POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM **TPAN**

SPRING 2019

LIVING LONGER, LIVING BETTER

CHANGING HOW WE AGE WITH HIV

THREE ACTIVISTS BLAZING THE TRAIL FOR PEOPLE AGING WITH HIV

GERIATRIC ASSESSMENTS: 'GERI'-RIGGING YOUR HEALTH CARE

'I GET KNOCKED DOWN, AND I GET BACK UP'

WHAT TO WATCH OUT FOR—AND WHAT YOU CAN DO

WAHEEDAH SHABAZZ-EL
Diagnosed at age 49, she soon became an activist and a leading voice for older people living with HIV.

SPRING 2019

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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment information with anyone affected by HIV.

GUEST EDITOR'S NOTE

THEO SMART

Changing how we age

When the dashing and magnificently bearded Dr. Giovanni Guaraldi took to the stage at last fall's HIV and Aging conference in New York City, and described a nearly 100-year-old person living with HIV, I was more than a bit skeptical. Not of the researcher—he's done some of the most brilliant research on aging with HIV. Guaraldi also advocates a "rethink" of care services provided for people living with HIV as we age, particularly now that about half of us are over 50—and by 2030, as many as 40% of us will have reached the age of 65.

Rather than our routine HIV care, we increasingly need comprehensive multidisciplinary services to match our more complex needs. Even in middle age, we need a more aggressive approach to screening, diagnosis, and management of many conditions associated with aging.

The firebrand activist Jules Levin of the National AIDS Treatment Advocacy Project (NATAP) has been broadcasting this message for years now—sounding the alarm that we, the aging HIV community, are headed for a services gap. Based upon study after study documenting rates of frailty, aging-related complications, and disability among people living with HIV that are much higher than what is seen in people of the same chronological age in the general population, he believes that HIV care systems are totally unprepared to provide the services many of us will need (see 13).

His warnings seem to be falling on deaf ears, due at least partly to ageism and denial. People don't like to think about all the ailments associated with "growing old." Quite possibly, there is some measure of survivor's guilt as well. After all, when we received our diagnoses, many of us never expected to even make it to 50 (with the exception of a growing number of us who weren't diagnosed until later in life). We're still kicking—why should we be complaining about the natural aging process?

But it does not seem to be entirely natural. First, there's all the damage that HIV does to the body: our brain, our gut, our other organs such as the heart and the immune system—both before we can get onto treatment, and then due to chronic inflammation caused by low levels of ongoing replication, co-infections (such as CMV and hepatitis), and other factors. In addition, the long-term survivors among us are often dealing with the legacy effects of the older, more toxic antiretrovirals. Even the new ones have side effects, some of them insidious, subtly altering our metabolism and even damaging our mitochondria—the energy generators of our cells. On top of that, many of us have had rough lives emotionally, punctuated by loss, dealing with structural inequalities and bias, internalized stigma, and depression. Consequently, we haven't always taken the best care of ourselves, and some of our lifestyle habits are self-destructive.

It's no wonder that many of us are showing more wear and tear than is usual for our age. In fact, several years back, Dr. Guaraldi published a study showing many of the complications of aging seemed to be happening 10–15 years early in people living with HIV.

That said, other studies have shown that many going to the larger HIV clinics and on the current antiretrovirals do pretty well compared to other middle-aged people, at least over the short term. And there's a good explanation for this—simply being in routine care may allow well-trained clinicians to detect problems early and nip them in the bud.

Which brings me back to this 99-year-old gentleman from Lisbon, Portugal. My initial instinct was to dismiss him as an anomaly. A case of one. But the more I thought about it, it was not so simple. He was very ill when he was diagnosed at the age of 84—very late, with a nadir CD4 count below 100—but recovered and seems to have flourished with good attentive care. There's a good report on him online (bit.ly/99-year-old), with a cute video clip of Dr. Guaraldi at bit.ly/Guaraldi-clip.

