rejection, or prejudice. I lived as a semi-recluse, spending time mostly with family and friends, who were supportive, compassionate, and non-judgmental. Four years passed. I took antiviral drugs, and I was blessed: I stayed well and free of opportunistic infections. Yet, I remained shamed and humiliated, still hiding my infection from all but my confidants.

During this time, I researched HIV and AIDS and read all I could find on the sub-
Last week I heard about an article that defined “senior citizens” as anyone over 45 years old. Clearly, old age is not what it used to be. But, I’ve always thought that age was more about perception (and perspective) than reality, and this definition seems to confirm my conclusion.

This incident reminded me that age has become a demographic ping-pong ball in the world of HIV. If you trust surveys of knowledge, attitudes and behaviors about AIDS, then you know that young people believe HIV is a disease of the old, and old people believe it is a condition of youth. Based on such perceptions, no one should be HIV-infected.

A Personal Revelation

But, despite notions to the contrary, people continue to have sex well into old age—a fact lost on most of us. And while age may not be associated with the risk-taking of youth, older people do take risks involving sexual and drug-using behaviors. As Jane Pecinovsky Fowler points out in this issue of FOCUS, 11 percent of AIDS cases are among people past the age of 50.

Fowler’s own story of learning she was infected at age 52 and living as a person with HIV at age 64 is a poignant reminder to people working with HIV that they will be seeing older clients and that these clients will face psychosocial challenges that will differ from those of younger clients. In their article, Sari Kasper and Thomas Cavalieri add to this understanding by describing how the medical manifestation of HIV disease may be different for people over 50.

These distinctions are significant, and working with older people with HIV will require shedding assumptions and understanding some of the forces at work as people age. But, these differences may also be amplified by perceptions among both people with HIV and providers who work with them. So, it is important to also recognize the similarities among all people: people have sex, use drugs, contract HIV, and respond with fear, disbelief, anger, resignation and a host of other individualized responses.

People with HIV Getting Older

As the epidemic continues and the population ages, there may be an increase in the number of older people with HIV. With the success of new treatments, many with HIV who were young when they were infected are heading into middle age (even “old age” if you judge according to some definitions). Caring for “senior citizens” may, in fact, become increasingly common among AIDS service providers and preparing for this group’s needs should be on the minds of health and mental health providers alike.

Participants reported elevated perceptions of loneliness and isolation, denial of their illness, difficulty in accessing medical and mental health care, and illness-related physical discomfort. The study also found that major issues for HIV-infected women included fear of the ways their illness or possible death may affect their children, dependence on religion or spirituality, and lack of coping mechanisms, particularly among those who abused substances in the past. For infected older men, major issues included negative side effects of medications, difficulties in adhering to rigorous treatment regimens, and fear of disclosing their HIV status to partners.²

Coming Out as an Older Person with HIV

Discovering that my physician was treating another four HIV-infected women who are older, I asked her to give my name and telephone number to each, hoping one or more would contact me. Since then, however, I’ve heard nothing, which may confirm how difficult it is for elderly people with HIV to disclose their infections to...
friends and even family and their reticence to reach out for support. To disclose is, in effect, an admission of having engaged in sex or drug use, practices that are not normally associated with people who are aging. For this reason, seniors as a group remain far less visible than other HIV-infected groups, fearing rejection by family, friends, or society in general.

Finally, in 1995, after four years of being secretive about my HIV status, I had a change of heart. Why not liberate myself by publicly revealing my predicament and, perhaps, in this manner, meet some others living with the virus and—even more importantly—reach the non-infected population with a prevention message? Encouraged by my only child, my son Stephen, and my friends, I decided to stand up and say, “Look at this face, this old wrinkled face. This is another face of HIV. It’s not who you are. It’s what you do and don’t do, regarding transmission of the virus.”

