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The Aging of the Epidemic: Caring for Older People Living with HIV

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Introduction

Effective antiretroviral therapy (ART) has enabled people living with HIV (PLWH) to survive into their senior years and experience HIV as a chronic disease. The Centers for Disease Control and Prevention (CDC) surveillance report indicates 35% of older PLWH have both HIV infection and AIDS.¹ Nearly half (47%) of all PLWH in the United States are over 50 years of age and 17% of those newly diagnosed with HIV are in this age group.¹ Similarly, in New Jersey (NJ), 41% of all PLWH are 55 years of age or older and 7% of all new cases of HIV occurred in that age group in 2017.² Consequently, 70% of all PLWH will be over the age of 50 by 2030.¹ The epidemiological data highlights the need the complex interplay of HIV disease, the aging process, and multi-morbidity in order to provide clinical care for a large cohort of older people living with HIV.

Antiretroviral Therapy in Older PLWH

The U.S. Department of Health and Human Services (DHHS) guidelines for ART are the same for all adults.^{3,4} However, as PLWH age, they experience decreased immune and metabolic functioning that may result in lower CD4 cell counts, increased risk for opportunistic infections, and more difficulty achieving viral suppression.³⁻⁵ Older PLWH who need medications to treat co-occurring chronic conditions in addition to ART have an increased risk of polypharmacy, drug-drug interactions, drug toxicities, and non-adherence.^{6,7}

Clinicians should review the patient’s medication list at each visit to ensure it is complete, up to date, and most importantly, to screen for potential drug-drug interactions. Validated instruments such as the Beers Criteria, the Medication Appropriateness Index, or the Screening Tool of Older Person’s Prescriptions /Screening Tool to Alert doctors to Right Treatment (STOPP/START) can be used to identify medications that present a risk for adverse effects in the older adult.^{6,7} The Beers Criteria focuses on potentially inappropriate medications for older adults; the Medication Appropriateness Index determines the appropriateness of a particular medication, and the STOPP/START criteria focuses on inappropriate medication-disease combinations.⁶⁻⁸ The table below lists electronic resources clinicians can use to check drug-drug interactions.

Electronic Resources to Check for Drug Interactions	
Epocrates	www.epocrates.com
Lexi-Comp	www.lexi.com
Tarascon	www.tarascon.com
AETC National Coordinating Resource Centers’ Helpful HIV Medications for Pharmacists	https://aidsetc.org/resource/helpful-hiv-medication-tables-pharmacists
University of Liverpool’s HIV Drug Interaction Website	https://www.hiv-druginteractions.org
HIVinSite Database of Antiretroviral Drug Interactions (UCSF)	http://arv.ucsf.edu
DHHS Guidelines on the Use of Antiretroviral Medications	https://aidsinfo.nih.gov/drugs

Age associated changes such as reduced renal and hepatic function as well as physiological changes in the proportion of fat to lean muscle mass, body water content, and weight may require dose adjustments.⁶⁻⁸ For older PLWH who have renal insufficiency, the Cockcroft-Gault derived creatinine clearance calculation should be used to calculate the appropriate medication dose or frequency adjustments.⁶⁻⁸ Common medications prescribed for PLWH that require renal dose adjustment include acyclovir, fluconazole, gabapentin, H2-antagonists and most Nucleoside Reverse Transcriptase Inhibitors (NRTIs). Medications metabolized by the liver can accumulate in toxic levels in older PLWH who have hepatic dysfunction, therefore, the Child-Pugh score should be calculated to determine the appropriate medication dose.⁸ Medications that require dose adjustment based on hepatic function include abacavir, non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs).³

Multi-Morbid Conditions in PLWH

Multi-morbidity refers to the experience of living with several co-occurring chronic conditions.⁹ Among PLWH, multi-morbidity occurs earlier in the aging process and is more common compared to persons without HIV.¹⁰ This may be a result of chronic immune activation caused by HIV and

the consequences of long term ART.¹⁰ As a result, there is an increasing incidence of non-HIV defining chronic conditions such as cardiovascular disease, metabolic disorders, renal complications, and malignancies in older PLWH.⁹

Cardiovascular disease. Cardiovascular Disease (CVD) occurs more frequently in PLWH.¹¹ The risk of myocardial infarction (MI) is almost twice as high in PLWH compared to those without HIV, even accounting for arteriosclerotic factors.¹² Some HIV medications, chronic inflammation related to HIV infection, and tobacco use may account for the increased risk of MI in PLWH.¹³ The Framingham Risk Score and the American College of Cardiology/American Heart Association CVD risk tools do not include chronic immune inflammation as a variable and thus underestimate cardiac risk in PLWH.¹⁴ Patients should be counseled about tobacco cessation, diet, and maintaining a healthy weight to reduce CVD risks. Clinical management of CVD is the same for PLWH as that for persons without HIV, however, clinicians should be mindful of potential drug-drug interactions with these medications and ART.

Diabetes. Similar to CVD, HIV medications, chronic inflammation, and coinfection with hepatitis C (HCV) are associated with higher rates of diabetes in PLWH.¹⁵⁻¹⁷ Clinicians should screen PLWH for diabetes using hemoglobin A1C (HbA1C) at least yearly, as well as before and after initiation of ART.¹⁵ For PLWH



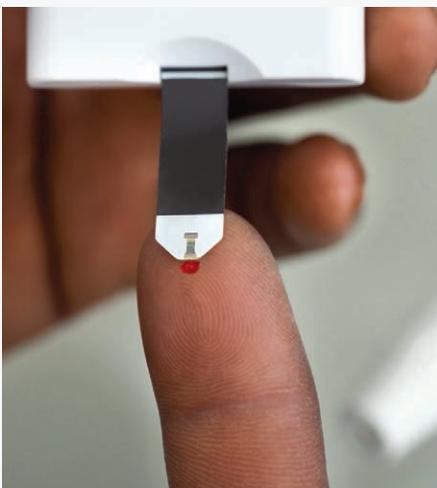
who have diabetes, HbA1C should be checked at least twice a year.¹⁵ Treatment guidelines established by the American Diabetes Association include a HbA1C goal of 6.5%.¹⁵ In contrast, the American Academy of HIV Medicine recommends increasing the HbA1C goal to 8% for older PLWH who have diabetes and are frail, have a life expectancy of less than 5 years, and are at high risk for hypoglycemia, polypharmacy, or drug interactions.¹⁵ However, screening for diabetes with fasting blood glucose (FBG) may be more appropriate in PLWH on NRTI or PI therapy because these medications lower HbA1C.¹⁸

Lipodystrophy. PLWH may experience central fat obesity (lipohypertrophy), related to aging and/or use of older ART medications.¹⁵ Clinicians should counsel older PLWH to maintain the recommended BMI. If central fat obesity is related to ART, clinicians can recommend a change in ART, surgical removal of fat, or prescribe growth hormone analogues.¹⁵

Renal Disease. Kidney function declines with age, and older PLWH are at increased risk of renal disease because of ART toxicity (in particular indinavir, atazanavir, and tenofovir disoproxil

fumarate) and the increased prevalence of diabetes and hypertension.²⁰ PLWH who are female, African American, or have an AIDS defining disease are at increased risk of HIV-related nephropathy compared to other HIV-infected groups.²¹ Proteinuria may be overlooked as an indication of HIV infection in older adults because it also occurs in heart failure and diabetes mellitus.²¹

ART preserves kidney function in PLWH who have HIV related nephropathy, although there is evidence that some PIs (indinavir and atazanavir) are associated with crystal-induced obstruction. TDF should be avoided due to renal toxicity in individuals with chronic kidney disease (CKD) and GFR <50 mL/min/1.732.²¹ In the case of HIV and hypertension, evidence of decreasing eGFR indicates the need for aggressive management in order to minimize the risk of MI.²¹ Use of angiotensin converting enzyme inhibitors or receptor blockers should be considered for those with CKD and evidence of proteinuria or who are in need of an anti-hypertensive.²² Limiting nephrotoxic drugs (such as non-steroidal anti-inflammatory medications [NSAIDs]) is recommended.²² Reduced renal function alters drug clearance and increases the risk for nephrotoxicity, drug-drug



interactions, and adverse drug effects. At minimum, clinicians should screen PLWH for changes in renal function with a urinalysis and an eGFR at least twice a year.²¹

Cancer. Lung cancer prevalence is increasing among PLWH while AIDS-defining cancers such as Kaposi's sarcoma, non-Hodgkin's lymphoma, and cervical cancer have decreased.²³ PLWH are at increased risk of developing non-AIDS defining cancers (NADC) related to anal, cervical, vaginal, penile, nasopharyngeal, laryngeal, and oral infections; liver cancer from hepatitis and nasopharyngeal cancer and Hodgkin's lymphoma related to Epstein-Barr Virus.²⁴ PLWH are also at risk for tobacco-related NADC such as non-melanoma skin cancer and other head or neck cancers; screening for tobacco use and assisting current users with cessation can modify risks associated with these conditions.²⁴ Rates of breast and prostate cancer in PLWH are comparable to persons without HIV.

