HealthHIV STATE OF Aging with HIV™

Third Annual National Survey

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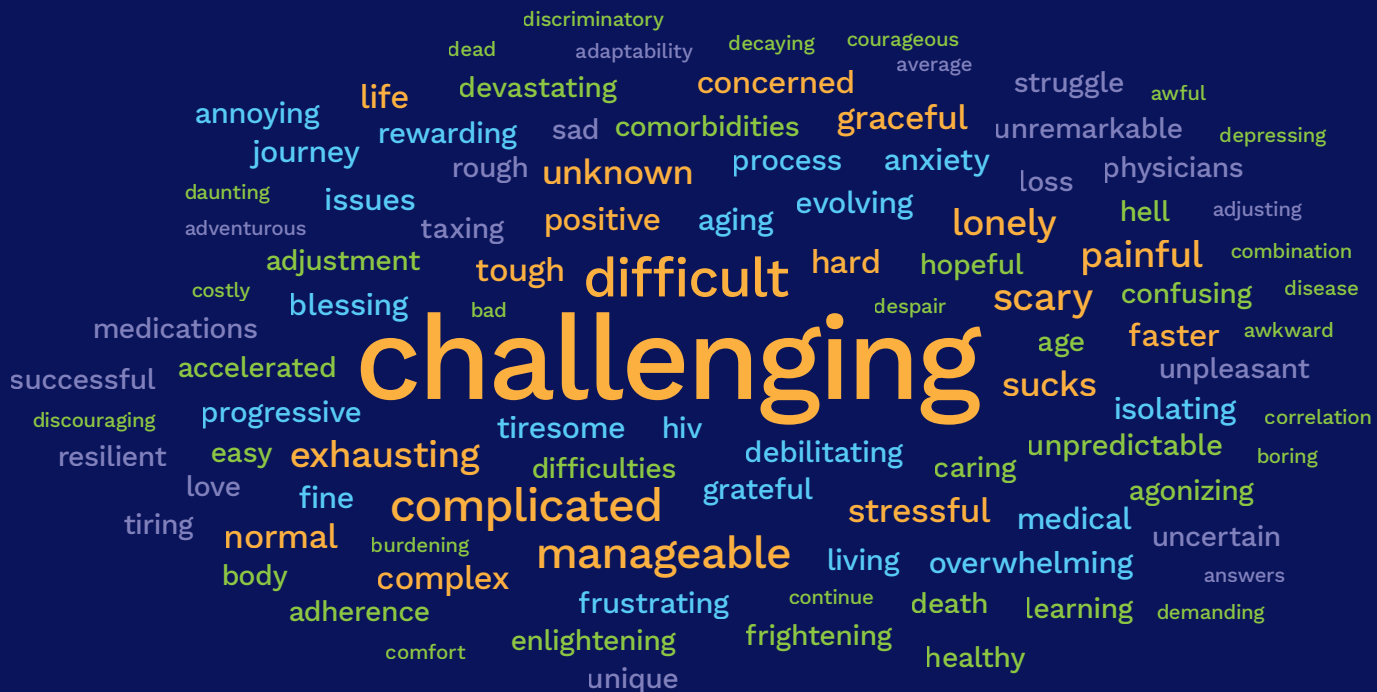
Introduction

In 2020, older persons with HIV (OPWH) represented half of all persons living with HIV in the U.S. Current estimates predict that by 2030, nearly 70% of persons with HIV in the U.S. will be over the age of 50.[1] This demographic shift poses a unique set of challenges for HIV care providers, with tremendous implications for how we prioritize and deliver services.

HealthHIV's Third Annual State of Aging with HIV™ National Survey was developed to gather information on the current experiences of OPWH in the U.S. We heard from hundreds of people across the country who shared information about their personal health journey and their understanding of the most pressing needs facing adults aging with HIV.

When asked to describe aging with HIV in one word, more than 50% chose **"challenging,"** followed by the descriptors **"difficult"** and **"complicated."**



Survey Methodology

The survey consisted of a mix of 151 open- and closed-ended survey questions. An external Aging with HIV Community Advisory Board reviewed the survey to ensure the questions encompassed salient issues of HIV and aging described in the literature.

DISTRIBUTION, SAMPLING, AND RECRUITMENT

The survey was administered online via Research Electronic Data Capture (REDCap) from October 20, 2022 to January 3, 2023. Respondents were recruited through HealthHIV's constituent relationship management (CRM) database, SalsaLabs, which includes approximately 80,000 persons who reflect the diverse cross-section of populations disproportionately impacted by HIV in the U.S. There was representation of racial and ethnic minorities and sexual and gender minorities, across geographic location, educational status, and income levels. No incentive was provided for participation.

DATA ANALYSIS

Basic descriptive statistics were calculated in REDCap. Additional univariate, bivariate, and multivariate statistical analyses were calculated using RStudio 4.2.1 statistical software. Thematic content analysis was used to explore qualitative data and identify themes that captured respondent experiences.

ELIGIBILITY REQUIREMENTS

To be eligible to take the survey, respondents had to indicate that they were either 1) a person with HIV age 50 or older, or 2) a person living with HIV for 15 or more years (to include respondents diagnosed before the first single-tab regimen was introduced in 2006). Of the 755 who expressed interest in the survey, 673 met the eligibility criteria to participate.

Key Findings

The State of Aging with HIV is challenging and complicated.

OPWH face a range of daunting problems as they age with HIV, including navigating a fragmented healthcare system that can make it difficult to access the care they need.

Key Findings From This Report

- **Multimorbidity and polypharmacy is a near-universal issue.** 2 in 3 respondents reported at least two comorbidities and 3 in 4 reported taking at least two daily medications.
- **Mental illness is on the rise.** 64% of respondents reported mental health concerns compared to less than 40% of respondents last year.
- **Retirement savings are minimal.** Half of respondents had no financial retirement plan and 4 in 5 had not saved enough for long-term care or supportive home care.
- **An uncertain future looms.** There was a strong sentiment among respondents that OPWH are often forgotten and left out of the conversation around HIV care.