At the HIV and aging conference, Dr. Guaraldi identified factors that could help explain why this man has done so well. First, he lives in a healthy environment. He's never had financial difficulties (and the related stress), and he has assistance from a loving 70-year-old daughter who lives next door. Then there's that Mediterranean lifestyle and diet, with good cardio every day walking up and down the hills of Lisbon, and, I would imagine, plenty of olives and fish.

Dr. Guaraldi referred to these factors collectively as "social protection," which based upon his research in a larger HIV-positive cohort, might be used to help predict which people might be at greater risk of frailty and age-related illness. But lest one think that such outcomes might be limited to those lucky enough to live in Portugal, another study presented by Dr. Nancy Mayo of McGill University at the HIV and Aging conference found similar factors associated with "aging well" in a cohort of over 800 Canadians living with HIV. Looking specifically at frailty, the study found that some health conditions greatly increased the risk, such as having lung disease, arthritis, or cognitive problems.

But about 14% of the cohort seemed to be aging particularly well. Among modifiable factors associated

We need a more aggressive approach to screening, diagnosis, and management of many conditions associated with aging.

PHOTO: LANCE SHERRIFF

with greater resilience were being physically active, not smoking, not suffering from stigma, having friends and family (not being lonely), and keeping mentally fit.

"You have a big role in how you are going to age," Dr. Todd Brown of Johns Hopkins University said at another meeting organized by NATAP's Jules Levin last fall in New York, in a talk emphasizing what people could do for themselves to build resilience and to maintain a good quality of life as they age. I, for one, would be happy to live in good health well into my 70s and later, as my older siblings are doing. In my own life, I've seen how changing my diet and losing a significant amount of weight has profoundly improved my quality of health—and even my concentration.

Building resilience is something we have to do both on a personal level but also in our communities and in our health systems.

Building resilience is something we have to do both on a personal level but also in our communities and in our health systems.

At the personal level, now is not the time to be burying our heads in the sand. Knowledge is power. Many of us will recall how, back before antiretrovirals made HIV into a chronic manageable condition, we had to learn all about the various opportunistic infections and drug development—often becoming more aware of the scientific research than our own doctors. This issue takes that approach, reviewing what is currently known about the health risks we face—we need to know what our health care providers should be watching for, and what steps we can take to improve the way we age (see pages 3–7).

One of the challenges is that access to quality care for aging people with HIV is uneven in this country. There is a lack of trained skilled providers and services prepared to deal with consequences of these complications and health emergencies in this population. Many of our HIV clinicians simply aren't trained in the nuances of providing care for people who are aging, and it can be extremely difficult to get timely referrals to a specialist when we need one. Efforts are underway to address the services gap which require our communities' full support (see "Addressing the Needs of Older Adults Living with HIV," on page 20).

For many of us, the care we receive is limited by what Medicaid or our insurance plans will cover—and this needs to be as much a part of our national activist agenda as the current efforts around prevention. We can also build resilience for aging well into the health system and communities through our activism. On page 9, we focus on a few of the activists who are each responding in their own way to scale up research and improve the service package and psychosocial support for our communities—and to improve elder care in general.

"It's not just HIV. We don't take care of our older people and that is a problem across the country and many parts of the world," said Dr. David Wohl of the University of North Carolina at NATAP's forum. "The problems with age transcend any one disease. But HIV is really unique in many ways. HIV and the epidemic forced the FDA to think harder and differently about how to approve drugs. The epidemic helped us think about how, as communities, to organize to push politicians and policy makers to push drug companies to do the things they ought to do. There are many examples in medicine where HIV has leapfrogged us and helped other disease states. And maybe it is HIV that can help us revolutionize geriatrics because we need a different model for how we take care of, and how we consider, older people. We can do that. We are the tip of the spear."

