



AGING WITH HIV: CARE CHALLENGES

AGING WITH HIV

The face of HIV is an aging one. Research and therapeutic advances have transformed HIV from a deadly disease to a chronic condition that can be effectively managed. Similar to how the prognosis for HIV has changed over the years, so has the standard of care since HIV first was identified.

In the early years of the HIV epidemic, it was not uncommon for patients to take multiple medications on a daily basis to treat their HIV—something that posed very real barriers to patients’ adherence to their treatment plans. Thanks to medical advances, the majority of people living with HIV (PLWH), including those served by the Ryan White HIV/AIDS Program, now receive more effective treatments with fewer side effects through the use of antiretroviral therapy (ART) medications (often one pill per day) and high-quality HIV care and support.

The Health Resources and Services Administration’s (HRSA) Ryan White HIV/AIDS Program has had a critical role in the United States’ public health response to HIV for more than 27 years. Program clients who were diagnosed with HIV earlier in the epidemic and who are now aged 50 and older have been living with and managing their HIV infection for decades. Other adults aged 50 and

➔ DIRECTOR’S NOTE

This edition of *HRSA CAREAction* addresses the evolving dynamic of providing care for older people living with HIV (PLWH).

HIV is now a chronic, manageable condition with many people living with—rather than dying from—the disease, thanks to advances in and access to HIV treatment and care. At the same time, people are living longer, and the face of HIV is aging. Many people aged 50 and older have been living with HIV for years, while others are being diagnosed with HIV later in life. Older patients must address not only their HIV-related health concerns, but also such age-related chronic diseases and co-occurring conditions as diabetes; cardiovascular, kidney, and liver diseases; cancer; dementia; and osteoporosis or bone loss.

For more than 27 years, the Ryan White HIV/AIDS Program has been providing HIV care and treatment to low-income PLWH who are uninsured and underserved, including racial/ethnic minority populations, youth, older adults, transgender individuals, and women. Ryan White HIV/AIDS Program providers have adapted their HIV care approaches to address the health challenges of older PLWH. Ryan White HIV/AIDS Program providers offer comprehensive and integrated primary care, specialized services, and a range of support services across the HIV care continuum that focus on patient needs, including screening and treatment for other chronic conditions and co-morbidities. This edition of *HRSA CAREAction* features “stories from the field,” or examples of how Ryan White HIV/AIDS Program recipients address issues related to HIV and aging.

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older may be newly infected or recently diagnosed. Aging and the prevalence of chronic diseases and comorbidities bring new health challenges for PLWH and complexities for health care providers. Ryan White HIV/AIDS Program providers are meeting these health challenges through a patient-centered care approach and a continuum of services.

Being Diagnosed With HIV in Later Years

People in the United States are living longer and many are being diagnosed with HIV later in life. According to the Centers for Disease Control and Prevention, approximately 45 percent of adults aged 50 and older had a diagnosis of HIV in 2015, including about 17 percent of new HIV diagnoses.¹

Older adults have the same risk factors for HIV transmission as younger people and may have a general lack of knowledge about HIV prevention. Many older adults are sexually active and may have multiple sex partners. Older adults, however, also face unique HIV prevention challenges:^{1,2}

- Older adults are less likely to discuss their sexual histories and HIV risk factors, such as drug use, with their health care providers. Likewise, health care providers may not feel comfortable talking to older patients about these issues.
- Older adults are less likely to undergo HIV testing than younger people. In fact, less than five percent of adults aged 50 to 64 have been tested for HIV; this number decreases as people grow older.
- Because they are less likely to be tested for HIV than younger adults, older adults are more to have late-stage HIV infection at the time of diagnosis and more immune system damage. A delayed diagnosis also means beginning treatment later than is recommended.
- Many older divorced and widowed adults are dating again for the first time in years. They may be less aware of their risks for becoming infected with HIV than younger people are, and, therefore, they may not realize that HIV transmission is a potential concern for them.