My first action was to affiliate with Good Samaritan Project, an AIDS service organization in Kansas City. Then, I helped found and became co-chairperson of the National Association on HIV Over Fifty (NAHOF), an organization that promotes a full range of educational, prevention, service, and health care programs for people over the age of 50 who are infected with or affected by HIV disease.

It was the NAHOF co-chairperson, Nathan Linsk, PhD, professor of social work at the University of Illinois–Chicago, who told me that older people infected with HIV often think about death earlier than do those who are uninfected. In general, he said, as people advance in years, they find various ways to make peace with the idea of dying, particularly if they have lived full lives. With HIV, however, the presumption is that the life course will be interrupted prematurely, that the disease will abbreviate the period between a person’s age at diagnosis and when he or she believes life should end.

### References


2. Personal communication with Arlene Kochman, MSW/CSW, Program Coordinator of the Center for AIDS Intervention Research (CAIR), Medical College of Wisconsin, Milwaukee. July 1999.


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**Preventing HIV among Older People**

During these years of activism, my NAHOF colleagues and I have learned that behaviors of the aging population can put them at the same risk for HIV infection as teenagers and young adults because, despite myths and stereotypes, many seniors are sexually active and some are drug users. According to a 1998 survey conducted by the National Council on the Aging, nearly half of 1,300 men and women over the age of 60 responded that they have sex at least once a month, and 39 percent indicated they would like to engage in sex more often.

But, too often our elders do not understand HIV prevention. They do not realize that they should not engage in unprotected sex unless they are in mutually monogamous relationships.

I have heard the comment, “Until we can talk about the ‘cause’ [how HIV is transmitted], we can’t talk about the disease.” Therefore, we must acknowledge that seniors remain sexual beings. I often hear from audience members after I give a speech, especially from students who have assignments to write thank-you notes and tell me what they had learned from my presentation. My favorite comment came from a 12-year-old girl who wrote, “Dear Jane Fowler. Well, I sure never knew anybody over 50 had sex.” That comment is three years old now, but it is as telling today as it was then. It is an idea widely embraced, not only by pre-teens and teenagers, but also by young adults, who cringe at the thought of their parents and grandparents “doing it.”

We know that health care and service providers often are reluctant to discuss or question matters of sexuality or drug use with their aging patients and do not normally check for sexually transmitted diseases (STDs). I am reminded of a time, about 1989, during my annual physical examination, when I asked my family practitioner if I should take an HIV test. I had begun to hear that the virus was moving into the heterosexual community, and, after all, I had enjoyed some intimate relationships after my divorce. Her
answer: “Oh, not you, Jane Fowler. You don’t need the test for AIDS.”

Recently, a meeting planner told me about an exchange she had with a group of physicians at a major university teaching hospital, who were scheduling an older women’s health conference. When my friend proposed a session on HIV prevention, she was literally laughed at. “These women don’t need a program like that,” the doctors scoffed, and she could not persuade them otherwise.

Because many HIV symptoms are similar to those associated with aging—including a weakened immune system, fatigue, weight loss, swollen lymph nodes, vision problems, depression, and memory loss—the infected older person often is misdiagnosed or not diagnosed until an AIDS-defining opportunistic infection has developed. As a result, the elderly often die sooner from AIDS complications than younger people do.

Conclusion

Try as one might to age with good humor and grace, it’s not always easy to accept the limitations of decreased physical and mental capabilities—the loss of muscle strength, the lack of energy, and, most discouraging, the forgetfulness. Couple these frustrations with the variety of feelings experienced by any HIV-infected person, and it is simple to conclude that seniors, especially those with self-image issues, may endure more emotional and physical stresses than do others living with the disease.

In a society that does not respect or value the aging population, older HIV-infected people may confront social and professional bias regarding allocation of health care services and resources available to the AIDS community (“The elderly have lived their lives, why waste money on them?”). The prevailing American attitude about age was reinforced for me by a smug teenage girl who commented, at the conclusion of a school presentation, “Look, we all know we’re going to die someday. You’re old. So, what’s the big deal?”