Demographics

Participation in this survey reflects the demographics of those currently living with HIV in the United States.

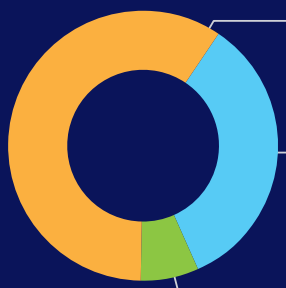
93% of respondents were older than 50 and one third of those were older than 65. Respondents who reported living with HIV for 15+ years tended to be older than 50 and more established in terms of education and income than those living with HIV less than 15 years.

Survey respondents were predominantly White, gay identifying, cisgender men. 66% had obtained at least one post-secondary degree.

Representation came from 40 U.S. states, the District of Columbia and Puerto Rico. The majority of responses came from California, followed by New York and Virginia.

While over 25% of respondents made above $65,000 annually, nearly half made below $32,000 per year, and just under a quarter made less than $17,000 per year. More than 54% had no financial retirement plan.

AGE

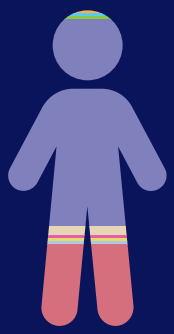


- 50–65 years **59%**
- 65 or older **34%**
- Less than 50 but living with HIV for more than 15 years **7%**

RACE AND ETHNICITY

- Black **27%**
- Hispanic/Latinx **14%**
- Multiracial **7%**
- White **62%**

GENDER IDENTITY



- Agender **<1%**
- Gender Fluid **<1%**
- Gender Nonconforming/ Genderqueer **<1%**
- Man **68.7%**
- Nonbinary **2.6%**
- Other/Prefer Not to Say **1%**
- Transgender Man **1.2%**
- Transgender Woman **1.2%**
- Woman **26.9%**

SEXUAL ORIENTATION

- Asexual **1.2%**
- Bisexual **6.3%**
- Gay **51.6%**
- Lesbian **<1%**
- Other/Prefer not to say **3%**
- Pansexual **1.6%**
- Queer **4.9%**
- Straight **25.9%**
- Two Spirit **<1%**

HIV Status Tells a Complicated Story

Viral suppression is only part of the picture. Late diagnosis threatens health, regardless of viral load.

Nearly all respondents had been living with HIV for 15+ years. Of the more than half of respondents (54%) who reported ever being diagnosed with AIDS, 50% of those received a late HIV diagnosis. A late diagnosis was defined as having AIDS at the time of HIV diagnosis or within 12 months of diagnosis.

Of the
89% living with HIV for more than 15 years

54% have received AIDS diagnoses

Of those,
50% received a late HIV diagnosis

HIV Testing Guidelines May Overlook Older Adults at Greater Risk of Late Diagnosis and Serious Health Outcomes

Current recommendations from the CDC state that individuals between the ages of 13 and 64 be tested for HIV once in their lifetime.[1] More frequent screening is recommended for individuals with known risk factors. The CDC does not recommend routine screening for persons 65 years or older.

However, OPWH are more likely to be diagnosed at a later stage of HIV than younger people despite having more frequent contact with health care systems.[2] Late diagnosis in combination with the fact that OPWH have poorer CD4 cell recovery after initiating ART leads to increased risk for serious health outcomes.[3]

Antiretroviral Therapy (ART)

The vast majority of respondents were currently virally suppressed and adherent to ART.

Viral suppression was reported at a slightly higher rate in respondents who had never had an AIDS diagnosis (94%) compared to respondents who had a history of AIDS diagnosis (92%).

A quarter of respondents reported current issues with medication side effects and most had experienced medication side effects on a previous regimen. Many expressed worry that not enough is known about the effect of long term ART use on the body — an especially salient concern as the average number of years reported on ART was 23. One respondent explained, **"[we need] more options for dealing with the side effects of long-term infection and long-term use of [ART] that don't include more medications with their own related side effects."**

Respondents thought more research and development was needed for treatment options with fewer side effects and newer treatment options for treatment experienced people with medication class resistance. One person stated the need to ensure that **"medications continue to provide undetectable levels for long-term use without side effects or decreased efficiency of the medications."**

98% currently taking ART

25% experiencing side effects

Of those with an AIDS diagnosis, **92**% are virally suppressed

Of those without an AIDS diagnosis **94**% are virally suppressed

While newer ART has better safety profiles and few documented side effects than older regimens, the cumulative effects of long-term ART on aging is still being explored.

Long-term ART has been associated with risks to bone density loss, central nervous system dysfunction, kidney and metabolic disorders, cardiovascular disease, liver disease, and disruptions to the microbiome.[4, 5]

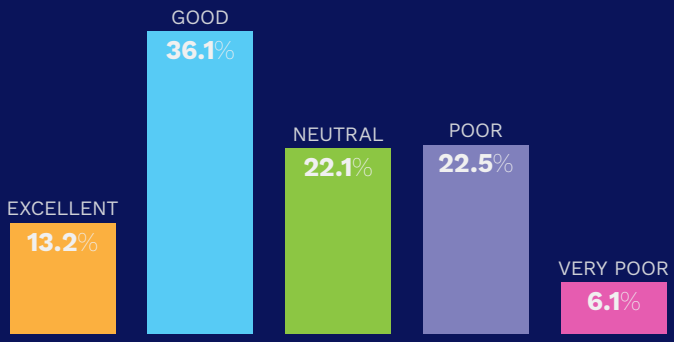
The Path Toward "Health" is Rarely Linear for Older People with HIV

Despite high self-reported physical health ratings, most respondents are living with at least two comorbidities and are at risk of rising frailty.