Your body as it ages

What to watch for, and the steps you can take to improve the way you age with HIV

BY **KEITH ALCORN**

ISTOCKPHOTO

LOOKING AFTER YOUR HEART

Your heart and your circulation become some of the biggest areas of maintenance—and potential problems—as you get older. Abnormal lipid levels—cholesterol and triglycerides—raise the risk of heart attacks and other cardiovascular problems. People living with HIV are more likely to have abnormal lipid levels off HIV treatment due to the virus. Even on treatment, a high proportion of people living with HIV (PLWH) have low levels of "good" cholesterol, raising the risk of heart disease.[1]

Maintaining healthy cholesterol levels—keeping total cholesterol below 200 mg/dl and the ratio of total cholesterol to HDL cholesterol below 5 to 1—reduces your risk of heart disease. If lifestyle and diet changes aren't getting your numbers into the right range, it's time to talk with your doctor about how your HIV meds might affect your lipid levels. Protease inhibitors may increase your lipid levels, whereas integrase inhibitors and newer NNRTIs such as rilpivirine or doravirine have less effect on lipids.

Your physician should calculate your 10-year risk of

HIV raises the risk of heart disease, especially in women and younger people.

a heart attack or other cardiovascular problem, using your weight, age, blood pressure, and cholesterol scores. If you're at high risk, your physician will prescribe a statin medication and set a goal for cholesterol reduction.

HIV also raises the risk of heart disease, especially in women and younger people. Some experts have suggested that the additional impact of HIV on the risk of heart disease means that everyone living with HIV should take a statin. The jury is still out on whether this is a good idea, and a big trial is running to answer the question. (See "Should you be taking a statin if you're living with HIV?" on page 5.)

Raised lipid levels are often accompanied by other problems—such as increased glucose, high blood pressure, excess fat round the waist, and a fatty liver—that also raise the risk of heart disease. This cluster of problems, described as metabolic syndrome, requires careful monitoring and intervention before it leads to type 2 diabetes, heart disease, stroke, or serious liver damage.

Metformin is usually the first option to manage glucose levels. Other drugs to manage glucose are less well studied in people with HIV, and may have problematic drug-drug interactions with some anti-HIV drugs.[2] Whereas boosted protease inhibitors may increase levels of many drugs used to manage glucose, non-nukes such as efavirenz may reduce levels.

HIGH BLOOD PRESSURE AND BEING OVERWEIGHT ARE MAJOR RISK FACTORS FOR HEART ATTACKS. ALL THESE FACTORS WERE MUCH MORE IMPORTANT THAN HAVING A LOW CD4 COUNT A DETECTABLE VIRAL LOAD, OR HEPATITIS C.

Smoking is still a major culprit in heart disease for PLWH, just as for the rest of the population. Kery Althoff of Johns Hopkins University, Baltimore, looked at the medical history of nearly 30,000 people in HIV care in North America. She found that people who smoked were 80% more likely to have a heart attack than those who had never smoked. If everyone stopped smoking, around 40% of all heart attacks in PLWH would be avoided, she estimates.

Althoff also found high blood pressure and being overweight were major risk factors for heart attacks. All these factors were much more important than having a low CD4 count, a detectable viral load, or hepatitis C.[3]

Maintaining a healthy weight can become more difficult as you age, especially if you have a disability. Having a higher body mass index (a BMI above 30) increases your risk of heart disease.[4] In the general population, people who are overweight are more likely to develop heart disease, develop it earlier, and spend more of their life with heart disease. It is unclear if the same holds true for PLWH, but weight gain after starting HIV treatment is associated with an increased risk of developing abnormal glucose levels, including type 2 diabetes (a major risk factor for heart disease).[5]

YOUR BODY BEGINS TO SHOW ITS AGE

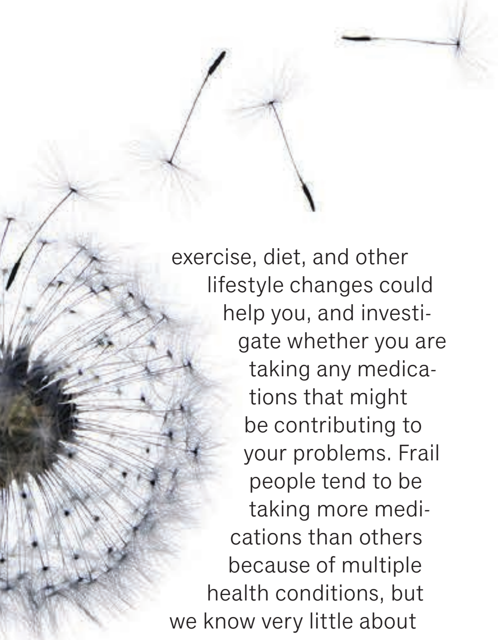
Signs of physical wear and tear are an inevitable part of aging, but for some PLWH, aging is accompanied by premature frailty and loss of muscle mass, along with other conditions.