Cancer screening is the same for PLWH and those who do not have HIV, with two notable exceptions: cervical and anal cancer screening. Cervical cancer screening for women with HIV should continue after age 65 and the screening interval with cytology and human papilloma virus (HPV) co-testing is 3 years due to increased risk of HPV-related cancer.²⁴ Anal cancer associated with HPV is significantly more prevalent in PLWH, therefore an annual rectal exam is recommended for both men and women living with HIV.²⁴ Cytology screening with an anal Pap smear has also been recommended by some experts.²⁴ It is recommended that clinicians consider the functional status and life expectancy of the older PLWH when using the current cancer screening guidelines.²⁴

Osteoporosis. Experts recommend screening for and treatment of osteoporosis because many older PLWH experience accelerated bone loss

and are at increased risk of Vitamin D deficiency as well as other debilitating bone diseases such as avascular necrosis of weight-bearing joints.^{25, 26} Women living with HIV experience menopause at an earlier age and men living with HIV experience androgen deficiencies; both conditions contribute to increased risk for osteoporosis. ART, specifically TDF and some PIs, may also increase risk for osteoporosis.²⁷ Smoking, a sedentary lifestyle, and poor nutritional status are also risk factors for osteoporosis.

Older PLWH who have osteoporosis are at increased risk of fragility fractures. Clinicians should use the Fracture Risk Assessment Tool (FRAX) for all PLWH who are 40-49 years of age, and dual energy x-ray absorptiometry (DXA) in men over 50, postmenopausal women living with HIV, and PLWH who have a history of fragility fracture, are on chronic glucocorticoid treatment, and those at high risk for falls.^{27, 28} Treatment for osteoporosis includes avoiding the use of TDF and PIs, adding bisphosphonate therapy, optimizing calcium and vitamin D intake, limiting or reducing alcohol and tobacco, and incorporation of weight bearing exercise.²⁸

HIV-Associated Neurocognitive Disorder. HIV-associated neurocognitive disorder (HAND) ranges from mild neurocognitive deficits to HIV-associated dementia.²⁹ More than half of older PLWH experience some level of neurocognitive impairment.²⁹ Older PLWH at risk for HAND are those with a history of central nervous system (CNS) disease, a low nadir CD4 cell count, detectable HIV viral load, and a low CD4 cell count.²⁹ Diabetes, hypertension, HCV, medication toxicities, and substance use disorders contribute to poor neuropsychological performance.²⁹ Clinicians need to consider Alzheimer's disease and the impact of cerebrovascular disease when evaluating the cognitive functioning of PLWH.²⁹ HAND can result in poor ART adherence, worsening depression, and earlier mortality.³⁰

Several screening tools exist for cognitive deficits but may miss more subtle presentations of HAND and may not be applicable across all cultures. The Montreal Cognitive Assessment (MoCA) is recommended for initial screening.³¹ The HIV Dementia Scale and the International HIV Dementia Scale are validated screening tools; however, some studies indicate that they do not reliably identify more subtle forms of cognitive impairment.²⁹ The Mini-Mental State Exam does not assess cognitive functioning impaired by HAND and therefore is not recommended.²⁹

Treatment options for HAND include ART (for those not already on ART) and addressing reversible underlying causes, such as thyroid disease or vitamin B12 deficiency.²⁹ Encouraging older PLWH to remain socially engaged, get regular exercise, and monitoring for depression and cerebrovascular risk factors are additional strategies to prevent or delay HAND.²⁹

Frailty and Physical Functioning. Decreased mobility and physical function in older PLWH is associated with depression, multi-morbidity, neurocognitive impairment, and low CD4+ cell count.³² Presence of functional decline and frailty is almost twice as common in PLWH compared to non-HIV populations.³³ Clinicians can assess functioning using a combination of patient self-report and in-office performance tests. The review of history for the older PLWH should include questions about performing daily tasks, driving, managing money, taking medications, and any falls or injuries.^{32, 33}

The Short Physical Performance Battery (SPPB) developed by the National Institute on Aging provides a composite assessment of balance, walking speed, and ability to stand from a sitting position.³⁴ Low SPPB scores predict risk for falls, impaired mobility, declines in physical performance, and mortality. If mobility or physical functional deficits are identified, evaluate

the patient's socioenvironmental condition and mental status. Social isolation, decreased physical activity, poor diet, multi-morbidity, depression, and ART non-adherence contribute to physical decline.³⁴ Provide older PLWH with education about aerobic and weight bearing exercises to increase muscle mass, strength, flexibility, and balance.³⁴

Peripheral Neuropathy. The prevalence of peripheral neuropathy (PN) in PLWH is 30% to 62%.³⁵ HIV medications, specifically older NRTIs and PIs have been linked to PN.^{37,38} Some evidence implicates gp120 mediated neuronal apoptosis mitochondrial toxicity as a contributing factor.³⁹ Diabetes, HCV co-infection, low CD4 nadir, advanced HIV disease, and substance abuse increase the likelihood of developing PN.⁴⁰⁻⁴³ Diagnosis of PN is based on subjective symptoms and clinical examination findings. Two available screening tools are the Brief Peripheral Neuropathy Screen and the Subjective Peripheral Neuropathy Screen.^{44, 45}

Distal sensory polyneuropathy (DSP) is the most common form of PN in PLWH.⁴⁶ DSP symptoms include impaired sensation and/or paresthesia in a stocking/glove distribution and sluggish or absent Achilles tendon reflex.⁴⁷ DSP in PLWH has been associated with reduced quality of life, impaired lower extremity function, sleep disturbances, and limited ambulation.^{48,49}

Treatment of PN addresses causes as well as symptoms. To treat causes of PN, clinicians can avoid prescribing neurotoxic medications, correct vitamin B6 (with caution, overdosing can cause PN), B12, and folate deficiencies, and consider thiamine replacement if the patient is malnourished.⁵⁰ OTC pain medications or NSAIDs can help relieve mild symptoms. For more severe neuropathic pain, gabapentin or pregabalin are often prescribed.⁵¹ Additional agents include capsaicin cream or lidocaine patches, and anti-depressant drugs.⁵²

TENS, manual therapy, stretching exercises, yoga, and use of night splints can also help manage PN pain.^{53,54} Self-care strategies include avoiding extended periods of standing or walking, soaking feet in warm or cold water, or use of contrast baths.

Chronic Pain. The prevalence of chronic pain in PLWH ranges from 54-83%.⁵⁵ Chronic pain in PLWH can lead to impaired physical functioning, disability, depression, and adversely affect adherence to ART.⁵⁶⁻⁵⁹ The etiology is often multifactorial and can include direct effects of HIV infection, chronic systemic inflammation and immune responses, side-effects of medications, co-morbidities such as musculoskeletal disorders and PN, opportunistic infections, and psychosocial influences.⁶⁰⁻⁶² A small number of randomized controlled trials suggest that patient education, cognitive behavioral therapy, and exercise can help reduce pain ratings in PLWH.⁶³⁻⁶⁶





Mental Health in Older PLWH.

Depression, loneliness, anxiety, and chronic stress is higher in older PLWH compared to older adults without HIV, regardless of race, ethnicity, gender, or sexual orientation.⁶⁷ Lack of mental health treatment in older PLWH contributes to cognitive deficits. Untreated mental illness is a risk factor for HIV and non-adherence to ART.

Depression. The risk for depression increases in older PLWH as HIV symptom burden increases.⁶⁷ Newly infected older adults may develop depression because of isolation

from supportive networks related to the dual stigma of HIV and ageism. Early onset of HAND in older PLWH may present as depression.⁶⁷ Untreated depression is a predictor of non-adherence to ART. In addition, older PLWH who experience depression may self-medicate with illegal substances, tobacco, or alcohol to relieve their symptoms, increasing the potential for non-adherence to ART and contributing to poorer health outcomes.⁶⁷

Older PLWH should be screened for depressive disorder with the Geriatric Depression Scale and may be treated with the same medications that would be indicated for younger PLWH. Drug-drug interactions should be considered when prescribing antidepressants; medications with minimal effects on the CYP 450 isoenzyme system are preferred.⁶⁷

Anxiety Disorders. Anxiety Disorder in older adults may result from the diagnosis of HIV.⁶⁸ Post traumatic stress disorder is also diagnosed at higher rates in PLWH.⁶⁸ Uncertainty about health and resources as PLWH age can further contribute to anxiety. Similar to depressive symptoms, anxiety disorders are associated with non-adherence to ART. Clinicians should prescribe SSRIs instead of benzodiazepines for the treatment of anxiety disorders in older PLWH.⁶⁸ Stress management, guided imagery, progressive muscular relaxation training, self-hypnosis, biofeedback, and other behavioral modalities are effective in treating anxiety.⁶⁸

Substance Use Disorders.

Substance use disorders, including alcohol abuse, are higher in older PLWH compared to the general population.⁶⁹ The impact of substance use includes poor adherence to ART, cognitive impairment, and risk of HIV transmission through sexual or injection drug use behaviors.⁷⁰ Clinicians can screen for substance use with standardized tools such as AUDIT-C.⁷⁰ Patients who screen positive

should be referred for treatment with a mental health or substance abuse specialist.⁷¹ Information about substance abuse treatment in NJ is available in *NJ HIVLinks* Winter 2018 edition. <http://www.fxbcenter.org/downloads/AIDSLINE/HIVLinks-Winter2018.pdf>

Prevention and Health Maintenance in Older PLWH

Sexual Health. Sexual health is integral to quality of life for older adults, yet many clinicians do not address sexual health during medical visits. Mobility, mood disorders, medication side effects, history of sexual abuse, HIV-related stigma, complications from other chronic illnesses, and physiological changes affect sexual health.⁷² A further hindrance to sexual health assessment is reluctance on the part of older PLWH to discuss sexual issues with clinicians. This reluctance puts older PLWH at risk for acquiring and transmitting HIV as well as other sexually transmitted diseases.