Overall Health

Almost half of respondents felt that their health was either "good" or "excellent" compared to other older adults not living with HIV.

How do you feel your health compares to people your age who aren't living with HIV?



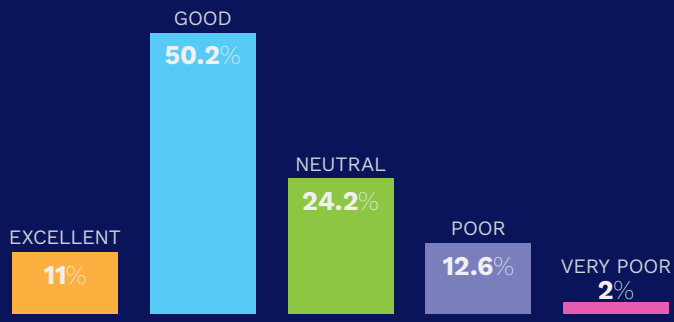
Physical Health

60% of respondents rated their overall physical health as either good or excellent.

However, 62% of respondents reported living with at least two comorbidities. The most common being joint and back pain, hypertension, loss of sexual drive, and neuropathy.

Respondents expressed concern about how they would manage comorbidities as they aged, noting it as a top priority facing their cohort.

How would you rate your overall physical health?



76.6% are taking at least one daily medication for a chronic comorbidity

COMORBID CONDITIONS REPORTED

Anal Dysplasia	18.3%
Cancer	23.8%
Diabetes (Type 2)	17.5%
Frailty/Mobility Issues	27.9%
Hepatitis B	39.2%
Hepatitis C	14%
Heart/Cardiovascular Issues	32.3%
Hearing Problems	21.7%
Hypertension	59.9%
Hypertriglyceridemia	39.5%
Joint or Back Pain	64.4%
Kidney Disease	17.7%
Liver Disease	10.5%
Lung Disease/COPD	16.8%
Impaired Cognition	22%
Neurological Conditions/Stroke	16.8%
Neuropathy	45.7%
Osteoporosis/Osteopenia	29.3%
Periodontitis/Oral Health Issues	38.3%
Prediabetes	31.1%
Sex Drive/Libido	47.4%

Double the Burden: People with HIV Face Increased Multimorbidity Risks as They Age

The burden of managing two or more comorbidities—also known as multimorbidities—is more common among people with HIV.[6]

Cohort studies of OPWH have shown that the number of comorbidities increase with age, and at a higher rate than older adults without HIV.[7] One study of US veterans with HIV estimated that 53% of those 50-59 years old and 66% of those 60 years and older had at least one comorbidity.[8]

Some of the most common comorbidities in OPWH include hypertension, dyslipidemia, diabetes mellitus, kidney disease, cardiovascular disease, respiratory disorders, bone disorders, depression, and non-AIDS defining cancer.[9] Several analyses have shown that comorbidities are less likely in older adults with private health insurance, suggesting that better access to care reduces this burden.[10]

Polypharmacy is defined as the concurrent administration of 5 or more medications, increasing the likelihood of drug-drug interactions and poor health outcomes.[11] As the number of comorbidities rise, so does the number of medications to manage these conditions.

Frailty and Activities of Daily Living

1 in 4 respondents reported some level of frailty.

28% report frailty

12.7% need assistance with ADLs

Frailty refers to a clinical state or condition that increases vulnerability to declining health across multiple physiologic systems. OPWH are aging with rising rates of frailty which increases risk for hospitalization, polypharmacy, and multimorbidity.[12]

Comprehensive Geriatric Assessments (CGA) and Frailty Index (FI) screenings are recommended for PWH starting at 50 years old, but few providers have incorporated this into standard practice.[13]

Sexual Health

Over half of respondents were sexually active in the past year. However, navigating sexual relationships was noted as a concern for OPWH; one respondent stated: **"Once [you're] diagnosed with HIV, [you] can't just have sex with anyone and people aren't very accepting of your condition if they don't have it and it's scary to let someone [you're] attracted to know."**

Encouragingly, nearly all respondents were aware that maintaining viral suppression on ART nearly eliminates the likelihood of transmitting HIV to a sex partner (U=U).

53.3% have been sexually active in the last year

14.2% have been diagnosed or treated for an STI in the last year

98% are knowledgeable about U=U

Navigating Sexual Relationships: Fear and Discrimination Preventing Safe and Healthy Connections

Older adults are often not offered the same sexual health services as their younger counterparts, despite high levels of sexual activity.[14] Assumptions of asexuality by family members and health care providers inhibits important sexual health conversations.[15]

It is well documented that OPWH are more fearful of disclosing HIV to a sex partner and less confident in their ability to negotiate safe sex practices than younger persons with HIV.[16]

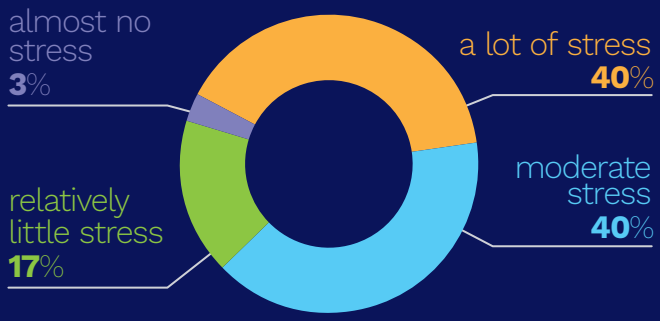
Nearly two thirds of respondents had experienced mental illness in their lifetime and 80% of respondents had experienced a moderate to significant amount of stress in the last 6 months.

One respondent stated: **"I think the most immediate area for older persons living with HIV [is] with mental health issues because in addition, for some of us, to other things that we have going on in our life and in our body, depression is very real."**

Many echoed that mental health was one of the most important issues for OPHW, stating that current mental health services need **"...more focus and improvement."**

63.6% experienced a mental health condition, including depression and anxiety

How much stress have you experienced in the last six months?



