
Caring for the (Near) Majority

Addressing the Needs of Older Adults with HIV



by Liz Seidel

Thanks to the success of HIV treatment, and the fact that one in six new HIV infections occurs in older adults, people ages 50 and older will account for the majority of people with HIV in the U.S. by 2015. But they face many barriers to HIV testing and treatment.

HIV testing

Older adults are often absent from discussions around the testing and treatment of sexually transmitted infections, including HIV. The majority of older adults continue to have sex well into later life, but the myth that they are not sexually active persists. Ignoring the high rates of sexual activity among older adults can delay the care they need, and research suggests that doctors are not addressing these patients' sexual health issues. The National Social Life Health and Aging Project (NSHAP) found that fewer than half of patients had talked to their doctors about sex after the age of 50. Many physicians do not think of their older patients as being sexually active or at risk for HIV. If they don't discuss sex with patients, they are unlikely to offer them HIV testing, and the patients themselves may not feel comfortable asking. In addition, older adults are sometimes unaware of their risk for HIV. For many, HIV continues to be viewed as a gay disease or a young disease. Heterosexual older adults in particular may be unfamiliar with HIV risk factors.

Older lesbian, gay, bisexual, and transgender (LGBT) individuals also encounter barriers to HIV testing. Doctors often make assumptions, and some treat all their patients as if they are heterosexual. LGBT people who are unsure whether their provider is gay-friendly may be reluctant to talk about sex for fear of discrimination. A study of older LGBT clients at the Center on Halsted in Chicago found that only half had talked to their doctors about their sexual problems. In addition, discrimination can result in lower use of health care and other social services.

Failure to test for HIV has serious health effects for those who have HIV but are unaware of their status. Late testers are less likely to recover CD4 cells after starting medication and may progress faster to AIDS.

Doctors are not the only group responsible for the failure to test older adults for HIV. Current CDC guidelines do not recommend HIV testing for people over age 64. To reduce barriers to testing that result in late diagnoses, the CDC should update its guidelines to recommend HIV testing for all adults. More needs to be done to promote HIV testing for older adults, including targeting older adults themselves through social messaging campaigns. For example, these campaigns can let older adults with Medicare know that their coverage includes once-a-year HIV testing. Finally, doctors need to be trained to talk about sex with their patients regardless of their age, and to include HIV testing as a routine part of medical care.

Barriers to Care

People with HIV regularly encounter barriers when seeking care. These barriers can take many forms, including how others make them feel about the fact that they are positive, how the people with HIV themselves feel about the disease, and whether they have the tools and support they need to manage HIV. Newly diagnosed older adults, as well as older adults who have been positive for many years, may face additional barriers because of their age. HIV is still viewed as a young person's disease, and older adults with HIV may encounter ageism and additional stigma.

Older adults with HIV also have to deal with aging-related illnesses and a declining immune system. It can be difficult to find a doctor who can address both HIV and aging issues. Generally, HIV doctors do not know a lot about aging, and geriatricians are not up to date on HIV management. ACRIA's *Research on Older Adults with HIV* (ROAH) study found that older adults with HIV have an average of three times more comorbidities (other health problems) than

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HIV-negative adults over 70. For HIV-positive people with multiple conditions like arthritis, high blood pressure, and diabetes, it can be difficult to handle taking the many medications required. Tips for dealing with this include having a “brown bag” session with their doctor to see if it’s okay to combine all their medications. This means putting all their prescription drugs, over-the-counter drugs, vitamins, and herbal supplements (which can react with HIV meds) into a brown bag and bringing it to their doctor.

While many challenges to the care of older adults with HIV remain, there has been much progress on the issue, including the creation of guidelines to address their medical needs (aahivm.org/hivandagingforum).

Depression and Isolation

Depression is a concern for people with HIV, especially among older adults. People are more at risk for depression as they get older, and it can be a barrier to care, since people with depression are less likely to take care of their own health. Almost half the people surveyed in ROAH reported being depressed at some point in the previous year. Untreated depression can have serious health consequences, since it is known to weaken the body’s defenses. It can also lead to not taking HIV meds as directed, which can cause drug resistance and lower CD4 counts. Health

care providers need to develop better strategies to diagnose depression and to reduce the stigma of getting mental health care. Depression is treatable, and more programs for people with HIV should target and treat it.