Incorporating sexual health screening and counseling, including tailored prevention messages, as part of the overall assessment of older PLWH normalizes discussions about sex.^{72,73} Sexual health screening is an opportunity to address barriers to sexuality in older adults; treating erectile dysfunction or vaginal dryness can be linked to specific education about safer sexual practices to prevent transmission.

Undetectable equals Untransmittable or U=U is a prevention intervention based on research that indicates there is no risk of sexual transmission from PLWH who are undetectable (HIV viral load of <200 copies/ml).⁷⁴ Pre-exposure prophylaxis (PrEP) is another prevention intervention to reduce the risk of HIV infection. Currently, only TDF/FTC is approved for PrEP.⁷⁵ Clinicians need to consider the effect of TDF/FTC on renal function and bone mineral density when prescribing PrEP for older PLWH. Guidelines recommend that clinicians monitor renal function in patients on PrEP every 3-6 months. Guidelines are not established for the frequency of bone mineral density screening. U=U, PrEP, and sexual health screening, refer to *NJ HIVLinks* at: <http://fxbcenter.org/downloads/AIDSLINE/HIVLinks-Spring2018.pdf>.

Immunizations. Vaccine preventable illnesses occur with greater frequency and are more severe in older PLWH.⁷⁶ Although live-attenuated organism vaccines are generally contraindicated for PLWH, clinicians can administer mumps, measles and rubella (MMR) and varicella vaccines in PLWH whose CD4 count is greater than 200/mm.³ The Table of Recommended Vaccines for Older PLWH outlines recommendations from the CDC and American College of Immunization Practice.

Table of Recommended Vaccines for Older Adults

Vaccine	Dosing Considerations	
Influenza	Administer inactivated, adjuvant inactivated, or high-dose inactivated influenza annually. Live attenuated influenza is not recommended.	
Tdap/Td	One dose of Tdap if not previously vaccinated, then Td every 10 years	
Hepatitis A	Havrix®: initial dose, then the 2nd dose at 6 to 12 months Vaqta®: initial dose, then 6 to 18 months for the 2nd dose Twinrix® (hepatitis A-hepatitis B): 1st dose in 1 month, 3rd dose in 6 months.	
Hepatitis B	Single-antigen hepatitis B vaccine or combined hepatitis A and B vaccine (Twinrix®): initial dose, 2nd dose 1 month later, 3rd dose 6 months later.	
Meningitis	2 doses of serogroup A, C, W, and Y meningococcal vaccine (MenACWY®) 2 months apart; revaccinate every 5 years. Serogroup B meningococcal vaccine (MenB®) is not recommended.	
MMR	Two doses if born after 1957 and/or CD4+ count >200 cells/ml (if not previously vaccinated) DO NOT administer if CD4+ count <200 cells/mL	
Varicella	Two doses if CD4+ count >200 cells/mL. DO NOT administer if CD4+ count is <200 cells/mL	
Zoster	Do not be use if CD4+ counts <200 cell/mL. Consider the recombinant zoster vaccine (Shingrix® or RZV) for PLWH 60 years of age or older with CD4+ counts >200 cells/mL.	
PCV13 & PPSV23	Under 65 years	65 years or older
	PCV13 x 1 dose followed by PPSV23 at least 8 weeks after. Revaccinate with PPSV23 after 5 years (max two doses of PPSV23 under the age of 65). Administer final dose after age 65. Final dose should be at least 6 years after dose #2. Total of 3 lifetime doses of PPSV23.	If not previously vaccinated: ▪ Give 1 dose PCV13 followed by PPSV23 at least 8 weeks after. ▪ If PPSV23 is administered first, wait at least 1 year before administering PCV13.

Smoking Cessation. COPD, atherosclerosis, osteopenia, periodontal disease, and human papillomavirus infections are higher in PLWH who smoke.⁷⁷ Approaches to smoking cessation include behavior modification, motivational interviewing, group therapy, and nicotine replacement. Clinicians should assess tobacco use at each medical visit and counsel older PLWH to stop smoking; pharmacotherapy can be offered.

On-Line Support for Smoking Cessation	
NJ Quitline	http://njquitline.org/
NJ Department of Health Tobacco Control	https://www.nj.gov/health/fhs/tobacco/quitting/
National Institute of Health's Smokefree 60+	https://60plus.smokefree.gov/

Advanced Directives. Older PLWH may not want their closest blood relative or other default surrogate decision maker, based on state law, to make important medical decisions for them. Clinicians should discuss advanced directives with older PLWH, particularly those with heavy disease burden, who exhibit functional debilitation, frailty, have a limited lifespan, or are beginning to show signs of cognitive impairment.⁷⁸

Conclusion

As the number of older PLWH increases, clinicians will need to address the intertwined complexity of aging, HIV infection, and multi-morbidity. Considering the need for medications to manage multi-morbid conditions in PLWH, vigilance is needed when prescribing medications, including ART, to prevent polypharmacy, adverse effects, and drug-drug interactions. Primary care assessments for older PLWH should address cognitive status, physical functioning, sexual health, mental health and immunizations in addition to treatment for chronic conditions and HIV infection. Encouraging self-management activities such as ART adherence, exercise, healthy diet, and smoking cessation can improve the quality of life for older PLWH. In addition, active screening programs to detect HIV in older adults are needed along with the implementation of strategies to prevent transmission of HIV in older adults. ❖

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The Impact of Menopause on the Sexual Health of Older Women Living with HIV

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Introduction

Often, healthcare professionals do not talk to older adults about their sexual health and this is a missed opportunity for HIV testing and prevention. Research indicates that only 68% of healthcare professionals discuss risk factors related to HIV with patients who are 59 years of age or older.¹ In one community sample of 101 older adults (70% women), 90% of participants reported that their health care providers never discussed HIV or other sexually transmitted diseases (STD) with them.² Rates of HIV testing in the population indicate that only 10–15% of people aged 45–64 years are tested and some studies report that as few as 3% of older adults receive a recommendation for HIV testing.^{2,3} Often, older adults are tested later in the course of HIV and as a result, they are more likely to have opportunistic infections, progress more rapidly to AIDS, or die within a year of HIV diagnosis.⁴ According to the Centers for Disease Control and Prevention (CDC), nearly half of the people in the United States living with HIV are aged 50 and older.⁵ Although new HIV diagnoses are declining among people aged 50 and older, in 2016, approximately 1 in 6 new HIV diagnoses occurred in people 50 years of age or older.⁵

There are several reasons for the prevalence of HIV and rate of new infections among older adults. An estimated 80% of 50–90 year old adults are sexually active.⁶ Results of studies about sexuality in people living with HIV (PLWH) 50 years of age and older showed that about 41% of sexually active PLWH reported engaging in unprotected anal or vaginal sex and condom use rates were lowest

Approximately 68% of doctors rarely or never discuss risk factors related to HIV/AIDS in patients over 59 years of age.



among gay and bi-sexual males compared to heterosexuals.^{7–10} In addition, older women living with HIV (WLWH) are at a higher risk of STDs because of vaginal atrophy associated with aging.^{7–10} Health care professionals do not believe that older adults, especially older adults with HIV, are sexually active.⁶ As a result of this misperception, they fail to engage older adults in a conversation about sexual health and the need for safe sex practices, which has consequences including the risk of HIV transmission.¹¹

Sexuality is an important factor in the quality of life for older women, including WLWH. Sexuality and sexual activity make women feel desirable and attractive and increases a woman's sense of self-worth in a society that equates beauty with youth. We are all familiar with many of the myths that exist about sexuality and older women. Some of the common myths are that sexual desire decreases with age, older women lose interest in sex, all older adults are heterosexual,

and only young people have sexual intercourse.⁶ Although the frequency of intercourse decreases with age, sexuality remains important for older women; many older women actually have a higher sex drive compared to when they were younger.⁶ Research studies confirm that sexual intercourse is enjoyed by older women into their 80's, 90's and beyond.⁶ This article discusses the impact of menopause on the sexual health of older WLWH.

Age-Related Changes in Female Sexuality

Multiple factors may affect sexual response in older women. Hormonal changes associated with menopause can lead to dyspareunia because of decreased elasticity and lubrication of the vaginal walls and increased fragility of the vaginal mucosa.¹² One-third of sexually active women over 65 years old complain of painful intercourse.¹³ Testosterone influences female sexual behavior; low levels lead to impaired

sexual desire, arousal, responsiveness, decreased genital sensation, and reduced ability to achieve orgasm.¹⁴ The following changes occur in the stages of sexual response in older women:

Excitement: Older women need more time to become sexually aroused. The clitoris may require longer direct stimulation. There is decreased genital engorgement and reduced vaginal lubrication.

Plateau: There is decreased expansion of the vagina. During sexual arousal, there is increased blood flow to the genitalia, resulting in vasocongestion.

Orgasm: Although women can still achieve multiple orgasms, they may experience fewer and weaker contractions and occasional spastic and painful uterine contractions.