- Older women may be less likely to practice safe sex by using a condom, since they are not worried about becoming pregnant. At the same time, older women have a higher risk for HIV infection because of age-related vaginal tissue thinning and dryness.
- Older adults who deal with isolation because of illness or loss of family and friends also may experience HIV-related stigma. They may be afraid to reveal their HIV status or to seek HIV care.

Growing Older With HIV and the Ryan White HIV/AIDS Program

As with the general population of PLWH, the Ryan White HIV/AIDS Program client population is aging. Program recipients and providers are working with clients who reflect the evolving dynamic of aging with HIV. The Program's current age-related demographics show that—³

- PLWH aged 50 and older accounted for 44.4 percent of all Ryan White HIV/AIDS Program clients in 2016, compared to 31.6 percent in 2010.
- The majority, or approximately 72 percent, of Ryan White HIV/AIDS Program clients aged 50 and older are male. Approximately 28 percent of clients in this age group are female, and less than 1 percent are transgender.
- The majority of Ryan White HIV/AIDS Program clients (approximately 68 percent) aged 50 and older are from racial and ethnic minorities. Approximately 45 percent of clients in this age group are black/African American, which is slightly less than the national Program average of 47.1 percent. Approximately 20 percent of clients age 50 and older are Hispanic/Latino, slightly less than the national Program average of about 23 percent.
- Most Ryan White HIV/AIDS Program clients aged 50 and older are from lower income levels. Approximately 57 percent of clients in this age group live at or below 100 percent of the federal poverty level, which is less than the national Ryan White HIV/AIDS Program average of 62.8 percent.
- Approximately 4 percent of Ryan White HIV/AIDS Program clients aged 50 and older have unstable housing. This is slightly less than the national Program average of 5.2 percent.

- Approximately 90 percent of Ryan White HIV/AIDS Program clients aged 50 and older receiving HIV medical care are virally suppressed, which is greater than the national Program average of 84.9 percent.*

Meeting the Health Challenges of Older PLWH Through Patient-Centered Care

Ryan White HIV/AIDS Program providers offer integrated primary medical and non-medical support services delivered by dedicated health care professionals in community health centers, clinics, and other sites. Patient-centered HIV care is implemented by the Program through a team-based, comprehensive approach focused on patient engagement, treatment adherence, and retention in care. The Ryan White HIV/AIDS Program recipients provide core medical services and support services, including the following:

- AIDS Drug Assistance Programs and the AIDS pharmaceutical assistance programs that allow PLWH to gain access to treatment and U.S. Food and Drug Administration-approved medications.
- Health insurance premium and cost-sharing assistance programs to help PLWH obtain health insurance and manage their co-payments.
- Medical case management services, which greatly help PLWH to manage, follow through with, and adhere to their treatment plans.
- Access to food banks or food pantries, transportation to and from medical appointments, and emergency financial assistance.

Ryan White HIV/AIDS Program providers now are caring for HIV patients who are developing age-related chronic diseases and comorbidities, such as diabetes and cardiovascular disease. These diseases are common in the general population as people age; however, older PLWH have more diseases and comorbidities than do adults without HIV. PLWH aged 50 and older particularly are at risk for—^{4,5}

Cardiovascular disease (CVD), including high blood pressure: PLWH are at higher risk for coronary artery disease, hypertension, myocardial fibrosis, congestive

heart failure, and ischemic stroke. Replacing older ART medications with newer ones may help to reduce CVD risk.

Kidney disease: The risk of chronic kidney disease is increased in all PLWH and is known as HIV nephropathy. Older patients particularly are at risk for kidney disease as a result of declining kidney function with age; use of such medications as tenofovir; and comorbidity of such conditions as diabetes, CVD, and hypertension.

Liver disease: Older PLWH who are co-infected with hepatitis are at higher risk for liver-related complications, including hospitalizations for liver-related diseases, than are younger people living with HIV. Screening for hepatitis A, hepatitis B, and hepatitis C with appropriate vaccination is currently recommended.