Rising Mental Illness Rates and Stress Levels Point Towards Urgent Need for Mental Health Services

Mental health challenges such as depression and anxiety are common in OPWH.[17] Personal experience with mental illness coupled with the stigma of mental illness contributes to poor health outcomes. Depression in particular has been shown to be one of the strongest predictors of poor ART adherence in PWH.[18]

OPWH are also less likely than younger cohorts of people with HIV to receive mental health care.[19]

An Uncertain Future: The Synergistic Effects of Aging with HIV

The synergistic effects of aging, HIV, comorbidities, and long term ART represents a complicated road ahead.

Respondents conveyed their fear of the unknown, unaware of what to expect and how to anticipate and manage impending challenges. One respondent stated they wanted: **"More discussion of known or potential HIV related health issues [that] are possible in my future."**

Another respondent offered a similar sentiment that we need more: **"Knowledge of what's [to] come as we age. I am aware that we are living longer, but there is much we don't know."**

When asked to describe their Quality of Life (QoL) in one word, respondents offered a wide range of responses — from **"blessed"** and **"fair,"** to **"lonely"** and **"poor,"** revealing a heterogeneous landscape of experiences. One respondent stated: **"Quality of life is more valuable to me than [the] mere quantity of it."**

Physical Activity

About 1 in 3 respondents reported regular exercise for 30 minutes, 5 days per week.

37% engage in regular physical exercise

19% are limited in their ability to perform physical activity

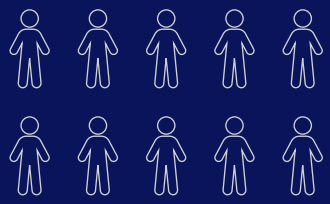
Respondents stated their desire to learn more about the benefits of exercise on physical and cognitive functioning as they age. One respondent shared: **"HIV seems to lead to accelerated symptoms of aging. Middle aged and younger [PWH] need to be aware and learn preventative measures such as preventative resistance training to delay muscle loss, methods to slow cognitive decline, etc."**

Unveiling the Mystery of Aging: Chronic Inflammation and Physiological Aging Leave a Mark on OPWH

The full impact of aging with HIV is still being explored as it involves a complex interplay of several factors. There is evidence that PWH are more likely to experience accelerated and accentuated aging related to physiological aging and chronic inflammation of the immune system.[20] While we see immunosenescence in elderly populations with other non HIV-related chronic disease, it's often present in all PWH, even in the context of well-controlled HIV.[21]

Food and Nutrition

One fifth of respondents either regularly worked with a registered nutritionist or dietician or planned to see one.

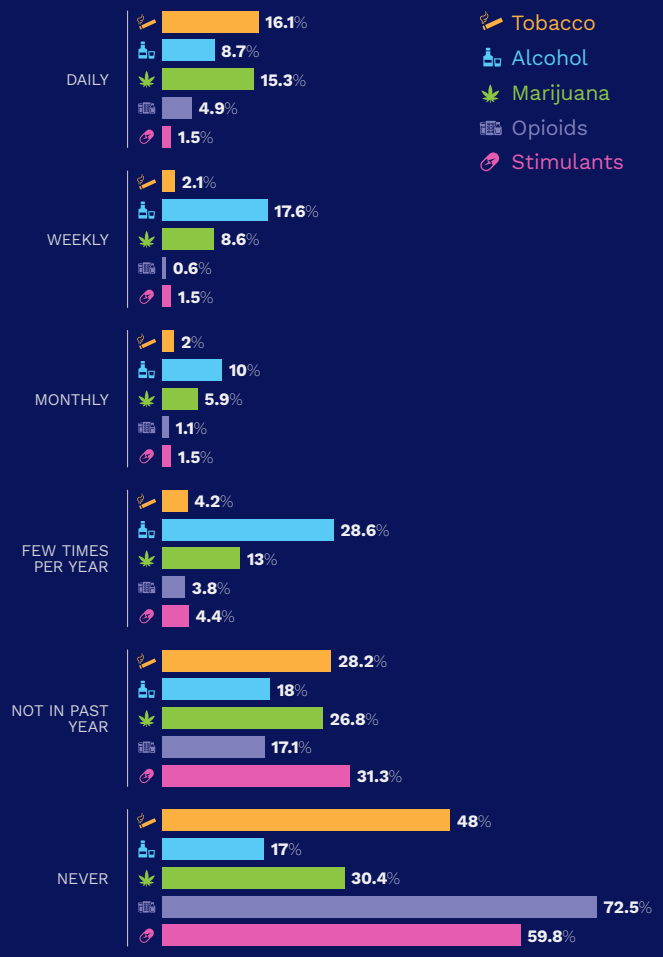


20% regularly work with a nutritionist or dietician or plan to see one

Substance Use

Tobacco and cannabis were the substances most frequently used by respondents on a daily basis, and alcohol and cannabis were the most commonly reported polysubstance (more than one) combination. More than a quarter of respondents reported ever being in recovery from substance use.

FREQUENCY OF SUBSTANCE USE BY TYPE



Substance Use Trends Pose Serious Health Risks and Complicate Care

OPWH have higher rates of substance use than older adults without HIV.[22] Substance use increases risks for people across the HIV care continuum, from impairing timely HIV diagnosis to prohibiting consistent treatment. Substance use has been associated with less engagement in care and inconsistent ART adherence in PWH.[23]

The Social Determinants of Health

A Critical Framework for Understanding the Experience of OPWH

The Social Determinants of Health (SDoH), which can include income, education, food insecurity, employment, housing, and social and community context, have been shown to have an outsized impact on health care utilization, cost, and outcomes.