Resolution: After sexual intercourse is completed, women return to the pre-aroused stage faster than they would at an earlier age due to rapid loss of vasocongestion.¹⁴

Pathophysiologic Changes that Affect Female Sexuality in all Women:

- HIV
- Diabetes
- Stroke
- Arthritis
- Surgeries that affect body image and diminish self-esteem (e.g. mastectomy, ostomies)
- Neurological disorders (e.g., Spinal cord injuries, or diseases of the central or peripheral nervous system)
- Effects of alcohol or recreational drugs
- Female urinary incontinence
- Cardiovascular disease¹⁴



Menopause

The World Health Organization (WHO) defines menopause as the self-reported cessation of menstruation for 12 months. The average age for natural menopause in the US is 51 years.¹⁶ Menopause does not require an evaluation of reproductive hormonal levels by a healthcare provider, which may be problematic for WLWH, who may have difficulty distinguishing between symptoms of menopause and symptoms of HIV.¹⁵ Menopausal symptoms, such as irregular menstrual cycles, anovulation, amenorrhea, decreased sexual interest, responsiveness, and increased urogenital symptoms are experienced by 85% of all menopausal women; these are also common symptoms experienced by WLWH.¹³

WLWH may have a lower average age of menopause and are at higher risk of developing early and premature menopause.^{16,17,18} The term early menopause refers to the occurrence of menopause between 40 and 45 years, and premature menopause as occurring before the age of 40. Early or premature menopause has important clinical implications. They are linked to alterations in mood and sexual function, decline in quality of life, development of comorbidities

such as cardiovascular disease, osteoporosis, and fragility fractures, which are associated with earlier mortality.⁷ Therefore, it is important for the provider to evaluate the older WLWH for these conditions, assess if she needs hormonal therapy, and offer counseling about the symptoms and effects of possible co-morbidities.^{7, 8}

The Effect of Menopause on HIV

WLWH experience particular challenges during menopause. They have difficulty distinguishing menopausal symptoms from HIV-related symptoms, accessing appropriate menopause care, and managing the impact of menopausal symptoms on HIV self-care, including adherence to antiretroviral therapy (ART). Barriers to intimacy that WLWH experience include the negative impact of HIV stigma on intimate partner relationships, body image concerns, and the dilemma of HIV disclosure.¹⁹ Research has provided some insight into how HIV infections affect menopause in older WLWH:

Estrogen Deficiency. Studies have not provided evidence of estrogen deficiency (i.e., menopausal state), affecting CD4 count or response to ART.²⁰ In addition, there is no evidence of

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differences in the percentage of pre- and postmenopausal WLWH achieving plasma HIV RNA viral loads <50 copies/mL.²⁰

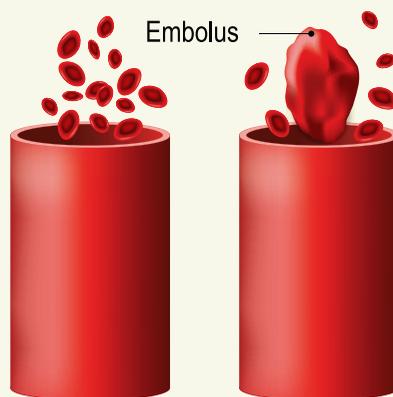
Libido. Libido depends on testosterone, even in women, rather than estrogen. Hormone replacement therapy (HRT) can improve vaginal lubrication and a sense of well-being but has little effect on libido. Ovaries and adrenals are the main sources of androgens in women. Older WLWH have significantly lower sexual functioning, diminished interest in sexual activity, sexual satisfaction, and fewer orgasms.²¹ Regardless of HIV status, lower sexual function is associated with menopausal status, depression, and not having a partner.²² Research about the effects of changing sexual desires and sexual health on the needs of older WLWH is needed.

Dyspareunia in WLWH. Dyspareunia is another problem experienced by older WLWH. Results of a cross-sectional study with 178 HIV-negative and 128 HIV-positive women aged 40–60 years found that 41% of the sample who were WLWH reported dyspareunia compared with 34.8% of the HIV-negative women ($p=0.242$).²³ Dyspareunia was associated principally with vaginal dryness and urinary incontinence in the WLWH group.²³

Symptomatology. The data on menopause symptomatology in WLWH are mixed. A comparison between HIV-positive and HIV-negative women in the US found no difference in the prevalence of hot flashes or vaginal dryness between the two groups.²⁴ WLWH who experience night sweats may be misdiagnosed as experiencing menopause-related hot flashes; however, the night sweats may be the result of HIV. Vaginal dryness may be mistaken for a yeast infection.²⁵ Women should be advised to keep track of menstrual cycles and report any changes to their primary care provider.²⁵



Cardiovascular Disease. Cardiovascular disease (CVD) rates are higher in WLWH compared to women who are not infected with HIV; however, there are no randomized controlled studies that compare CVD outcomes in menopausal WLWH with HIV-negative women.²⁶ Recent studies suggest that ongoing activation of the immune system and inflammation in PLWH may contribute to the development of plaque in blood vessels, which is known to increase the risk of heart attacks and strokes.²⁷



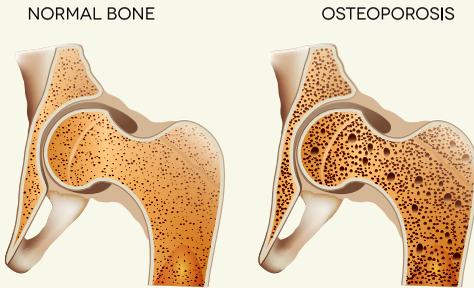
Venous thromboembolism. HIV infection is associated with a 2 to 10-fold increased risk of venous thromboembolism (VTE) related to acquired protein S and C deficiency, low CD4 count, and opportunistic infections.^{28, 29} No data exists on VTE risk in women with well-controlled HIV disease on ART, or on the risk of VTE in WLWH on menopausal hormonal treatment. Transdermal estrogen preparations have a lower risk of VTE compared to oral preparations and are preferable in WLWH.³⁰

ART Drug distribution. There is limited research about the effects of ART on menopause in older WLWH. Two small studies showed no difference in plasma levels of tenofovir and raltegravir between pre- and post-menopausal women.³¹ Alterations in drug pharmacokinetics that occur as a consequence of aging result in changes in volume distribution and renal and hepatic clearance of ART.³¹

ART and Hormone Replacement Therapy (HRT). HRT has clearly demonstrated a positive effect on vasomotor symptoms and bone health.³² There is little data about the safety of HRT and interactions with ART. Some practitioners are reluctant to provide HRT to WLWH for fear of worsening their HIV disease, or concerns regarding toxicity, increased pill burden, or drug-drug interactions with ART.³² Data exist about the interactions between hormonal contraceptives and ART. Because of pharmacokinetic interactions between HRT and HIV protease inhibitors, cobicistat, and non-nucleoside reverse transcriptase inhibitors on the shared cytochrome P450 pathway, there are reduced levels of estrogens, which may require dose adjustment of HRT.³²

Bone mineral density (BMD). HIV infection contributes to bone loss.^{33,34} A meta-analysis showed that HIV infection is associated with a 6.4-fold increased risk of osteopenia and low BMD and a 3-fold increased risk of osteoporosis.³⁵ Certain antiretroviral medications are implicated in changes in BMD and the initiation of ART may be associated with a reduction in BMD in the first few years of use; however, BMD stabilizes the long term.³⁶ Medications such as tenofovir disoproxil fumarate have demonstrated a negative effect on BMD, but data conflicts about the effect of tenofovir on the risk of fracture. The new tenofovir prodrug, tenofovir alafenamide, has little impact on bone density and is associated with recovery of previously lost BMD.³⁷ Risk factors such as cigarette smoking, alcohol use,

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African-American or Hispanic ethnicity, decreased body mass index, vitamin D deficiency, chronic steroid use, amenorrhea, and hypogonadism are more common in WLWH and contribute to low BMD.³⁷ Many aspects of the relationship between HIV and Low BMD are unclear; for example, researchers have not been able to determine the extent to which low BMD in HIV is explained by low body weight and smoking.³⁸

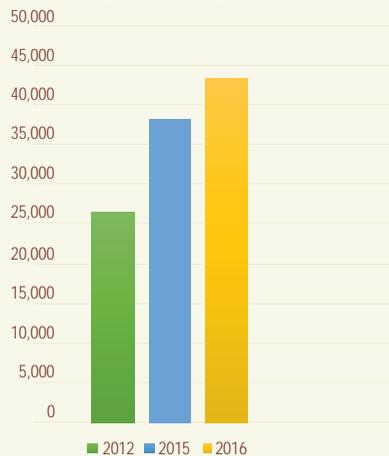
Mental health and menopause.

Anxiety, low mood, and clinical depression may occur at any stage during menopause. Depressive symptoms are increased two to four-fold during perimenopause.³⁹ A study conducted by Maki et. al., found no significant difference in the occurrence of depression between HIV-negative women and WLWH during menopause.⁴⁰ Among the HIV-positive cohort, lower CD4 count was associated with depression, whereas ART adherence was associated with a lower rate of depression.⁴¹ The lack of information concerning past mental health history was a limitation of the study according to the authors. This is important because the prevalence of depression among PLWH is higher than the rates of depression in the general population.⁴¹

Sexually Transmitted Diseases.