Diabetes: The prevalence of type 2 diabetes is reported to be four times higher in PLWH than in adults not living with HIV. These high rates of diabetes may be related to the use of older ART medications, such as protease inhibitors, and increasing age. More than half of new cases of diabetes are in adults aged 45 to 64.⁶

Osteoporosis: PLWH have a higher risk of osteoporosis or bone loss and fractures than do adults not living with HIV. Substance misuse, especially of alcohol, is a comorbidity seen in PLWH and is a risk factor for osteoporosis. Certain ART medications (e.g., protease inhibitors and tenofovir) also contribute to bone loss.

Cancer: While rates of skin and lung cancers are higher in PLWH than in adults not living with HIV, the risk of all cancers among PLWH increases with age, as it does in the general population. Cancer screening is recommended for all adults aged 50 and older as part of general health maintenance, in addition to HIV-specific screenings.

Dementia and other neurocognitive disorders: While ART has dramatically reduced the prevalence of HIV-associated neurocognitive disorders (HAND), about 50 percent of PLWH have some impairment. With aging, the risk of dementia, Alzheimer's disease, and HAND increases. Providers may use such screening tools as the Montréal Cognitive Assessment to assess patients.

Depression: Some studies suggest that adults living with HIV have an increased risk for depression. Side effects of ART and other medications may worsen mood and daily functioning. Some older PLWH may be socially isolated and may not have a support system—either

* Viral suppression among PLWH who had at least one outpatient ambulatory medical care visit and one viral load test during the measurement year is defined as a viral load result of less than 200 copies/mL at the most recent test.

because of stigma or the presence of fewer friends and family members. Such tools as the Geriatric Depression Scale can be used to screen patients for depression.

Polypharmacy: The use of multiple medications (polypharmacy) is common among PLWH. Older PLWH may be taking medications for age-related conditions, as well as for HIV. Both kidney and liver function decrease with age, affecting the clearance of many medications from the body. Ryan White HIV/AIDS Program providers can reduce the risk of polypharmacy and adverse drug interactions by reviewing patients' medications during each medical visit, conferring with treatment team members, carefully selecting antiretroviral agents, and monitoring and adjusting medication doses.

Ryan White HIV/AIDS Program providers are at the forefront of screening their older HIV patients for comorbidities and potential adverse drug interactions and providing the necessary treatments and referrals to optimize their patients' medical care.

AIDS RESOURCE CENTER OF WISCONSIN

As part of providing comprehensive HIV care, the AIDS Resource Center of Wisconsin screens patients with HIV who are older than age 50 with validated tools to identify such neurocognitive or neuropsychiatric issues as depression, as well as substance use disorders. "We integrate screening for substance use disorders and depression during a patient's medical clinic visit," says Dr. Debra Endean, Vice President and Chief Operating Officer, and Dr. Kevin Roeder, Senior Director of Behavioral Services. "All patients are assigned a care team that includes a behavioral health provider—usually a psychotherapist—a mental health and drug/alcohol counselor, a social worker, and a case manager. Provider options are offered according to a patient's needs, and practitioners work with patients to develop coping strategies."

RYAN WHITE HIV/AIDS PROGRAM RECIPIENTS ADDRESS HIV AND AGING

Stories From the Field: Boston Public Health Commission, Ryan White Services Division

The Boston Public Health Commission (BPHC) receives Ryan White HIV/AIDS Program Part A funding and serves 5,200 HIV-positive individuals across seven counties in Massachusetts and three in southern New Hampshire. BPHC is well-established in the community, having been a Ryan White HIV/AIDS Program recipient for more than 27 years. The programs and services provided by the 32 agencies that receive BPHC grants vary. In addition to primary care, case management and psychosocial support are core components of the programs; however, services also may include drug assistance and cost sharing, medical transport, meals, medical nutrition therapy, oral health, and residential treatment for substance abuse.

