Facing Barriers to Aging With HIV

A national survey identifies issues across five domains.

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People aging with HIV face significant barriers and critical disruptions in care and treatment that under-mine their clinical progress and social support, according to a report on the findings of HealthHIV's State of Aging with HIV Fifth Annual National Survey. The survey revealed the daunting reality of aging with HIV, including managing multimorbidity and frailty risk, mental health challenges and the structural barriers they face regularly.

Adults ages 50 and older already represent more than half of all people living with HIV in the United States and are projected to account for 70% by 2030. They face significant barriers and critical disruptions at every step in care and treatment that undermine their clinical progress and social support. The survey report describes the findings and implications of these and other issues and how the next phase of HIV care has to pivot toward the needs of people aging with HIV across five connected domains—HIV and geriatric care, comorbidities, behavioral health, access and payment, and workforce.

Over the past five surveys, consumers reported high rates of viral suppression. "These results reflect often hard-won clinical gains that can quickly erode when continuity of care is disrupted," says Circe Gray Le Compte, MS, ScD, senior director of research and evaluation at HealthHIV. "During COVID-19, suppression rates among people aging with HIV dipped sharply as consumers were cut off from care. Low-income, women and transgender/gender-nonconforming persons aging with HIV experienced even sharper declines."

Survey findings and implications include:

HIV and Geriatric Care

Finding: Viral suppression of 98% is the highest rate since HealthHIV started collecting data in 2020, yet aging with HIV is not being managed at the same level. This is especially true for low-income and sexual and gender minorities, whose connection to care declines more quickly under stress, as we saw during COVID-19.

Implication: Bolster infrastructure that supports this suppression rate to integrate frailty and geriatric screening into Ryan White HIV/AIDS Program (RWHAP)–funded clinical visits.

Comorbidities

Finding: Most consumers carry chronic non-HIV-medication burden, and a high-needs unmanaged group is invisible to every system except HIV antiretroviral therapy (ART). Respondents cited suboptimal management of comorbidities.

Implication: Fund clinical pharmacist consultations as a reimbursable RWHAP service category; reauthorize and align the Older Americans Act with earlier-onset aging-related needs so that supports are not limited by chronological aging. Better clinically address comorbidities, including frailty risk, cardiovascular disease and mental health burden.

Doriot Kim

Behavioral Health

Finding: Stress is widespread, while social connection is the strongest protective factor in the data; outwardly good quality of life can mask serious mental health burden.

Implication: Make mental and behavioral health screening a default in HIV primary care, and treat antidiscrimination training as a clinical intervention.

Access and Payment

Finding: Medication coverage is doing what it was designed to do, but the surrounding infrastructure, including payment and transportation, is fragile, with ART access no longer assumed to be stable.

Implication: Support treatment access by treating transportation as essential medical infrastructure, making Medicare telehealth permanent for HIV care and stabilizing the AIDS Drug Assistance Program (ADAP) rebate base.

Workforce

Finding: Most providers recognize that aging with HIV is a clinical priority, but few organizations have the staffing, training or workflows to act on that recognition. Workforce turnover is eroding the practical knowledge needed to deliver aging-informed care.

Implication: Nonprofits and government agencies need to provide more education and training for the workforce addressing HIV and geriatric care. Supporting the geriatric needs of people aging with HIV has outpaced operational capacity. Less than one fifth of consumers completing the survey reported receiving frailty screening in the past year, while many described dealing with often unaddressed mental health concerns and limited social support.

“People aging with HIV are navigating far more than the virus itself, even as viral suppression and sustained care remain unevenly supported across fragmented systems,” states HealthHIV director of advocacy and Pozitively Aging program lead Scott Bertani. “This survey reflects growing strain across care and prevention access, financial stability, mental health and the ability of providers and systems to keep pace with increasingly complex health needs and lived social realities.”

When asked to describe aging with HIV in a single word, both consumers and providers most often chose challenging, difficult and complicated—a pattern consistent with findings from the previous two surveys. One notable difference emerged around loneliness: Providers identified it more frequently than consumers, suggesting that social isolation may be recognized by others before individuals acknowledge it themselves.

A report on findings and implications from HealthHIV’s State of Aging with HIV Fifth Annual National Survey is available to view and download at HealthHIV.org/stateof/agingwithhiv.

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