Those responsible for HIV education and prevention messages have neglected older women, thus they know less about the risk of transmission and infection compared with younger women.¹³ Regardless of HIV status, older women are less likely to talk about their sex lives with their health-care providers compared to younger women and providers frequently do not ask older patients about sex.¹ In addition, older women often mistake the symptoms of HIV for the aches and pains of normal aging and are less likely to get tested.⁵ According to the CDC, STD surveillance rates, there was a 20% increase in STDs among older adults between 2015 and 2016.⁴²

Chlamydia among people 45 years of age and older



There were 43,409 reported cases of chlamydia among people 45 years of age and older in 2016, up from 38,185 reported cases in 2015 and 26,405 in 2012.

Gonorrhea among people 45 years of age and older



There were 33,879 reported cases of gonorrhea in 2016 among people 45 years of age and older, up from 26,005 in 2015 and 16,257 in 2012.

Primary and Secondary Syphilis among people 45 years of age and older



There were 5,650 cases of primary and secondary syphilis were reported in the 45 years of age and older cohort; up from 4,848 in 2015 and 3,176 in 2012.⁴²

Sexual Health Assessment

The need to include sexual health content in healthcare provider training is clear. Healthcare providers are inconsistent in their ability or willingness to conduct a sexual history assessment and this may be related to inadequate training. In one study, geriatric fellows reported that barriers to developing sexual health taking skills included the need to develop other competing competencies, lack of educational materials, and discomfort with this topic.⁴³

Sexuality Assessment: The PLISSIT tool provides an effective evidence-based sexual assessment guide. PLISSIT is not a diagnostic tool but does serve as an effective method to initiate a discussion about sexuality. The components of PLISSIT are:

P= Obtain **Permission** to discuss sexual behaviors/practices

LI= Provide the **Limited Information** needed to function sexually

SS= Give **Specific Suggestions** for the individual to proceed with sexual relations

continued on next page

IT= Provide **Intensive Therapy** about issues of sexuality for that patient

When taking a sexual history, it is important to take into account vision problems, cognitive impairment, hearing loss, communication barriers, movement and tactile loss, and psychological factors that may influence assessments.⁴⁴

Interventions. Healthcare providers should feel confident and comfortable when talking about sex and dealing with patients' sexual expression. Patient education should include:

- Explain federal regulations regarding STDs and HIV transmission.
- Encourage patients to inform sexual partners of their HIV status and/or any STD infection so the partner can get treatment, if needed
- Teach safer sex practices and offer methods patients can use to protect themselves from STDs and HIV, such as condoms, pre-exposure prophylaxis (PrEP) for patients who are HIV negative, and U=U for patients who are HIV positive
- Discuss alternative methods that people can use for sex and intimacy—positions, cuddling, touching
- Promote a healthy lifestyle, and offer guidance about diet, exercise, stress management, adequate sleep, and smoking cessation
- Show empathy and sensitivity when talking to patients; use active listening and refrain from negative comments and facial expressions
- Reinforce the need to take prescribed medications. Explain medications, including side effects, drug and food interactions, and the reason for taking the medication. Talk to the patient about the effect of medications on sexual performance.
- Encourage adherence to medical appointments.
- Explain normal aging changes in body appearance, age related physiological

changes, and changes in sexual functioning. Explain that older adults need a longer arousal time due to natural changes. Describe the use of sexual enhancement strategies to compensate for normal changes of aging, such as artificial water-based lubricants and/or estrogen creams.

- Assess the patient's ability to cope with HIV
- Discuss the impact of menopause on HIV

Conclusion

The CDC recommends regular HIV/AIDS testing in persons up to the age of 64; yet, few older adults are tested.⁴⁵ Older people are less likely to be tested for HIV for the following reasons:

Health care providers may not think to ask older adults about their HIV risk factors, including sexual activity, and may not recommend HIV testing.

Some older people may be embarrassed to discuss HIV testing or sexuality with their health care providers.

In older adults, signs of HIV infection may be mistaken for symptoms of aging or of age-related conditions. Particular to women, the symptoms of HIV may mimic the symptoms of menopause. Consequently, older adults are not offered HIV testing and HIV is more likely to be diagnosed at an advanced stage. When HIV is diagnosed late, it is more likely to advance more rapidly to AIDS.⁴⁵

Healthcare providers should initiate discussions about sexuality with older adults; this may facilitate earlier diagnosis of HIV or prevent infection with HIV in older adults. Healthcare providers can use the PLISST Model to address sexuality with older adults. For older women, healthcare providers should include a discussion about menopause, provide information about symptoms common to both HIV and menopause, and consider HRT for older WLWH experiencing symptoms of menopause. ❖

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New Jersey TB Update

by Frank Romano, MPH, Director TB Services, NJDOH, Division of HIV, STD and TB Services



Dr Robert Koch 1843 - 1910

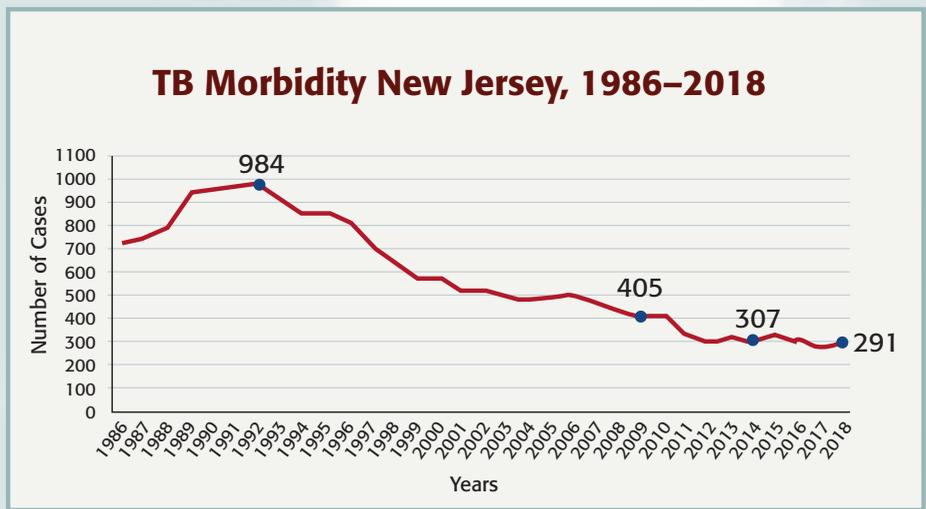
March 24, 2019 marked the 37th annual World Tuberculosis Day. World Tuberculosis Day commemorates the date in 1882 when Dr. Robert Koch discovered the bacteria that causes tuberculosis (TB). We observe the day each year to raise awareness of TB-related problems and solutions and to support worldwide TB control efforts. The New Jersey Department of Health (NJDOH) joins the Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and many other partners in promoting public awareness about TB, which remains an epidemic in many parts of the world.

TB is one of the world's deadliest diseases and a leading killer of people who are HIV infected, according to the CDC.¹ One fourth of the world's population is infected with TB.¹ In 2017, about 10 million people around the world became sick with TB disease, and there were about 1.3 million TB-related deaths worldwide.¹

TB is caused by *Mycobacterium tuberculosis* and is spread from person to person through the air. It typically affects the lungs, but can affect the brain, kidney, and spine. These bacteria become active when a person's immune system is unable to stop the bacteria from spreading and multiplying. Babies, young adults, the elderly, those with HIV, and those with weakened immune systems are at increased risk of contracting TB, including people with cancer, severe kidney disease, low body weight and those who have undergone an organ transplant.²

NJDOH grants and federal funding support six regional TB specialty clinics for the care and treatment of TB-infected patients throughout the state. The physicians at these clinics are experts in diagnosing and treating TB. The physicians at the TB clinics also consult with private physicians whose patients have complex medical issues, including drug resistant TB and adverse events related to TB therapy.

Other TB Resources in New Jersey
The CDC funds the Global TB Institute at Rutgers, which has been designated a *Center of Excellence* for training and



There were 291 new cases of TB reported in New Jersey last year. This represents a 70 percent decrease in cases since the resurgence of TB peaked in New Jersey in 1992, a 28 percent decrease since 2009 (10-year trend), and a 5.2 percent decrease since 2014 (5-year trend).³

medical consultation serving the north-eastern states. It offers state-of-the-art treatment, conducts research, and provides consultation, education, and training to physicians and health officials. The New Jersey Medical School's Public Health Research Institute offers sophisticated laboratory testing to identify TB strains quickly. This aids in patient treatment and investigation of cases that may be linked to an infectious TB patient.

For more information about New Jersey's TB program and information about the disease, visit: <http://www.nj.gov/health/tb/index.shtml>.

For more information on World TB Day, visit: <http://www.cdc.gov/tb/events/worldtbdays/default.htm>.

Health professionals can call the TB program at (609) 826-4878 to learn more about consultations, referrals, and accessing supplemental public health services for TB patients.