Approximately 72 percent of the patients BPHC serves are older than age 45. According to Dennis Brophy, Director, Ryan White Services Division for BPHC, "We have a long history of addressing the HIV epidemic, and many our patients are long-term survivors." About 52 percent of BPHC's patients older than age 45 are accessing

medical case management services, and approximately 67 percent are accessing psychosocial support services. Mr. Brophy states that at least half of the 32 funded agencies provide psychosocial services to patients older than age 45, and at least two have HIV support groups geared toward long-term survivors. For example, the Justice Resource Institute's long-term survivor support group addresses issues related to aging, such as chronic diseases, medication changes due to effects of aging, stigma, special financial considerations, and relationships. Mr. Brophy notes that it is important for these support groups to be peer-led. He states, "We find that peer learning is important in terms of connecting people to care, being compassionate, and understanding unique concerns."

A key element in ensuring that BPHC meets the needs of patients is the Active Planning Council, whose members provide BPHC with formal feedback and guidance on the needs and concerns of the community. Council members are older themselves—at least 20 of the 30 members are older than age 50—and many have been involved with BPHC and the community for a long time. Mr. Brophy reports that the Council addresses such challenging issues as aging and housing, insurance coverage after retirement, financial issues, and the types of services that

BPHC should or should not provide. The Council helps ensure that long-term survivors are not forgotten. However, even with the extensive input of the Planning Council, Mr. Brophy says that BPHC could use more information on the needs of older patients. For example, they know that hepatitis C is underdiagnosed in baby boomers, but it not clear how that connects to HIV. Additionally, he explains that they know that 41 percent of new HIV diagnoses in 2016 were among people aged 40 to 75 years, but it is not clear how the effects of a later HIV diagnosis differs from one at a younger age.

Although there have been some clear measures of success, such as nearly 90 percent viral suppression among patients receiving BPHC services in the Boston eligible metropolitan area, BPHC is working with HRSA to improve quality and develop better measures. According to Mr. Brophy, “You can’t make progress without accurate measures and a good measurement system. How do we do that better? Are viral suppression rates different for those 45 plus?” By digging deeper into the data and obtaining more information on adults older than 45 living with HIV, BPHC will be able to continue expanding and improving services to older adults with HIV throughout Boston and the surrounding areas.

Stories From the Field: Missoula City/County Health Department Partnership Health Center

The Partnership Health Center (PHC) offers critical primary care, behavioral health, and dental services to residents of Missoula County, Montana. With Ryan White HIV/AIDS Program Part C funding, PHC serves a wide geographic area, covering 44,000 square miles, 16 counties, and two Native American reservations. The majority of PHC’s clients are Caucasian, but the center also services a smaller Native American and Eritrean refugee population.

More than 45 percent of PHC clients are older than age 50. In caring for this population, PHC has found that integrated care—with an emphasis on behavioral health and support services—is critical to success. Older adults living with HIV face a number of complex behavioral and emotional health challenges, including depression; feelings of guilt and isolation due to loss of support networks, including friends and family members; and substance misuse. The still-prevalent stigmatization of HIV also can take a toll on the emotional health of this population. “Some of our patients live in extremely rural communities, where the idea of HIV is still perceived as kind of a death sentence,” says PHC’s

Interim Medical Director, Dr. Katherine Krebsbach. “PHC not only provides on-site behavioral health services, but also links clients to support organizations that allow them to have quality of life and a support system that doesn’t stigmatize them.” The Center’s Director of Innovations, Mary Jane Nealon, explains the importance of behavioral health services for older patients in Montana. “There’s still quite a bit of stigma in Montana, not just around HIV, but also around same-sex relationships, and so it’s not uncommon for younger folks to leave the state and go to Seattle or San Francisco. A number of our older patients have come home either because their local networks have passed, their city community has changed, they feel they are sicker, or because of aging parents, so their need for behavioral health support is especially acute.”

In addition to integrated behavioral health care, PHC provides its older clients with comprehensive primary care that is both evidence-based and tailored to the specific needs of the aging population. “We are always looking at our patients with primary care glasses, rather than just from the perspective of HIV care,” says Dr. Amy Matheny, a PHC physician and faculty member at the Family Medicine Residency of Western Montana. This commitment to primary care for those older than age 50 entails screening for common comorbid conditions, such as diabetes, heart disease, cancer, chronic pain, neuropathy, and depression. What really sets PHC apart from other HIV care centers is the emphasis on continuing education for providers. Many trainings are related to caring for older adults with HIV and managing chronic illnesses and comorbid conditions. PHC providers teach medical students rotating through the center to manage chronic illnesses and comorbid conditions in older patients with HIV.