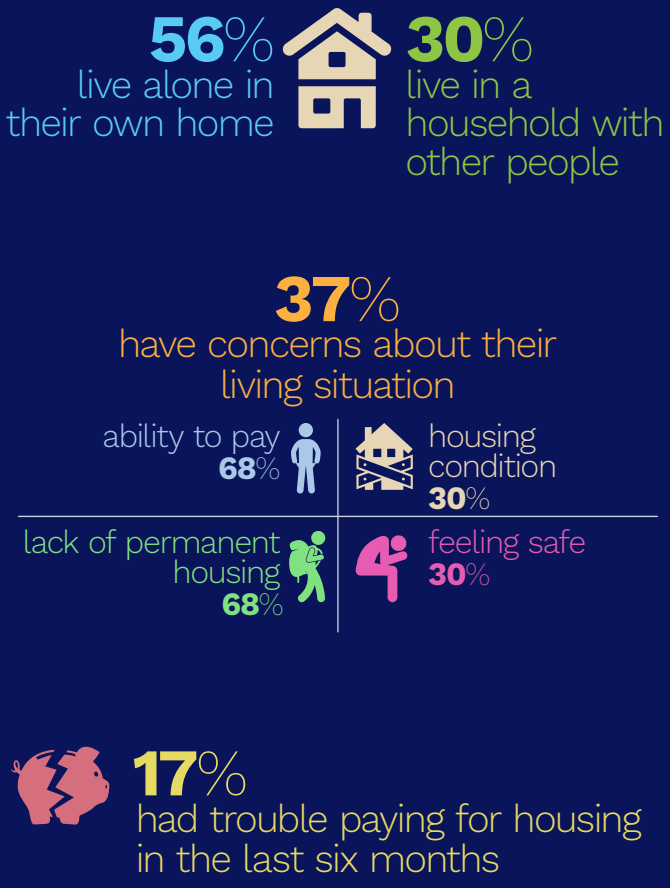
What good is a prescription if patients don't have transportation to a pharmacy? How can people experiencing homelessness follow a consistent prescription schedule when their primary concern is a meal or safe shelter? Many states have taken steps to include behavioral health services, pharmacy benefits, long-term support and services to contracts in their state — but not all. State Medicaid programs can add these non-clinical, support services to home and community-based services (HCBS) programs to support PWH and especially OPWH. Respondents answered questions relating to their experience navigating certain SDoH, and their answers echo the critical importance of understanding the environment in which people live and how that impacts healthcare and support services.

> "If isolation, stigma, financial insecurity, and depression are risk factors for general population aging, it's ten-fold for those with HIV who are alone: no supportive family, no friends living close by, no partner."

Housing

Overwhelmingly, housing was cited as the most pressing concern facing OPWH. More than a third of respondents indicated that they had current concerns about the affordability and safety of their housing.

One respondent explained the cascading effect of securing affordable housing: **"More help is needed in making housing affordable for the small fixed incomes many elderly HIV+ people survive on. All the other needs flow from that: transportation, food, etc. can vary depending on where one is forced to live in order to survive."**



Sustainable and affordable housing is paramount in helping OPWH take control of their health.

Aging with HIV on a fixed income can escalate housing concerns into emergency situations — concerns which are also exacerbated by today's concurrent crises of rising housing prices and falling housing stock.

Even with the federal housing program, HOPWA — meant for low-income PWH (≤80% of area median income) — accessing stable housing remains challenging for many. Homelessness and unstable housing represent a major barrier to accessing care and adhering to treatment, and are associated with worse HIV-related health outcomes.[24]

Long-Term Care

Respondents also lamented that they had concerns about their future housing options. Specifically, questions about how to maintain independence in their current homes as they age, and how and when to transition into assisted living or long-term care.

Several expressed a desire for long term care options that were tailored to LGBTQ folks. One respondent explained: **"I'm very concerned about finding future elder home care and/or housing that's LGBTQ+ supportive and inclusive."**

81% have not saved enough for long-term or supportive home care

Long-term care (LTC) facility nurses and support staff are the first line of healthcare providers in nursing homes. With the growing OPWH population, ongoing training for LTC facility staff is needed on the unique care needs of OPWH and the LGBTQ community.

Long-term care insurance (LTCI) is available to cover at-home and assisted living care, as well as nursing-home care. However, LTCI is a huge and uncertain investment, known for frequent claim delays or denials, and underpriced premiums that are later subject to high annual premium increases.

States may have to step in to enforce fair-and-equal housing policies for PWH and increase funding efforts.

Transportation

Reliable and affordable transportation was identified as a major concern and barrier to accessing care.

One respondent explained how **"A car would be a life changer! I had to give mine up to pay rent. For me (and all PLHIV >50!) a car would reduce isolation, [minimize] missed appointments, [increase] access to food and [medication without] relying on delivery."**

18% could not pay for transportation i the last 6 months

17% say transportation is a significant barrier to accessing healthcare

13% missed medical appointments in the last 12 months because they lacked access to transportation

Without Reliable Transportation OPWH Cannot Access Vital Health Services

Transportation is a critical need that impacts one's ability to attend medical appointments, pick up prescriptions, purchase food, access services, and engage with social networks.

Moreover, a lack of perceived access to transportation in OPWH was associated with poor health-related quality of life, social isolation, and higher rates of depression.[25]

Transportation as a barrier to HIV care is more prevalent in rural areas and in states without Medicaid expansion.[26]

Social Support

The majority of respondents reported some level of engagement with the community. However, the need for continued social groups, social activities, and social support was noted as a top priority for OPWH.