Follow the New Jersey Department of Health on Twitter at twitter.com/NJDeptofHealth and on Facebook at facebook.com/NJDeptofHealth. ❖

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HIV Care in Rural Communities

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Although New Jersey (NJ) is the most densely populated state in the US, less than 10% of its population live in rural communities.^{1,2} However, disparities exist between urban and rural residents regarding healthcare outcomes and limited data exists about HIV and rural NJ residents. Large studies comparing rural and urban residents in other parts of the US have identified the following differences between rural and urban residents:

- Rural residents are less likely to have been HIV tested^{3,4}
- Rural residents are more likely to be tested in an emergency department or hospital⁴
- Rural residents are more likely to internalize HIV-related stigma and experience more HIV-related discrimination⁵
- Rural residents are more likely to be tested in non-rural places⁵
- Rural residents are more likely to be diagnosed with AIDS at the time of initial HIV diagnosis⁶
- Rural residents are more likely to be linked to care⁷ (most likely because of poorer health at the time of first diagnosis)
- Rural residents are less likely to be retained in care⁷
- Rural residents are less likely to be virally suppressed⁷

Due to limited resources and healthcare access, increased levels of stigma, and perceived lack of confidentiality, rural residents are less likely to ever have been HIV tested, and when tested, to have more progressed HIV disease ("advanced stage"). Work is being done to increase HIV awareness, education, prevention, testing, and

treatment across rural communities in NJ and other US rural communities. The NJ DOH has set up an online directory of HIV and sexually transmitted infection testing sites and services including pre-exposure prophylaxis (PrEP) and harm reduction centers across NJ (<https://nj.gov/health/hivstdtb/hiv-aids/getting-tested/index.shtml>). ❖

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The People, Problems, and Policies of Aging with HIV

By
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President & CEO of AIDS United



I'm often introduced as a person living with HIV for "over thirty years." As the CEO of a national HIV organization, I appreciate the gesture. Nonetheless, I cringe every time it happens, because I suspect people are doing the math to figure out how old I am. Was he 20 when he acquired the virus, was he 35? How old must that make him now? I cringe because we live in an ageist society where youthfulness is revered, and aging has its own stigma.

Yet in the HIV community, announcing how long you have been living with the virus is almost a badge of honor. You've survived. If you acquired the virus or were diagnosed with HIV some 25, 30, or 35 years ago, you've survived the plague that killed our friends, our partners and lovers, our colleagues, our family. You survived the plague that could have surely killed you too. No wonder people applaud so loudly when someone announces he or she has been living a long time with HIV.

For the record, I was in my mid-twenties when I acquired HIV. That means I am well over 50 today. But I am not alone.

Today, approximately half of the 1.1 million people living with HIV in the U.S.¹ are age 50 and older.² They include men and women who I often turn to for inspiration and who I silently applaud. Many are very public about their age and years living with HIV. One is my dear friend and colleague Phill Wilson, a black gay man who almost died of AIDS in his 30's. Phill is the founding CEO of the Black AIDS Institute and turns 63 this year. He's taking advantage of his hard-earned longevity and decided to retire at the

top of this year. Ronald Johnson is another. Ronald is now 70 and living with HIV. He is a renowned HIV advocate and also a black gay man who served on the President's Advisory Council on HIV/AIDS. He is one of the few 70-somethings who brave sharing publicly they are living with HIV. Anselmo Fonseca is a leading HIV advocate in Puerto Rico who is now 56. Anselmo and Ronald were just honored in POZ magazine as two of the most influential people over 50 living with HIV.³ I applaud them all in my heart.

I applaud my white colleagues and women over 50 living with HIV too. Graham Harriman is director of Care and Treatment for the Bureau of HIV/AIDS at the New York City Department of Health and Mental Hygiene. He understands well the provider and patient perspectives. Pat Kelly is a founding member of the Positive Women's Network-USA. She lives daily the unique triple challenge of being a black woman, living with HIV, and over 50.³ And, there's my dear colleague Antigone Dempsey, who was in her teens when she contracted HIV. Antigone just turned 50 last year and is the director of policy and data for the national Ryan White Program. She is also a mother whose child just began asking why his healthy mom has to take medicine every day.

These friends and colleagues have worked hard in the HIV movement. But they also have something in common with the hundreds of thousands of everyday people over age 50 and living with HIV that do not work in the HIV field – something we all share that silently drives and scares each and every one

of us. Each one of us over 50 living with HIV were of age before ARVs. We were there in the 1980s. We remember the deaths, the fears, the funerals, the discrimination, the hatred, the lack of federal response, and most of all the lack of hope. We recall the wasting syndrome, the purple blotches of Kaposi's sarcoma, the night sweats, coughs of pneumocystis carinii pneumonia, and the vacant eyes of eminent death on the faces of people we knew. These are the indelible memories of people over 50 today living with HIV. Our memories are what we fear can still happen to us. They are what I, having lived with the virus for over 30 years, still fear can happen to me.

We who were diagnosed with HIV for 20 or more years understand the drill. We are deeply committed to working in partnership with our providers to address our unique health and wellness needs while living with HIV. Unfortunately, the newly diagnosed with HIV who are over 50 start from a very different place. They don't get applause for being over 50 with HIV. Some fear derision for not being "responsible," especially when the new effective prevention medication called PrEP (for pre-exposure prophylaxis) is available, and information about good old condoms has been around since the start of the epidemic. I know two persons under 40 newly diagnosed last year (one white, one Latino), and I learned from them the powerful stigma they experience of being accused of not being "responsible." Imagine the stigma of being newly



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All of us over 50 living with HIV – whether newly diagnosed or long-term survivor, have something additional and very pressing in common. Health conditions and diseases associated with aging will occur earlier with us.

diagnosed today in your 50s. Imagine if that person is a black woman, or a gay man in the South, or a transgendered person living anywhere.

People over 50 and newly diagnosed may have something of their own in common. Though they lived through the plague years of the 80s, unlike long-term survivors who have known their status for decades, many newly diagnosed today had no real understanding or personal awareness of HIV some 25 or 35 years ago. In 2016, approximately 24% of the newly diagnosed over age 50 were heterosexual women, and another 15% heterosexual men. Some 42% were African American and 18% were Latino.⁴ How could they focus back in the day on a disease that the media said was only impacting and killing white gay men. No wonder 35% of people diagnosed in 2016 with HIV at age 50 or older had ignored the signs in their own bodies and the risks in their own lives and were already at late stage AIDS when they were finally diagnosed.¹

Diseases and conditions that more typically occur with people in their 60s and 70s often occur with people living with HIV in our 50s and even our 40s.² The list of those conditions are a middle-aged person's worst fears – cardiovascular disease, liver disease, kidney disease, cancer, osteoporosis, to name a few, and for the youth conscious – loss of muscle.^{2,5} And, with HIV sero-sorting for dating so prevalent in the LGBTQ community, and with HIV still such a taboo subject in Black and Latino communities, it's no wonder from New York to L.A., stigma and isolation are repeatedly noted as common experiences among people over 50 living with HIV.^{6,7}

Also common for people over 50 and aging with HIV is our constant worry about our financial health. Long-term survivors who knew or suspected we were HIV-positive back in the 80s and 90s also knew or suspected we would likely die well before reaching age 55, and certainly before reaching 65 or 75. We made our wills and signed Powers of Attorneys, but 30 years ago that was the extent of our financial planning. Too few of us over 50 and living with HIV ever had the chance or thought of signing up for 401Ks, creating our own IRAs, and purchasing long-term care insurance was out of mind, if not out of reach.

I know that I bought only disability insurance (a policy I still own and pay into today) specifically because I feared I would have no income to take care of me should I fall ill from AIDS. Long term care insurance? Why bother? Like so many others my age, I regret not expecting that I might actually live this long or longer. How could you plan forward when hope did not exist? But I was wrong, and so were many, many others.

Over 600,000 people living with HIV will turn 65 over the next two decades,⁸ and by 2030 some 70% of us will be over the age of 50.² Moreover, a twenty-something young adult entering HIV treatment immediately upon diagnosis today is expected to live a normal lifespan of approximately 78 years.⁹ I hope today's youth, young adults, and those approaching middle age plan far ahead and have the support they need to do so. They will regret it if they don't. Leading public health experts, like Rutgers' own Perry Halkitis, Dean of the School of Public Health, have stated clearly that, "Medicare is ill-equipped to handle the needs of older HIV-positive adults."⁸

Medicare could become even less effective for the 250,000 people with HIV already receiving its benefits if the Trump Administration's proposed rule change for Medicare Part D becomes law. The proposal would eliminate the protected class status of six categories of drugs covered by Medicare including anti-retrovirals used for HIV care. Removing protected class status would give insurance companies prior authorization power to determine whether to pay for a prescribed drug.¹⁰ Providers know well what a burden obtaining prior authorization is, but it is especially daunting for vulnerable people like so many living with or newly diagnosed with HIV. With approximately 15% of people with HIV in the U.S. still undiagnosed, and with less than half consistently retained in care,¹ our healthcare system does not need to create one more hurdle that will impede or discourage

people from getting the treatment and care they need. The proposed rule change for Medicare Part D would also empower insurance companies to require “step therapy” for patients prescribed drugs in those classes. Step therapy means that people must try a cheaper and potentially less efficacious drug and fail on it first before the insurance company will approve and cover the medication their doctor originally deemed best for them. This is a disaster for people living with HIV seeking to achieve and maintain an undetectable viral load, especially for someone over 50 whose provider is assessing all their other health conditions in conjunction with determining the best HIV treatment option for them. This change to Medicare Part D will certainly make aging with HIV more difficult and costly for our health.

Yet, the science is clear that we can end this epidemic and that includes for all of us over 50 living with HIV. Ending the epidemic for long-term survivors with HIV and for people newly diagnosed means ending for us the possibility of ever falling to an AIDS-defining illness and – above all – never dying of AIDS. Ending the Epidemic is a mantra for our community. Now it is being raised at the highest level.