The “big deal,” I answered, is that any elder, even one who is HIV-infected, still has a life, and I want and hope that my life will continue for many years. I do not seek sympathy or pity. I made a mistake when I did not know the necessity of having protected sex, and I live with HIV as others live with cancer, congestive heart failure, or any potentially terminal disease. I do ask, however, that the existence of HIV in older adults be recognized and addressed.

My favorite comment came from a 12-year-old girl who wrote, “Dear Jane Fowler. Well, I sure never knew anybody over 50 had sex.”

Authors

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References


Clearinghouse: Older People and HIV
HIV-Related Medical Issues in Older People
Sari J. Kasper and Thomas A. Cavalieri, DO, FACP

References

Although HIV disease affects young and middle-aged adults in the greatest numbers, its impact on older adults is significant. The age of diagnosis for 11 percent of AIDS cases is 50 years or older, and the age of diagnosis for nearly 3 percent of AIDS cases is 60 years or older. At the same time, the literature suggests that because of the common perception that HIV is not a risk for older people and because many HIV-related symptoms mimic the effects of aging, health care providers are slow to diagnose HIV disease in older people and fail to question their older patients about HIV-related risk behaviors.

Until the advent of safe screening measures in 1985, the majority of older people with HIV became infected through blood transfusions. Today, men who have acquired HIV through homosexual activity account for 36 percent of the people with AIDS who are over 50 years old. Between 1991 and 1996, however, the number of older men who became infected with HIV through heterosexual contact nearly doubled while the rate of homosexual transmission in this population did not change significantly, and heterosexual transmission among women over 50 years old increased by 106 percent. In addition, 43 percent of all new AIDS cases in people older than 50 occur among African Americans.

Biological changes related to aging and a general decreased immune function may increase older people’s susceptibility to HIV infection. In women, estrogen deficiencies related to menopause can result in decreased vaginal lubrication and thinning of the vaginal mucosa that can enhance HIV transmission during sex. This risk is compounded by the fact that adults over the age of 50 years are, by some estimates, one-sixth as likely to use condoms as people in their twenties. This may result from their lack of concern about pregnancy, their decreased openness about sexuality, and the lack of safer sex messages targeting this age group.

Overlooking HIV in Older People
Misdiagnosis is common among HIV-infected older people because symptoms of HIV are often similar to other medical conditions related to aging. Early HIV infection may manifest as weight loss, fatigue, and decreased cognitive or physical abilities, which may be mistaken for depression, dementia, or thyroid or metabolic problems. In many cases, symptoms of HIV infection in the elderly may resemble unremarkable conditions such as upper respiratory illness or general itchiness, known as “pruritis.”

Pneumocystis carinii pneumonia (PCP), a common opportunistic infection, has often been misdiagnosed as congestive heart failure or lung diseases in HIV-infected older people.

The most significant and perhaps confusing diagnostic challenge in HIV-infected elderly involves neurological symptoms. HIV-related cognitive impairment (subacute encephalitis)—caused by
direct HIV infection of the brain—is often the initial presentation of disease for older patients, and it may be mistaken for Alzheimer’s-like dementia (ALD). Because of the variety of possible symptoms and the lack of definitive laboratory tests, HIV-related cognitive impairment is diagnosed by excluding other potential causes of the symptoms. HIV-related opportunistic infections such as cryptococcal meningitis or toxoplasmosis may also cause cognitive impairment and should be considered as part of this differential diagnosis, but they usually occur later in the course of HIV disease.

HIV-related cognitive impairment presents with behavioral changes, such as decreased attention span, apathy, and social withdrawal, and with motor symptoms, which may include balance problems (ataxia), leg tremors, peripheral neuropathies, electric-like pain or numbing of the extremities (parasthesias), and bladder and bowel incontinence. Significantly, these neurological signs are absent in ALD. Also unlike ALD, HIV-related cognitive impairment often improves with antiviral therapy and increased virological control. ALD also characterized by anaphasia, or language disorder, which is conspicuously absent in HIV-related cognitive impairment.