Frailty manifests as weight loss, slowed walking speed, reduced strength, tiredness, and a lowered level of physical activity—a noticeable escalation of "not being able to do as much as I used to." A Dutch study found that PLWH were more likely to be frail than their HIV-negative counterparts at any age, and that the condition was more common in people who had ever had an unusually low body weight. The study investigators concluded that "frailty may be a long-term consequence of having experienced advanced HIV disease."[6]

Greater frailty places you at risk of falls. Injury in a fall can interfere with your ability to shop, cook, and carry out all the other tasks of daily life. It may affect your ability to work, isolate you from friends and neighbors, and lead to greater frailty in the future. Fractures are a common consequence of a fall in older people; in the worst cases, a broken hip can lead to hospitalization.

As you get older, your doctor should regularly ask about your ability to carry out the normal activities of daily life and take note of changes in your weight. Moderate exercise may improve your resilience if you are frail, but we know little about how much exercise is needed to improve quality of life or prevent greater frailty in older PLWH.[7]

If you are showing signs of frailty, your health care provider should take time to explore how



exercise, diet, and other lifestyle changes could help you, and investigate whether you are taking any medications that might be contributing to your problems. Frail people tend to be taking more medications than others because of multiple health conditions, but we know very little about the effects of polypharmacy and drug-drug interactions on frailty in PLWH.[8]

As you get older, your doctor should regularly ask about your ability to carry out the normal activities of daily life and take note of changes in your weight.

THESE OLD BONES

Frailty is closely linked to, but not the same as, bone loss. Thinning of the bones—osteopenia—can occur despite healthy muscle mass in middle-aged people and in people with an average body weight. In PLWH, a combination of long-term untreated HIV disease, alcohol, smoking, low vitamin D levels, and antiretroviral therapy can lead to a loss of bone mineral density, or bone thinning. After starting HIV treatment, PLWH tend to experience a pronounced drop in bone mineral density of around 2–6% in the first two years. More serious bone loss—osteoporosis—tends to affect women after menopause and older men.

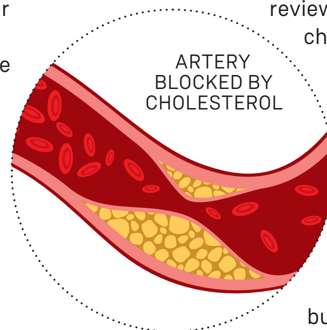
There are lots of things you can do to strengthen your bones and ward off bone thinning. Make sure to eat foods rich in calcium, which makes new bone. Dairy, tofu, spinach, and broccoli are rich in calcium. A supplement may help you get the 1,300 mg a day recommended for women over 50 and men over 70. Men aged 50 to 70 >>

ISTOCKPHOTO

Should you be taking a statin if you're living with HIV?

Over many years, high levels of harmful LDL cholesterol in the bloodstream lead to deposits of fat and calcium in your arteries. Eventually these deposits lead to blocked arteries, high blood pressure, heart attack, and stroke. Statins are a class of drugs widely prescribed to lower cholesterol levels and prevent heart disease. U.S. guidelines recommend that everyone with any form of cardiovascular disease should be on a statin. So too should people with LDL cholesterol above 190 mg/dL, and anyone age 40–75 with diabetes who has LDL cholesterol above 70 mg/dL. Other people age 40–75 without diabetes who have LDL cholesterol above 70 mg should be assessed for other cardiovascular risks and offered a statin if at high risk for cardiovascular disease.