President Trump, in his State of the Union Address this February, announced that his administration would work to end the epidemic within 10 years. While his announcement may seem inconsistent with other policies of his administration, including the proposed change to Medicare Part D, it was a welcome surprise. People living with HIV over 50 who remember President Reagan refusing to even say the word AIDS can hardly believe we’ve lived long enough to hear President Trump exclaim his administration’s commitment to saving our lives.

The Administration’s plan focuses on four main planks: Diagnose, Treat, Prevent and Respond.¹¹ The strategies include expanding access to today’s treatment and prevention tools. Phase I of the plan will target the 48 counties in seven states with high rural HIV burdens, plus San Juan and the District of Columbia that together account for half of all new diagnoses.¹¹ The plan does not include any restrictions on how old a person might be to benefit from it. Why should it? The science and the evidence apply to people of all ages living with and at risk for HIV. ARVs not only help those of us living with HIV achieve an undetectable viral that stops the virus from constantly expanding and destroying our immune system and leading us to AIDS and death, but treatment is also prevention. A consistent undetectable viral load means that the virus is untransmittable¹²—known widely as U=U.¹³ Along with PrEP that is 96% effective in stopping HIV transmission, U=U and achieving viral suppression can save our lives and stop all new infections — no matter how old or how young we are. Aging HIV-positive and healthy is now equally as possible as is living HIV-negative to a ripe old age.

We are all aging. Living and aging with HIV most certainly has its hard challenges, whether we are long-term survivors or newly diagnosed. We need our friends, our families, our faith communities, our networks large and small to help us live long and well. But we will always need our clinical providers as our lead strategists for achieving our health goals. Your HIV patient aged 50, 60, 70 or beyond needs you to understand our journeys as long-term survivors and where we started as the newly diagnosed. Our stories are different, but one thing is common to us all. We will not age another day or another year without the support of informed and concerned public health experts and providers like you. ❖

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NJ Update

New Jersey Governor Phil Murphy committed to ending HIV by 2025. New Jersey is working on that plan now with stakeholder and public engagement. #NJEndsHIV2025



A Life Well Lived, A Life of Peace

Michelle M. Thompson, Program Manager, François-Xavier Bagnoud Center, School of Nursing, Rutgers, The State University of New Jersey

Deloris

"I see myself as an HIV advocate. I see it as important for people living with HIV to be a part of all the decision tables. I just feel like we need to be involved in the policies that impact healthcare and access to healthcare. I have tried to represent the needs of people living with HIV at every single table I was invited. I see that as my success."

Deloris is a 59-year old African American female who was diagnosed with HIV 25 years ago. She has worked in the HIV field for 20 years and is currently a Clinical Director at a Community Based Organization (CBO). She has spoken on the national and international stage on HIV, stigma and women's issues.

What does it mean to you to be considered a "long-term" survivor?

When I was diagnosed in 1994, I didn't think I would have longevity. I know that I am here because of the advances in medication, and I am grateful for that. I am also aware of the reality of living with HIV for so many years. It is not so much my viral suppression and being undetectable, but it is the co-conditions.

There are co-occurring conditions that come along with getting older and living with HIV. When I speak with people in my community, although they may take

one pill a day for HIV treatment, they are taking multiple drugs for other conditions. I myself am borderline diabetic, have high blood pressure, arthritis and dealing with symptoms of menopause.

My community is most concerned about cancer. Many are dealing with different types of cancer.

What do you think has changed in healthcare in the last 25 years?

Because I work in the field, I can see the advances. I work in an urban arena. I still see people coming in with fear and anxiety around HIV. I thought we had solved that problem. I thought we were educated about HIV, but it is not reaching everybody. Most people have insurance and are down to one pill. There is also ADAP (AIDS Drug Assistance Program) and the phenomenal Ryan White wrap around program for people in New Jersey, but there is still a gap. The gap is created because some people do not know where they can still access services.

Have you observed or experienced HIV-related stigma in the healthcare system? Has anything changed?

To a large extent, in venues that consider themselves HIV experts, that has changed. In the larger community, no. People still ask inappropriate questions. I was in the ICU in 2013 and a nurse was standing over me and asked me how I got it. That is so inappropriate. I don't expect that from a provider. I didn't think she was being mean, just not trained on what are appropriate questions. **Why do you think she asked you that question?** I put on my trainer hat after I responded to her. Sometimes there

is an attempt for someone to try to distance themselves from people who have HIV. *How did you get it? What behaviors are you involved in? Oh, ok. I'm ok. I didn't do that.* It may have been her attempt at being empathic, but come on, I'm sick. What do you care? Treat me. I don't think she would have asked that question to someone with cancer or diabetes.

There are some older Americans going to Primary Care Physicians (PCPs), but not necessarily revealing their status, or are unaware of their status.

People don't disclose in an environment where they don't feel comfortable. If you go to the dentist, you might think they are just fixing your teeth. Early guidelines say PCPs should routinely test for HIV during yearly screenings. If you are not following basic guidelines, nothing may show up yet to cause you to question the patient further. The PCP needs to be more aware of the general question that should be asked. A PCP should always ask about sexual health and not leave it up to a woman's GYN, if she has one, or for a male to volunteer information.

There is sometimes a stigma attached to older patients, an assumption that they don't need to be tested for HIV, or need to be questioned about their sex life. Think about PrEP. If you are not asking me about sexual health or screening me for HIV, you've already created an environment where I am not comfortable. Married people have often said they are never asked about sex or tested. That spouse could still be at risk. A physician may unconsciously put up barriers to address HIV needs and HIV care. Again, ageism plays a big part to some of these barriers.

What do you think of the healthcare policies proposed to End the Epidemic (ETE)?

I currently sit on the New Jersey Task Force to end the HIV Epidemic. Getting to the end of the epidemic is a goal I fully support. My concern has always been, how do we define the end. Many in our profession and epidemiologists define it as 90% viral suppression rate and 90% of people know their diagnosis. In New Jersey we are going for 100%.

But I ask myself, *Aren't I still living with HIV? Don't I still need the support services that will allow me to have a normal, active lifespan?* Even as I sit at the table and agree with the indicators, I ask myself, *If there is no cure, is there honestly an end to the epidemic?* That comes from a personal place rather than an epidemiological view. As a person living with HIV, I have to find a balance in my head and my thinking. I understand epidemiology, but as a person living with HIV, I ask myself what does it really mean to me.

What do you think about PrEP and U=U as prevention?

PrEP is fine. I'm ok with PrEP. It should be for everyone. Efforts to reach out to women should be equal to efforts to reach out to the MSM community. Our system does not have an equal effort. A lot of women do not know about PrEP being an option. I think they are doing catch-up now to reach everyone.

U=U is a way to reduce stigma. I recently spoke to two mothers that wanted to know why they can't breastfeed if undetectable equals untransmittable. I explained that there is not scientific research in the US to support that. Globally, women have no choice to breastfeed because they are denied access to clean drinking water or alternative nutrition. The mothers feel an inner turmoil because

they can have a baby, but can't safely breastfeed. There would also have to be a change in the guidelines, as every provider thinks about liability.

On a whole, I think people, especially women are excited about U=U, but more important research needs to be done.

Do you think HIV-related stigma or ageism has evolved as we enter 2019?

There is still a lot of fear surrounding HIV. Although we are covered under the Americans With Disabilities Act, people don't know that. I'm sorry to say as you get older and are disabled or not disabled with HIV, there is a fear of being seen differently. Personally, I worry about that. I worry about hitting 60 and people thinking I may not be able to continue to function in the job that I have. I try to look as young and perky and energetic as I can manage. That may be internal stigma, but ageism is real for us. HIV-related stigma doesn't bother me because I have gotten to a point where I don't care, but it still greatly affects my community.

You mentioned menopause and discussed sexual health. Without going into personal detail, what are your thoughts?

I'm an open book. I'm single. As I get older, it would be nice to have a companion. I was scared when I was younger and locked myself away because of my own issues. My career fed me. I took care of my son. I limited myself to intimate relationships, but the desire for it doesn't go away just because you get older. In fact, it increases. If you are a person living with HIV or not, you need intimacy and sexual relations. Being menopausal does not change that. There needs to be a social opportunities for people to be able to interact with each other.

What do you want providers to know who are treating the aging population?

Geriatric doctors need to know more about HIV and refer patients when necessary. There should be cross-pollination. Geriatric conditions should be coordinated with HIV treatment.

I have an ID specialist who is my PCP because I was allowed to do that. There are some conditions where I will have to see someone else. There can be so many different things going on so care and treatment need to be coordinated among all the providers, not just in the hospital, but outpatient. It is important for all around health.

Sometimes there are constraints on physicians and they only have 15 minutes per patient for insurance reasons. Crucial conversations are being missed. This usually results in being farmed out to someone else for a different part of your body. It's like piecemeal care. **If a nurse had time for those conversations, would that help?** Yes, a nurse is fine or someone else from the care team needs to build a relationship with the patient to increase their level of comfortability. They would be more at ease to open up about other things that are going on.

What is needed for a person to advocate for themselves going into a provider visit?