To increase the likelihood of diagnosing HIV disease at an early stage, it is important to determine if older patients have engaged in risk behaviors and to encourage HIV testing in appropriate patients. This is especially true if the patient exhibits symptoms of cognitive impairment. Other indicators for HIV testing include: a history of blood transfusion; respiratory distress with signs of PCP; thrombocytopenia—or low platelet count; and a history of sexually transmitted diseases (STDs). In one study, 11 out of 32 older people with HIV had a history of STDs, and 19 out of 21 had been exposed to hepatitis B.

Prognosis and Treatment

Older adults generally have a shorter than average interval between HIV infection and progression to AIDS and death. At a given viral load, younger people have less CD4+ cell depletion and slower progression to AIDS than their older counterparts. Older patients are also more likely to have an opportunistic infection at the time of diagnosis with HIV disease, which often emerges during hospitalization for an infection of an initially unknown origin. It is notable, however, that older people face the same types of opportunistic infections as other adults with HIV disease. In order of prevalence, these include PCP, tuberculosis, mycobacterium avium complex (MAC), herpes zoster, and cytomegalovirus (CMV) infections. Across all age groups of adults, progressive multifocal leukoencephalopathy (PML) is the AIDS-defining illness in approximately 25 percent of patients.

Drug treatment of older patients with HIV follows the general principles for geriatric pharmacology. Because multiple diseases are common in older patients, these patients are often taking more medications and have more drug-drug interactions than younger patients. To complicate matters, some studies have suggested that up to 25 percent of medications prescribed for the elderly are unnecessary, and age-related confusion may confound adherence. In addition, age-related metabolic changes can alter the absorption, distribution, and metabolism of HIV antiviral drugs, and many of the newer HIV medications are unproven in older people because clinical drug trials typically do not include subjects from this population.

Conclusion

With the advent of new HIV drug therapies, many people who became infected during middle age are living longer and beginning to need geriatric care. People who become infected later in life, meanwhile, are often diagnosed with HIV relatively late, largely because health care providers may not consider older clients to be at risk for infection and because they may misinterpret symptoms of HIV disease as effects of aging. Because a delayed diagnosis often leads to poor prognosis, it is important for providers to more actively screen older patients for HIV infection.

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Effects of Older Age on Perceptions of HIV


According to a series of interviews with HIV-infected adults age 50 and older, attributes associated with older age result in some advantages, including wisdom and reduced expectations of health, and some disadvantages, including attributes that might lead to inferior care.

Researchers interviewed 63 HIV-infected adults between the ages of 50 and 68 years recruited from social organizations, support groups, advocacy groups, and drug treatment centers in New York City. Seventy percent of the participants were male, 40 percent were African American, 36 percent were non-Hispanic White, and 24 percent were Puerto Rican. Fifty-seven percent had AIDS, 30 percent were asymptomatic, and 13 percent were symptomatic.

The most prevalent belief among participants was that they had acquired wisdom with age and, as a result, had better resourcefulness and problem-solving skills. Because physical problems are common among older people, whether or not they are HIV-infected, participants also believed that health complications tend to be less traumatizing for older people than they are for younger people. Participants believed that they were less psychologically threatened by disability than younger people because they did not feel the need to “keep up” with healthy peers, and they were less likely to feel cheated out of living a complete life because they had accomplished many personal goals. But, they believed that they felt more socially isolated than younger people.

While participants believed that older people tend to have more time to focus on maintaining their health, they also believed that physicians were likely to set higher treatment goals for younger HIV-infected patients than for older patients, and that this might result in inferior care. In addition, although some participants perceived the patience that develops with age as positively moderating emotional reactions to disease-related problems, others considered patience to be a disadvantage, because it led them to be overly compliant and resulted in inferior service from health care workers.