Several large studies have shown that people living with HIV (PLWH) have between 1.5–2 times the risk of having a heart attack or other cardiovascular problem compared to HIV-negative people of a similar age, after accounting for other risk factors for heart disease. The risk increases in people over age 45. Inflammation due to HIV and metabolic changes due to HIV treatment are probably the chief causes. At the moment, guidelines say that it's impossible to tell whether HIV is enough of an independent risk factor to justify starting statin treatment.



A major clinical trial is underway to determine whether taking a statin reduces the risk of cardiovascular problems such as heart attack and stroke for PLWH who are not at high risk for heart disease. The study recruited 7,500 people age 40–75 who have been on HIV treatment for at least six months, and will follow them for up to seven years. Participants are randomly assigned to receive a daily dose of pitavastatin (Livalo) or placebo. Results of the study are expected in 2020 or soon afterwards. You can find out more at reprievetrial.org.

Taking a statin may also reduce your risk of death, although the mechanism isn't fully understood. Statins may also reduce the risk of developing cancer, but more research is needed to establish by how much.

Despite the recommendations on statin use for people at higher risk of heart disease, many PLWH who are already eligible to take a statin are not receiving this medication. The Infectious Diseases Center of Northwestern Memorial Hospital in Chicago reported recently that only half of PLWH who qualified for statin treatment had been prescribed one. People without diabetes or symptoms of heart disease were less likely to be taking a statin, even if they were at high risk for future heart attack or stroke.[1]

At the moment, guidelines say that it's impossible to tell whether HIV is enough of an independent risk factor to justify starting statin treatment.

PLWH who are eligible for statin treatment may be missing out on an important preventive treatment because their doctors have not done a recent assessment of 10-year heart disease risk. This simple review uses your age, gender, race, cholesterol, blood pressure, diabetes, and smoking behavior to calculate your risk.

Some statins are more suitable than others for PLWH. Rosuvastatin (Crestor) has no drug interactions with HIV drugs in the NNRTI or integrase (INSTI) classes, but should be dosed with care in anyone taking a protease inhibitor, and avoided altogether alongside atazanavir (Reyataz).

Dosing of atorvastatin (Lipitor) needs to be adjusted carefully when used with any boosted protease inhibitor or any NNRTI apart from rilpivirine. Pravastatin (Pravachol) doses also need to be adjusted when used with any ritonavir-boosted protease inhibitor or with efavirenz.

Statins have side effects, especially at higher doses. Muscle pain, raised liver enzymes, memory loss, and confusion are common side effects and occur more frequently in older people and in women.

Alternatives to statins are available. Ezetimibe reduces LDL cholesterol in PLWH.[2] Newer drugs, PCSK9 inhibitors, are still being tested in PLWH and are intended for people who are not achieving cholesterol goals on statins. Fibrates can reduce triglycerides and improve HDL cholesterol, but have little effect on LDL cholesterol. —**KEITH ALCORN**

FOOTNOTES AT POSITIVELYAWARE.COM

>> with a risk of fractures should aim to get at least 1,000 mg a day. A supplement that contains a small amount of vitamin D may be helpful if you aren't getting a daily dose of sunshine or if you aren't eating dairy, eggs, fish, or liver.

Weight-bearing and resistance exercise, quitting smoking and drinking, and drinking less alcohol all help maintain bone mass. Guidelines say that your bone mineral density should be measured using a DEXA scan if you are a postmenopausal woman, a man over age 50, or if you may be at high risk for fractures based on your age, gender, weight, or smoking and alcohol history. Three months of glucocorticoid treatment would also indicate the need for screening.[9]

Treatment with tenofovir has been shown to result in greater bone loss than other drugs. A newer formulation of tenofovir, TAF, has been touted as kinder to the bones, but when researchers looked at whether people taking TAF had fewer fractures than people taking the older version of tenofovir (TDF), the evidence from clinical trials suggests that TAF only provides an advantage if it is being used with the boosters ritonavir or cobicistat.[10] What's more, when French researchers looked at everyone receiving HIV treatment in France between 2000 and 2010, they were unable to show that any HIV drug—including the older form of tenofovir—resulted in a higher risk of a fracture.[11]

Nevertheless, many physicians will advise switching away from TDF if you have a high risk of fractures.