Social support is critical in helping people cope with chronic illness, but it can be difficult for some older adults to obtain. As people age, they can experience losses of spouses, partners, and friends, as well as employment. In addition, chronic health problems can make it difficult for people to get out of the house or leave their neighborhood, limiting the activities they once enjoyed. Many older adults with HIV report receiving support but say they need more.

Studies have shown that older adults with HIV may not have the social supports that people without HIV have. Family is often a main source of caregiving, but some research has demonstrated that many older adults with HIV do not have family to rely on. Some LGBT adults are separated from their families because of their sexual orientation. But regardless of sexual orientation, HIV-positive older adults are much less likely to be partnered than the general population. They also are more likely to live alone – some research has shown as many as 75% of those with HIV over 50 are living by themselves. Not receiving emotional and functional support can result in loneliness, and people in ROAH reported significantly more loneliness than the general population.

Transgender individuals had the highest rates of loneliness, followed by men. More programs that support socialization could be a key factor in fighting these issues.

Stigma

HIV stigma is widespread, and it continues to be linked to “taboo” behavior. Older women and heterosexual men may face different stigma issues – many people are unaware that they are at risk for HIV, and this can increase stigma for those with HIV or for those trying to protect themselves. Stigma can increase the stress of disclosure, and people with HIV who do not disclose find it harder to obtain the services needed to manage their HIV and other conditions.

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A study of older clients of GMHC in New York City asked about the barriers they encountered when trying to receive services. A quarter reported they were afraid they would not get treatment or that their HIV status would be disclosed without their permission. Over 40% felt that service providers “don’t like people like me”, and that number rose to 65% for the women in the study. Over half of the respondents did not know where to get services, were unable to get free services, had to wait too long for services, and did not think services were available locally. Finally, having to care for others and difficulties making appointments were reported by 25% of people in the study. Providers, including aging providers, need more cultural competency training to meet the needs of their HIV-positive and LGBT clients.

Retention in Care

Staying in care is critical, yet fewer than half of people with HIV are consistently in care. The Continuum Engagement Model, which was developed to rank retention in care for people with HIV, breaks down users of health care as regular, sporadic, and non-engagers. A regular user is defined as someone who makes an appointment every six months and doesn’t miss more than two appointments a year. A sporadic user is someone who completes only one appointment a year, misses at least two appointments a year, and uses an urgent care clinic once a year. Non-engagers are people who have an initial visit but do not return after that. A 2010 study found that among people with HIV, 25% were regular users, 32% sporadic users, and 43% non-engagers.

Providers should be aware of the factors that negatively affect people’s ability to stay in care:

- current or prior injection drug use
- low social support
- lack of engagement with the health care provider
- unemployment
- mental illness
- child care needs
- transportation needs
- hospitalization

The benefits of staying in care are well documented:

- increased access to HIV medications
- improved adherence
- suppression of viral load
- improved immune function
- less chance of drug resistance
- reduced health care costs
- less risky sexual behavior
- less risk of an AIDS diagnosis

There is some good news: Research finds that older adults are more adherent to HIV medications than younger people. And once connected to care, older adults are more likely to stay connected.

What can be done to assist people who are newly in care to help them become regular users of services? For one thing, health care providers need to increase their outreach efforts. This includes reminder calls, regularly updating patients’ contact information, maintaining emergency contact numbers, conferring with other providers, and phone counseling by peer educators. Also, providers should consider using health care navigators, who assist patients in negotiating the difficulties of the health care system – things like making appointments, lack of transportation, inconvenient appointment times, long waits for appointments, and conflicts with work or family responsibilities. The good news is that care coordination helps keep people in care and that support systems improve retention in care. Teams of doctors, nurses, social workers, aging service providers, and patients must work together for successful outcomes.

Conclusion

Too many barriers remain for HIV testing of the older adult population. These barriers can be reduced through prompting doctors to have conversations with their patients about sexual health. Doctors should also receive LGBT cultural competency trainings so that they avoid making assumptions about their clients. Lastly, the CDC should recommend HIV testing for all adults, not just those under the age of 65. For older adults living with HIV, more can be done to decrease obstacles to care. This can include more research on aging with HIV and programs that include socialization and support individuals as they face other illnesses. Health and social service providers need additional training in HIV to increase knowledge and decrease stigma towards those with HIV. Finally, teams of providers should work together to assist keeping HIV-positive individual in care and therefore better health. ■

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