Some respondents worried that social isolation was always looming, stating **"[you need to] stay connected to community; isolation is intense even when you've always been outgoing and involved. One serious illness & all connections vanish."**

Respondents were also aware of the deleterious effects of isolation on health outcomes: **"I find that a significant number of my peers tend to isolate and just exist. Isolation leads to significant mental health disorders."**

66% participate in community groups

32% don't have anyone who takes care of them when sick or injured

7% say they have no one to call on in case of emergency

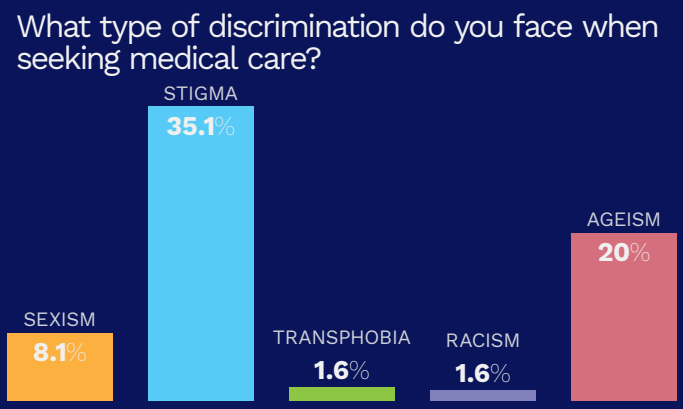
Struggles with Loneliness and Isolation Persist Among OPWH

Research has shown that greater perceived social resources are key to promote ART adherence and reduce substance use in OWPH.[27] Despite being a significant resource for this population, OPWH perceive barriers to obtaining and maintaining social relationships over time.[28]

Stigma and Discrimination

More than one third of respondents indicated they had experienced stigma when trying to access healthcare. Decreasing stigma experiences was noted as an important issue for OPWH.

One in 5 respondents had experienced ageism. Ageism was also listed as one of the most important issues facing OPWH. Throughout the survey, there were comments that OPWH are **"the forgotten few"** who will be left behind and left out of the national conversation about HIV care. Another respondent urged: **"Do not count us out, we still need help."**



Ageism and Intersectional Stigma Prevent Health Equity For OPWH

HIV-related stigma negatively influences physical and mental health and acts as a major barrier to health equity in PWH.[29] Whether anticipated, perceived, or enacted, HIV-related stigma is also linked to poorer health care engagement.[30] Stigma and other forms of discrimination are experienced at the individual, interpersonal, and structural level.

PWH often belong to other marginalized groups and experience intersectional stigma — related to race, sexual orientation, gender identity, and class–reinforcing systems of oppression.

Ageism represents another barrier as it has a detrimental impact on the well being, mental state, and self-conceptualization of older adults managing HIV.[31]

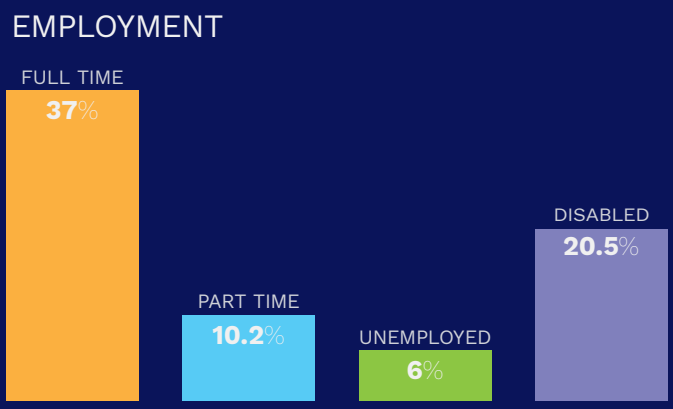
> "It has been lonely for me. There is 'treatment fatigue.' There is still stigma, but worse than that is feeling forgotten."

Employment

The majority of respondents were employed either full time, part time, or self-employed. Around 1 in 4 reported they were unable to work due to disability.

Some respondents explained the need for employment that would allow them to keep their state benefits. Others sought to leverage their knowledge for meaningful work, stating: **"We are the experts of our own experience; there should be more career opportunities in HIV for people with lived experience."**

Respondents also recognized that accessible employment could help improve their health status, stating: **"[There should be] jobs for disable[d] people like me to have better mental health."**



Age and Long-Term Disability Pose Barriers to Sustainable Employment and Income Among OPWH

In PLWH, employment is associated with consistent HIV care engagement, better physical and mental health, and improved quality of life.[32]

The Social Security Administration (SSA) sets the criteria for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits. To qualify, an individual has to be determined disabled and unable to do substantial work. The process of applying for SSI/SSDI can be arduous and lengthy.

OPWH have higher rates of disability than other cohorts of older adults without HIV, yet many are capable and willing to return to work. However, working could lead them to lose their (immediate) eligibility for Medicaid, SSDI, or other forms of public assistance — assistance that helps supplement their longer-arc needs. This is especially true for those that may be virally suppressed, but have multimorbidities that exacerbate difficulties with activities of daily living.

It is advisable to reduce the Medicaid income eligibility requirement to assist OPWH in returning to the workforce. This will ensure that they do not lose their social and health benefits.

Food Access

1 in 4 respondents had difficulty accessing food in the last 6 months. Improving access to SNAP (food stamps) and other financial assistance for food was highlighted as a need.

23% had trouble paying for food in the last six months

20% are concerned about having enough to eat or where their next meal would come from

Food Insecurity Represents Significant Threat to Health of OPWH

Food insecurity is associated with poorer health outcomes in all populations. However, PLWH are much more likely than those without HIV to face regular difficulties obtaining food.[33] Ensuring adequate access to nutritional food is an essential component of addressing frailty and comorbidity among OPWH.

Care Must Be Effective and Accessible

OPWH face unique challenges accessing care that require precise population-driven interventions.

Primary, Speciality, and Complimentary and Alternative Care

Easy access to affordable primary care, HIV speciality care, and gerontological care was a top priority for respondents. Many stated they also wanted an opportunity to access complementary and alternative options — such as chiropractic, acupuncture, and massage — to promote wellness and healthy aging.