Numerous medications have been approved for the treatment of bone loss in post-menopausal women and older men, but the only ones tested in PLWH are calcium and vitamin D, alendronate, and zoledronic acid. A trial of alendronate added to calcium and vitamin D showed that adding alendronate (Fosamax) improved bone mineral density but did not result in fewer fractures than calcium and vitamin D supplementation.[12] A recent study either switched people away from tenofovir (TDF) or gave participants zoledronic acid (Reclast) while they took tenofovir. Zoledronic acid infusions resulted in substantial improvement in bone mineral density over two years, but the study found no difference in fractures.[13]

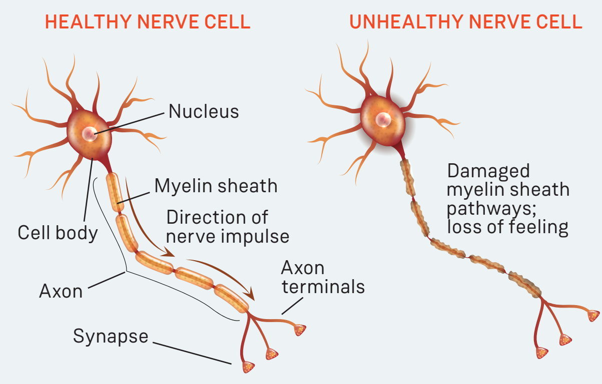
Guidelines recommend that PLWH with low bone mineral density or a risk of fractures should get alendronate (70 mg once a week) and receive monitoring for vitamin D levels.[14]

Stopping smoking is the single most important thing you can do to avoid the development of COPD or prevent it from getting worse.

SPINACH, AS WELL AS TOFU, BROCCOLI, AND DAIRY FOODS ARE RICH IN CALCIUM.

NEUROPATHY

Peripheral neuropathy (nerve damage in the feet, legs, and hands) may be caused by untreated HIV or past treatment with one of the old NRTIs—stavudine (d4T), didanosine (ddI), or zalcitabine (ddC). Peripheral neuropathy may also be caused by type 2 diabetes or by alcohol abuse. No treatment has been shown to repair nerve damage, so pain relief is essential, starting with over-the-counter painkillers and escalating to prescription painkillers according to the severity of pain. A skin patch called Qutenza, which contains capsaicin, the chemical that makes chili peppers hot, has been shown to provide moderate pain relief. Anticonvulsants or tricyclic antidepressants may also provide some pain relief.



BREATHING DIFFICULTIES

Chronic obstructive pulmonary disease (COPD) and emphysema are common problems for older PLWH. Both conditions lead to breathing difficulties and a loss of mobility, and COPD can become a progressive condition. Although smoking worsens both conditions, there's some evidence that long-term HIV infection also increases the risk of breathing problems, emphysema, and COPD[16, 17, 18], and these problems can begin to appear at a younger age in PLWH.[19]

Stopping smoking is the single most important thing you can do to avoid the development of COPD or prevent it from getting worse. Ask your health care provider what support is available to help you quit if they haven't already suggested it.

Treatment of COPD is just the same for PLWH as for anyone else, with a word of warning: levels of fluticasone, an inhaled corticosteroid used in the treatment of severe cases of airway obstruction, can be raised by boosted protease inhibitors. Be sure that your primary care or emergency room physician checks for drug-drug interactions with HIV meds before giving you a systemic corticosteroid or theophylline to help your breathing.