Stories From the Field: St. Mary’s Hospital and Medical Center

St. Mary’s Hospital and Medical Center provides a robust array of comprehensive medical care across all 22 counties of Western Colorado. Direct Ryan White HIV/AIDS Program Part C funding allows the medical center to offer core medical services to its 255 current clients, while a Part B subcontract provides the supplemental funding necessary to round out their client care with dental and behavioral health services.

In 2016, almost 55 percent of clients served at St. Mary’s were older than age 45. The medical center has evolved to focus on the many comorbid conditions that often

plague its older clients. According to Kristy Watkins, Program Coordinator, “HIV often falls to the bottom of the problem list.” To better serve this population, providers at St. Mary’s stay abreast of the latest guidelines for care for older adults, screening for common ailments associated with the aging population—including renal and heart failure, shingles, and high blood pressure. Additionally, because polypharmacy (the use of multiple medications) can cause issues for older clients, St. Mary’s has an in-house pharmacist who runs drug interaction reports onsite.

This evolution in St. Mary’s approach to care also has extended to how patient appointments are described. Appointments are no longer called “HIV visits,” as they were when the medical center opened in 2000; they are now simply called “routine care follow-ups.” Ms. Watkins states, “This is routine care, this is not just HIV care. We’re looking at the whole person, we’re looking at everything.” This small tonal shift not only signals the expansion of St. Mary’s approach to care, but also works to center attention on the client, rather than the disease.

Although St. Mary’s has enjoyed great success with its current model of care—viral suppression rates at the medical center are about 90 percent—the group still faces challenges, particularly with referring patients to specialists. Older patients often need referrals to specialists to properly manage their comorbidities, but long wait times for appointments can translate to inefficiencies in care. To overcome this obstacle, St. Mary’s collaborates with local clinics to ensure that their clients are able to see specialists in a timely manner and get the care they need.

Stories From the Field: New York City Department of Health and Mental Hygiene (NYC DOHMH) (Parts A, C and D)

Funded through Ryan White HIV/AIDS Program Part A, the New York City Department of Health and Mental Hygiene (NYC DOHMH) served 15,378 clients in 2016. Just over half of its clients are over the age of 50. Approximately 90 percent of patients are African American and Hispanic, and 64.1 percent are men.

The NYC DOHMH has found that social isolation and depression are common issues facing PLWH over age 50. “Many people don’t have a support network, which is such a crucial piece for instilling hope and energy to support your health,” said Graham Harriman,

Director, Care and Treatment, NYC DOHMH Bureau of HIV. Comorbid health conditions that are more common among these patients include chronic obstructive pulmonary disease—resulting from chronic smoking—and hepatitis C. Many clients who are long-term survivors and older than age 50 also have to manage such complications as kidney and cardiovascular diseases. Those who are newly diagnosed and older than age 50 are more likely to present with an AIDS diagnosis and have significant health challenges. These patients enter one of NYC DOHMH clinics’ comprehensive care programs to learn how to live with and manage their HIV.

The NYC DOHMH is engaged in several efforts to build more responsive and effective systems of care for their older clients who are either long-term survivors or newly diagnosed. Many of these patients utilize Ryan White HIV/AIDS Program-funded programs and services, such as the AIDS Drug Assistance Program, case management, mental health, housing services, and legal services. Many are likely to participate in the health department’s Positive Life Workshop program, which helps PLWH who struggle with treatment adherence or staying engaged in health care. Patients also access food and nutrition services and harm reduction programs.

The health department also is participating in several efforts to assess the needs of providers to improve care of their older patients. The health department conducted a resource inventory to determine how well Ryan White HIV/AIDS Program Part A-funded providers are able to address physical, sensory, and cognitive barriers to care for older patients. This provider survey found that 87 percent of Ryan White HIV/AIDS Program providers had at least one accommodation for patients with ambulatory difficulties, but one-third of the surveyed providers reported not having wheelchair-accessible walkways and/or restrooms. The health department convened the providers to discuss the survey findings and how they can improve care to their older patients, what better support services were needed, and what additional opportunities for learning can help them better serve their older patients.