16% have avoided or delayed medical care in the last 12 months because they could not pay the medical expenses

A scoping review published in AIDS Care on the challenges of PWH accessing healthcare identified five major areas of concern: 1) the acceptability of a patient's HIV status by healthcare staff and providers; 2) the availability of appointments and services; 3) the affordability of treatments and medication; 4) the accessibility of location by transportation; and 5) appropriate accommodation of patient needs.[34]

Telehealth

The majority of respondents have used telehealth in the last 12 months to meet with a provider. However, close to a third of respondents have not used telehealth in the last 12 months citing lack of comfort accessing telehealth visits and a belief that telehealth offers less flexibility than in-person services.

68% have used telehealth in the last 12 months

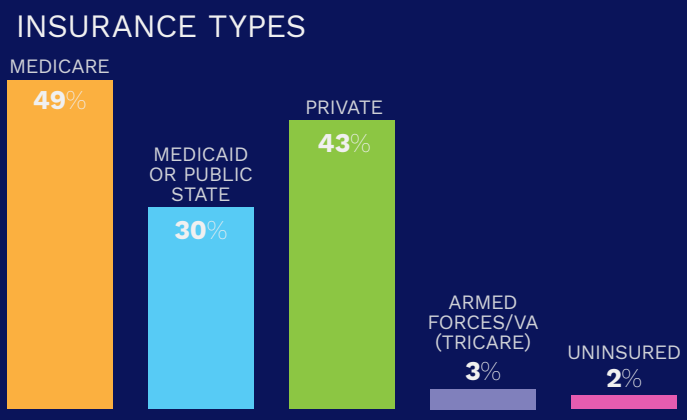
32% have **not**, finding it uncomfortable or inflexible

Telehealth Declines in Popularity as Services Move Back In Person

Telehealth services have been instrumental in increasing access to care for underserved and hard to reach patients. In general, PWH have reported high satisfaction rates with telehealth options.[35] However, surveys of PWH suggest there are still some lingering concerns about telehealth literacy, loss of privacy (security breaches), and loss of personal connection between provider and patient.[36]

Insurance

Most respondents had health insurance and were covered by Medicare, Medicaid, or private employee-sponsored insurance plans. Some selected multiple insurance types to reflect their primary and secondary plans.



What are the most common barriers you encounter when seeking healthcare?

- **25%** Cost of co-pays/co-insurance
- **24%** Long wait times
- **18%** Lack of convenient appointments
- **18%** Not able to find a provider covered by my insurance

What are the most difficult healthcare costs to cover?

- **25%** Co-pays/ Co-insurance
- **12%** Deductibles
- **11%** Prescriptions

Medicaid is the largest source of insurance coverage for PWH. Health programs like Medicaid can play a more integral role in extending assistance, including home and community-based services (HCBS).

Federal Medicaid regulations prohibit spending for most non-medical services. However, state Medicaid programs have developed strategies to address social needs of enrollees within managed care and outside systems. Under their Medicaid state plans, states may include rehabilitative services, including peer navigation and case management services.

Medication Insurance

Respondents who reported having to switch medications due to insurance restrictions were less likely to be on Medicare, more likely to be on private insurance, and four times more likely to be uninsured.

Escalating medication costs were a huge concern for respondents, suggesting copays should be lower and subsidies should be more readily available to assist with this burden.

39% access ART through their state's AIDS Drug Assistance Program (ADAP)

6% have had to change meds because their insurance didn't cover it

Access to Medication Impacted by Insurance Restrictions: Respondents Call for Lower Copays and Greater Subsidies

AIDS Drug Assistance Programs (ADAP) and Medicaid programs need to balance client demand and available resources on a regular basis. Recent economic conditions make it common to implement cost-containment or utilization management practices, like requiring prior authorization or fail-first (step) therapy, due to the increasing demand for services.

An "open formulary" has no limitation to access to a medication. However, fewer ADAP states offer an "open" formulary each year (only six states in 2022). Instead, ADAP relies on specific federal appropriations, or capped funding.

WHAT ABOUT ADVOCACY?

94% agreed that more advocacy efforts are needed to address the needs of people living with HIV. One respondent suggested that there should be more representation from the community on boards and committees that develop treatment guidelines. Another offered that "**more emphasis is needed on encouraging resilience and self-advocacy"** as well.

Health Care Engagement

High levels of adherence and viral suppression among OPHW reflect consistent and honest engagement with healthcare services.

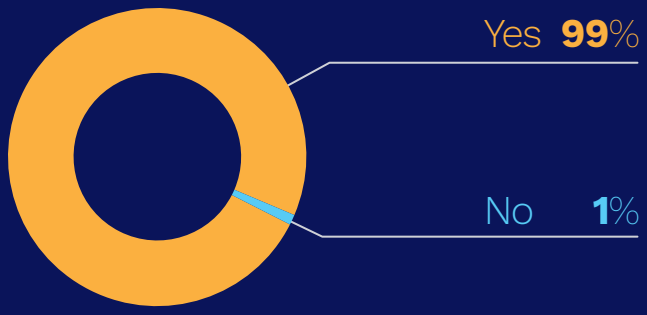
Empowered and Informed: Highlighting a Need for Knowledgable HIV Gerontologists

Nearly every respondent was engaged in HIV care. Two thirds indicated that their PCP and HIV care provider were the same person. Overwhelmingly, respondents felt they could openly communicate with their providers.

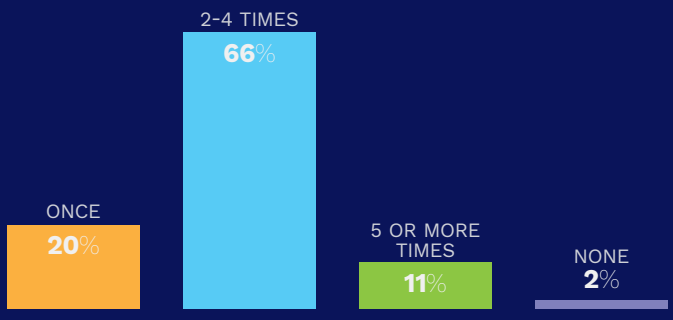
For those who did not feel comfortable sharing issues with providers, the most common reasons listed were 1) lack of provider time, 2) lack of provider interest, and 3) lack of shared decision making.