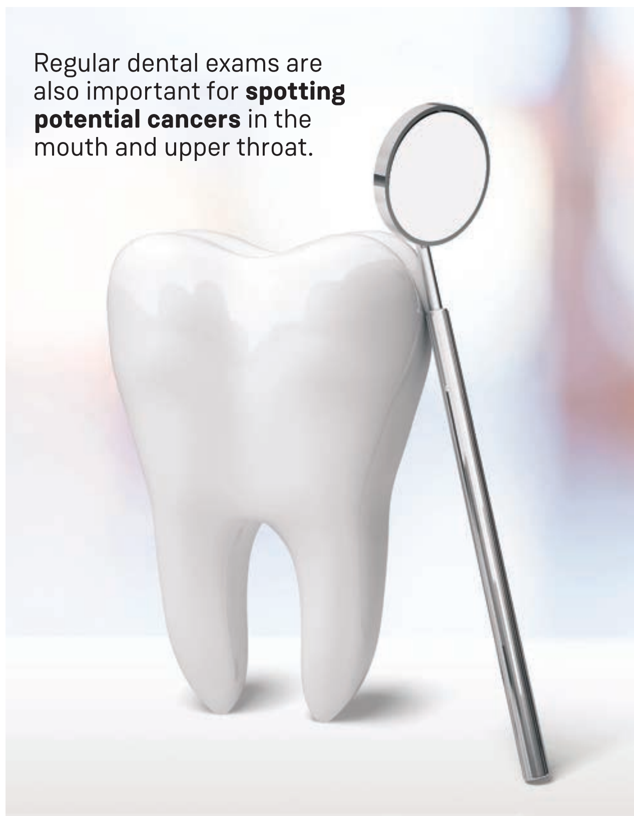
ARTHRITIS

Osteoarthritis (degenerative joint disease) is common in older adults. HIV does not increase the risk of osteoarthritis, but can cause some other forms of arthritis that lead to pain and swelling in the joints. These HIV-associated flare-ups of arthritis in the joints are usually temporary and can be treated with NSAIDS (aspirin, Advil, and others) or steroids. Some other forms of arthritis, such as psoriatic arthritis or rheumatoid arthritis, may require management by a rheumatologist.[20]

FATIGUE, INSOMNIA, AND SLEEP APNEA

Chronic tiredness in PLWH has many causes, including disturbed sleep, stress, depression, anemia, untreated hepatitis C or chronic liver disease, testosterone deficiency, or hypothyroidism. Sleep disturbance—either difficulty falling asleep or poor-quality sleep—is less likely to occur as a side effect of newer HIV drugs such as integrase inhibitors, but if you are experiencing problems, talk to your physician.

One problem that becomes more common in older people is obstructive sleep apnea. This is a condition in which the muscles of the throat relax during sleep, leading to temporary blockage of the airways. The blockage may last for only a few seconds, but it may occur frequently during sleep, leading to poor-quality sleep and daytime fatigue. The condition is more common in men, in older people, and in those who are overweight. Smoking and excessive alcohol consumption make the condition more likely too.



DENTISTRY

Teeth are often neglected when thinking about aging and HIV, but one problem common to everyone as they age is declining dental health. These problems can be complicated in PLWH by a lack of HIV-friendly dental care within easy reach. A recent study in Texas showed that the need for dental care was especially acute among PLWH who had fallen out of care; more than half had an unmet need for dental treatment when they later turned up as in-patients at a Houston public hospital.[15]

Regular dental exams are also important for spotting potential cancers in the mouth and upper throat. The high prevalence of smoking and alcohol consumption among PLWH, together with human papillomavirus strains that cause some oral cancers, means that they are at higher risk of oral and pharyngeal cancers.

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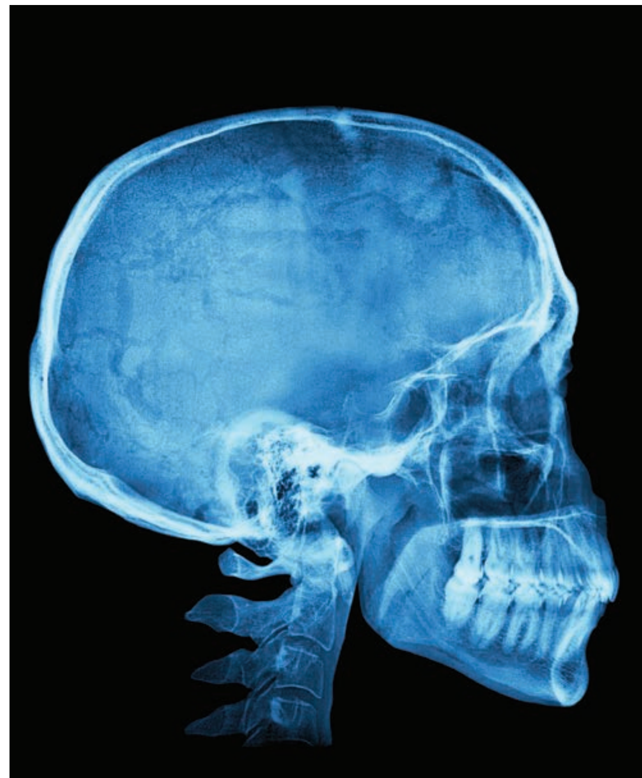