First off, educate yourself on the disease. If you are not educated you only go in with how you are feeling. The more you know, the better your conversation. Make a list of all your questions in advance. Keep a record of your symptoms. Be prepared for the visit. Speak up if you don't understand. Speak up if you disagree. Stay involved in your care. Ask yourself these questions: *Do I have symptoms? How are my meds affecting me? Why am I taking certain tests?*

These are the things you want to discuss with you physician.

Do you have a support system?

My son (*Smiles*). I have one son who is 38 years old. When I was on my last crisis, he was just there. I would say my son and my family. I work in the field and I go home. But , who is there for me?

It's my son.

What do you want people to know about Deloris?

I'm a poet. Through this journey I feel that I express myself through poetry. It has not been easy, but I have never given up. I've always been determined. Honestly, in my heart, I believe that HIV is not a death sentence. You need to recognize you are sick and that's all to it. You're going to get the care you need and continue to live life. Take all of your pain and woes and find an outlet to express them through poetry, writing, dance or anything creative. Build your network of support through family or any other support system.

When I die, I will have lived my life to the fullest. ❖

Fear, My Companion and Motivator

By Deloris Dockrey

Fear is my constant companion,
Fear is my motivator.

Fear was there when I was molested as a child,
Fear was there in my guilt and shame,
Fear motivated me to say STOP!

Fear was there when I had my son,
Fear was there when I knew I was alone,
Fear motivated me to keep HIM.

Fear was there when I journeyed to a new country,
Fear was there as I ran away from guilt and shame,
Fear motivated me to succeed and ACHIEVE.

Fear was there when I became HIV positive,
Fear was there in my guilt and shame,
Fear motivated me to survive and LIVE!

Fear was there when I was rejected and unloved,
Fear was there in my guilt and shame,
Fear motivated me to find a new PATH.

Fear was there as I lie in a coma,
Fear was there in my regret and guilt,
Fear motivated me to go on LIVING!

Fear I have grown to respect you,
My guilt and shame is gone,
Fear remains, but fear motivates me to a LIFE
A life well lived, a life of PEACE.



You Can't Complain If You're Not At The Table

Michelle M. Thompson, Program Manager, François-Xavier Bagnoud Center, School of Nursing, Rutgers, The State University of New Jersey

Aaron

"I thought I was going to die. Let the townhouse go, the housing go, the insurance go, the savings and a whole lot of other stuff. I was ready to go. When I was diagnosed, it seems like my friends were dying by the dozen. I thought I was one. I'm still here, but living in a whole different manner"

Aaron is a 59 year-old African American male. He is a poet, self-published author and a community activist who has been living with HIV for more than 30 years.

Aaron mourns the loss of community spirit. He was part of a village of citizens who invested in the community. Aaron was named Youth of the Year for the Newark Boy's Club and was even Mayor for a Day. He thinks the care and concern shown "back then" is missing in today's world and it affects him deeply. Sometimes he feels as if he is fighting a losing battle and often feels isolated.

How have you navigated through the healthcare system?

I am on disability. I have Medicare which only covers 80% of my medical bills and I'm not eligible for supplemental insurance. I parted ways with my PCP of 25 years because I can't pay the 20%. I'm so grateful for the Ryan White program to help me with the cost of visits for my eyes, dental and foot needs. Applying for Charity Care is overwhelming and just too much.

Not all patients are uneducated. We must advocate for ourselves. Do your research and bring it to your doctor's appointment. Not every doctor is informed about new treatments and what might be beneficial to the patient. Don't be afraid to ask questions. There are no dumb questions. It could cost you your life.

I feel that if I disagree with some of the people who make policy, I kind of get ostracized for having an opinion that doesn't agree with them. I think it's wrong. There are large numbers of people who have been recycled within the service community who are providing services. I don't want to be perceived as a trouble maker. If your job is to provide services to the community, put your personality aside and provide services.

Talk about your activism/advocacy work in the community.

A lot of aging people living with HIV are dying silently and quietly from cancer, diabetes and other age-related stuff. Their partners or friends died early in the epidemic or the family members and friends they had have passed away as they started getting older.

I want to advocate for the voice, the voiceless and the disenfranchised. We don't all have the same voice or look alike, but that odd person may be the one with the most to say. I was one of those people, a sort of social outcast. I pick and choose my fights. I want to help older people living with HIV to get involved. Stop isolating and thinking you are the only one. Be proactive. Everything does not have to be given to us. We should stop getting caught up in entitlements.

Come to the table. To advocate for change in the system, you have to sit

with the people who are supposed to be providing services and let them know what you don't like. You can't complain from the outside or across the street and expect change. You don't have a voice if you're not at the table. Being proactive and understanding the process is the only way things are going to change.

I was on committees that helped make changes so that young people could get tested for HIV/STDs without parental consent and tax reductions towards HIV services. I have fought for inclusion of the LGBTQ community. I've been involved in a study with the NIH since 2009.

What are your thoughts on PrEP in Ending the Epidemic?

The educational piece is lacking especially for our youth. Youngsters are still engaging in high-risk behavior. They are not thinking about tomorrow and don't understand the process and want what they want right away.

A person may have just received a positive diagnosis and can't mentally process the results, and to be asked to have your partner go on PrEP is just too much. Some people are just not ready. They need to process their diagnosis, come to terms with the stigma of being HIV positive and decide if they are going to live or die. For the older generation, it may or may not be more successful. If we can get the correct information out there it may help in prevention.

Have you ever experienced HIV-related stigma or ageism?

A combination of both. I try to educate our LGBTQ youth. Some of them call me old. I remind them that young people are dying. I have attended meetings or spoke where there was resentment

towards me because I'm surviving and aging and still here, whereas they may have lost a family member or loved one.

Do you have a support system?

Yes, I feel like I do. I have a big family. I have 8 living siblings. My mother had 11 siblings and my father had 12. I would love to have a better rapport with my sisters and brothers, but I have a big extended family and a very good network. I don't lack for love.

I was talking to my mother about the days when I have been hungry and only had beans in the house, but was able to make a meal to last 2-3 days until I had some money. My father taught us how to make a meal or a sandwich so we wouldn't starve. Those are the lessons that sustain me today. I'm grateful.

I was in a dark space not too long ago thinking about suicide. My very close friend swooped in and encouraged me to go on and finish my poetry book, and I did. Like the movie "It's A Wonderful Life", I feel like I'm one of the richest men in the world. In those dark moments of non-encouragement my family and friends swoop in to lift me out of my ugliness.

What do you want people to know about Aaron?

My next book will be about the struggles through my journey of living and surviving through what I thought back then was a death sentence, but I'm still here.

I want people to get involved. I want people to stop dying in silence. I want people to be pro-active.

I'm ready to go, but while I'm here, I'm going to speak up and try to make a difference.

I'm grateful for the people who are still in the fight, in the trenches and for the providers who view HIV services as more than just a job. ❖

We Too Share the Pain BY: Aaron Frazier

We too share the pain of HIV/AIDS

Abused, battered, beaten and maimed

Some of us survive, some have no name.

We too share the shame of low self-esteem, loneliness, abandonment, torment

Oppression into depression.

With the rain, we too share the pain.

Feeling so confusing not reeling nor refusing, we still accept the blame

Years and years of pain. Some survive, some don't.

Those who know, know the pain.

Whether heterosexual, gay, lesbian transgender or bisexual, the names different, yet the same, the incidents different yet similar or the same.

None the less we too share the pain.

If you put aside all the shame, all the pain and the blame, look into the mirror real, real hard. You and you with all your heart, you too would realize it's all the same and then notice we too share the pain.

But once realizing this, we too must attempt to connect, to correct that which is wrong. Accepting the differences without judging. Knowing what you know.

Once all that happens, beauty is our differences. We gain strength in numbers as a community connection. Real joy and peace and understanding.

We too can know joy, we too can have joy.

We too can walk in the light of day.

We can be different yet gay.

We too are the same.

Knowing it's not my stuff, We too share the pain.



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HIV/AIDS Training & Information Resources

AIDS Education and Training Center (AETC) Program

- National Coordinating Resource Center:
www.aidsetc.org
- Northeast/Caribbean AETC: www.nynjaetc.org
- National Clinician Consultation Center:
<http://www.nccc.ucsf.edu/>
HIV Warmline: (800) 933-3413
Post-Exposure Prophylaxis Hotline/PEpline:
(888) 448-4911
Perinatal HIV Hotline: (888) 448-8765
Pre-Exposure Prophylaxis Hotline (PreEpline):
888-HIV-PREP
Substance Use Warmline: (855) 300-3595
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AIDSinfo: a service of the US Department
of Health and Human Services, offers access
to the latest, federally approved HIV/AIDS
medical practice guidelines, HIV treatment and
prevention clinical trials, and other research
information. <http://www.aidsinfo.nih.gov/>

US National Institutes of Health: a registry
and results database of publicly and privately
supported clinical studies conducted around the
world. <http://clinicaltrials.gov>

**US Centers for Disease Control and
Prevention (CDC):** [http://www.cdc.gov/hiv/
default.html](http://www.cdc.gov/hiv/default.html)

**Health Resources and Services
Administration (HRSA):** <http://www.hrsa.gov>

FDA MedWatch: (800) FDA-1088; Subscribe to
e-bulletin: www.fda.gov/medwatch/elist.htm

**Center for Quality Improvement and
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quality of HIV care nationwide.
www.nationalqualitycenter.org

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