Respondents commented they wanted to have confidence that their providers could manage the complex needs of aging with HIV. The word "knowledge" was stated multiple times–specifically a need for **"knowledgable HIV gerontologists."**

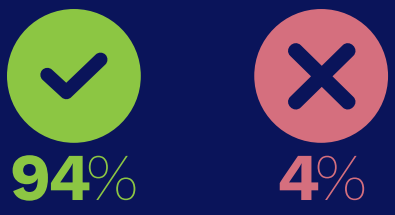
Does your healthcare provider know you are living with HIV?



In the last 12 months, how often have you seen a provider for HIV-related care?



Are you open and honest with your providers about most of your health care and quality of life concerns?



Care Coordination

Care Coordination and Medical Case Management are central to improving quality of life for OPWH.

Coordination of Services

A need for a coordinated approach between providers and services was recommended by respondents.

Respondents shared frustration that they even need to consult a PCP and HIV specialist separately. For example, one person stated: **"Once a PLWH achieves durable viral suppression, then it ought to be managed by one's PCP. Two separate medical providers, two sets of labs, etc, takes time and is a waste of money raising the cost of health insurance for everyone. Not everyone wants to go to a clinic for this either."**

19% have been referred to a outside agency for additional services

38% currently receive case management services at a CBO or clinic

25% have received these services in the past

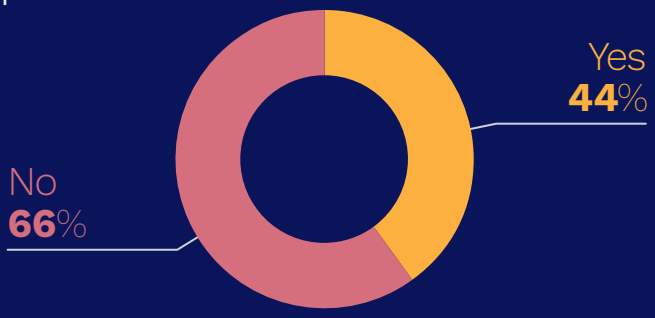
14% have a peer navigator or wellness coach who connects them to services

Coordination Between Providers

Less than half of respondents report that their providers communicate or coordinate with one another about their care and prevention needs.

A lack of coordination is concerning given the increase in care complexity. As one respondent stated: **"Each year, my healthcare management becomes more confusing and complicated, as the common diseases/illnesses of aging converge with the direct and indirect complications of longtime HIV survival and long term medicating with ARVs."**

Do your providers coordinate or communicate with one another about your care and prevention needs?



Coordination of Pharmacies

More than a quarter report having to visit two or more pharmacies to fill all their prescriptions.

This reality was captured by one respondent, who described: **"I am on many different HIV and non-HIV medications, and the timing of refills is often challenging."**

In the past twelve months...

20% had difficulty getting HIV medications on time

20% had trouble getting non-HIV medications on time

28% had to visit two or more pharmacies to fill their prescriptions

Breaking Barriers: Respondents Urge for Coordinated Care Approach Between Providers and Services

Many OPWH rely on a host of services to meet their heterogeneous needs. The inefficient coordination of these services, however, remains a significant barrier to care. Experts have recommended reconfiguring geriatric care models to optimize care of people with HIV.[37]

Ongoing Health Crises Create Additional Stress for OPWH

COVID-19

Less than a quarter of respondents reported ever contracting COVID-19 and 85% were up to date on COVID-19 vaccinations.

Nearly half agreed that COVID-19 impacted the delivery of healthcare and other services. Some cited the loss of group counseling and support groups at local organizations. Others stated that COVID-19 contributed to feelings of isolation.

37% have had COVID-19

85% are up to date on COVID-19 vaccines

Fear of COVID Weakens but Impact of the Pandemic Remains

COVID-19 continues to have a detrimental impact on the lives of OPWH. For example, mental health challenges have been exacerbated by COVID-19, contributing to increased anxiety, stress, and social isolation in all ages of persons with HIV.[38]

Mpox

Less than one percent of respondents had contracted Mpox, but nearly one third was concerned about infection.

31% are concerned about contracting Mpox

.9% have already contracted Mpox

38% have received one or both vaccines

61% have not received any Mpox vaccines

40% of people diagnosed with Mpox also have HIV; those with poorly controlled HIV and/or low CD4 counts are more likely to be hospitalized with Mpox if acquired (CDC, 2022).[39]

Conclusion and Implications

Hammered by mounting obstacles — polypharmacy, multimorbidity, mental illness and increasing barriers to care — an emerging portrait of frustration and ire among OPWH is building.

Despite high rates of viral suppression and engagement in care, 94% of respondents agreed that more advocacy efforts are needed to address the needs of people aging with HIV. This reflects the increasingly complex reality of providing comprehensive care to OPWH. While medical providers are often adept at addressing HIV, there remains a significant need for enhanced training and medical education that prepares providers to develop interventions that address, not only the many comorbid conditions associated with aging with HIV, but also the pervasive and intersecting systemic barriers that face OPWH, including housing instability, gaps in social support and insurance coverage, and stigma.

The following implications represent crucial sites for future research, advocacy, and policy interventions to improve quality of life for people aging with HIV:

- **Building a competent workforce of HIV gerontologists** is crucial to address the multifaceted issues confronting PLWH as they grow older.
- **Efficient coordination of care between healthcare providers** is essential to ensure that OPWH receive the comprehensive support they need.
- **Addressing social determinants of health is fundamental to improve health outcomes** as health extends beyond the clinic setting.
- **Access to safe and stable housing** is needed as fixed incomes and housing emergencies escalate for OPWH.

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