NYC DOHMH is also interested in exploring and encouraging interventions designed to promote wellness and resilience in older PLWH. Research efforts are underway to better understand the factors that contribute to successful aging with HIV and to promote a culture of health and wellness—both within the New York City Department of Health and within many of its partnering agencies. The DOHMH strives to take a strength-based approach to serving the needs of its older patient

population living with HIV. “How can we promote wellness and connection and instill resilience, so more people can have the energy to strive for health and improve their health?” asks Mr. Harriman.

HIV TREATMENT GUIDELINES FOR OLDER ADULTS

To assist practitioners in providing care to their HIV patients, the U.S. Department of Health and Human Services developed recommendations for treating adults and adolescents with HIV infection in the United States. These Guidelines for the Use of Antiretroviral Agents and HIV-1 Infected Adults and Adolescents are based on current knowledge of ART and include special considerations for treating older PLWH.

Key considerations for providing care to older adults living with HIV include the following:⁷

- Early diagnosis of HIV and counseling to prevent secondary transmission of HIV remains an important aspect of the care of the older patient.
- Health care providers should include a sexual history assessment as a component of general health care and encourage HIV testing of patients at least once, and more frequently for those at risk.
- HIV experts, primary care providers, and other specialists should work together to optimize the medical care of older HIV-infected patients with complex comorbidities.
- ART is recommended for all patients, regardless of CD4 T lymphocyte cell count. ART is especially important for older patients because they have a greater risk of serious non-AIDS complications and potentially a blunted immunologic response to ART. The choice of drug regimens should be informed by a comprehensive review of the patient’s other medical conditions and medications.
- Adverse drug events from ART and concomitant drugs may occur more frequently in older HIV-

infected patients than in younger HIV-infected patients. Therefore, the bone, kidney, metabolic, cardiovascular, and liver health of older HIV-infected patients should be monitored closely. Changing medications may be necessary to reduce toxicities and drug-drug interactions.

- Polypharmacy, or taking many medications at same time, is common in older HIV patients, presenting a greater risk of drug-drug interactions between antiretroviral drugs and concomitant medications. The potential for drug-drug interactions should be assessed regularly, especially when starting or switching ART or other medications.

Premature Aging of the Immune System and HIV

Age-associated changes in the immune system often are referred to as immunosenescence. Decline in immune function occurs as people age. Premature aging of the immune system begins with immune activation, a short-term process that stops when wounds heal or when recovery from an infection is complete. After decades of exposure and response to a variety of infections, a tired immune system works harder but is less effective, causing a state of chronic inflammation.⁸

Researchers have linked chronic inflammation with age-associated conditions in the general population, including frailty, cardiovascular disease, bone loss, and cancer. Some chronic viral infections—such as Epstein-Barr, cytomegalovirus, and HIV—cause ongoing immune activation. In PLWH, immune activation and inflammation resulting in a too-strong or too-weak immune response and immunosenescence do not fully resolve with the use of ART. Research suggests that many of the T-cell abnormalities found in untreated HIV infection are similar to those found in aging. A recent study looking at epigenetic changes, or changes in gene function that do not involve changes in DNA sequence, showed that HIV infection prematurely ages PLWH by about five years. The researchers also found that these changes are linked to a higher risk of death, approximately 19 percent.⁹ Until further research can be applied to develop treatments that target epigenetic changes, PLWH aged 50 and older are encouraged to work with their providers to lower their risk for age-related conditions.

➔ ONLINE RESOURCES

HRSA Ryan White HIV/AIDS Programs

1. AIDS Education and Training Center—National Coordinating Resource Center: Adults Over 50
www.aidsetc.org/resource/hiv-among-people-aged-50-and-older-trainer-slides
2. Ryan White HIV/AIDS Program Annual Client-Level Data Report, 2016
hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2016.pdf

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