HIV Education and Older Adults


Although adults age 50 and older represent about 10 percent of the annual AIDS caseload, only seven of 100 directors of senior centers surveyed in Illinois and Southern California reported providing HIV information to their clients, according to a study included in a review of the literature on HIV education for older people. Of those who did not provide HIV education, 80 percent believed it to be inappropriate and unlikely to interest older adults.

In addition, not one of 30 HIV educators interviewed reported providing any primary prevention intervention to the older community. Among their reasons included insufficient resources, antagonistic senior center directors, and seeing adults age 50 and older as low priority.

Research indicates that 59 percent of adults age 50 and older have not adopted safer sex practices to prevent HIV infection. Compared to younger people, adults age 50 and older generally know less about HIV transmission and disease, consider themselves to be at lower risk for HIV infection, and possess fewer of the sexual communication skills they need to avoid risk. Studies reveal that older adults with HIV often feel isolated and guilty, refrain from early treatment, and face problems associated with taking more than one prescribed medication.

According to a study by the Centers for Disease Control and Prevention (CDC), of 94 percent of people age 50 and older who had seen their doctors in the previous five years, only 15 percent had discussed HIV risks with their physicians.
sexuality and drug use, attitudes about HIV disease or age, and resource constraints.

The Aging Immune System and HIV

Bender BS. HIV and aging as a model for immunosenescence. Journal of Gerontology: Medical Sciences. 1997; 52A(5): M261-M263. (Department of Veterans Affairs Medical Center, Gainesville, Florida; University of Florida.)

A review of the literature on the medical effects of HIV and aging reported that HIV-infected people who are at least 50 years old tend to experience a shorter interval between HIV infection and progression to AIDS, a shorter survival time after infection, and more HIV-related and non-HIV-related symptoms.

Previous research suggested that accelerated advancement of HIV disease common in older adults is the result of the presence of other diseases and delayed diagnosis. Recent research, however, suggests that immunological mechanisms play a prominent role in accelerated HIV progression in older people. With aging, more virus is produced, and as the virus spreads, more CD4+ cells become infected, which leads to rapid destruction of CD4+ cells. An aging immune system also cannot produce new CD4+ cells quickly enough to replace the destroyed cells, and as it becomes less effective in resisting HIV, viral burden increases.

Even in the absence of other medical conditions, HIV disease progresses more rapidly as people age. After a 10-year follow-up in a study of HIV-infected hemophiliacs, those who became infected at an older age progressed to AIDS more quickly and had a shorter survival time than did those who were younger. Health care providers face further challenges when treating older patients infected with HIV because there are no published studies about the effects of antiviral therapy on older people, and the Physicians’ Desk Reference contains no specific recommendations.

HIV and Older Ethnic Minorities


As is true for the epidemiology of HIV in all age groups in the United States, African Americans and Hispanics are disproportionately represented among new AIDS cases in people 50 years of age and older, according to a review of studies. African American men represent 31 percent of new male AIDS cases in this age group, and Hispanic men represented 15 percent. Among older women newly diagnosed with AIDS, 48 percent were African American, 19 percent were Hispanic, and 1 percent were Asian American or American Indian.

AIDS mortality rates are also disproportionately higher among African Americans and Hispanics. In 1995, 36 percent of AIDS-related deaths among men 55 years of age and older were African American, and 17 percent were Hispanic, while 57 percent of deaths among women in the same age group were African American, and 21 percent were Hispanic. These outcomes may be the result of overall poorer health status of older African Americans and Hispanics compared to Whites and the likelihood of other chronic conditions.

Finally, research indicates that older members of communities of color have relatively low rates of accessing health care and social services. Barriers to accessing services include distrust of health care providers, and, among Hispanics, cultural barriers, particularly the lack of bilingual providers, which often forces older Hispanics to rely on their children or other family members to serve as translators. Fear of disclosing their infections to their family members, however, may inhibit older Hispanics with HIV from seeking treatment.
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