NEUROCOGNITIVE IMPAIRMENT AND DEMENTIA

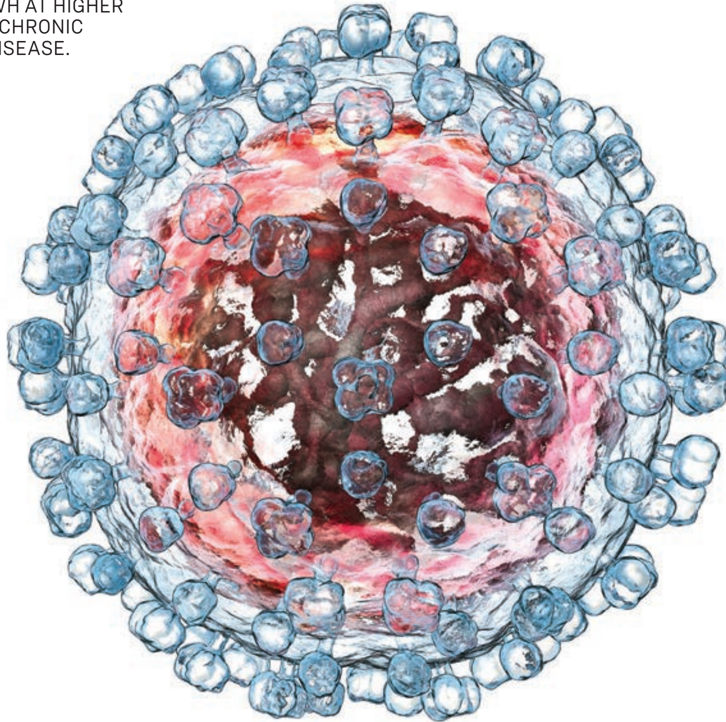
Changes in concentration, memory, decision making, and attention span are a common feature of aging. Neurocognitive impairment—deficits in memory and thinking compared to others of a similar age and background—can range from mild to severe (dementia) and has many potential causes.

PLWH are not at higher risk of major cognitive impairment resulting from HIV. Other risk factors, such as severe kidney disease, obesity, long-term excessive alcohol consumption, depression, high blood pressure, cardiovascular disease, and type 2 diabetes, are likely more important.[21] Having numerous health problems alongside HIV appears to raise the risk of cognitive impairment.[22] Although some studies show subtle deficits in PLWH when compared to others of the same age, there is little evidence that cognitive impairment gets worse.[23] The long-term implications of differences between PLWH and others are unclear.

Careful management of blood pressure, lipids, kidney function, diabetes, and cardiovascular problems can play a part in preventing cognitive decline, along with cutting down on alcohol.

Careful management of blood pressure, lipids, kidney function, diabetes, and cardiovascular problems can play a part in preventing cognitive decline, along with cutting down on alcohol. If HIV seems to be playing any part in cognitive decline, your doctor may suggest changing your HIV drugs to ensure that you are taking a combination that fully suppresses HIV in the brain and central nervous system. Abacavir, emtricitabine, raltegravir, and boosted darunavir penetrate the brain better than other HIV drugs.

HEPATITIS C VIRUS (HCV): CO-INFECTION WITH HEPATITIS C ALSO PUTS PLWH AT HIGHER RISK FOR CHRONIC KIDNEY DISEASE.



KIDNEY DISEASE

Our kidneys work less well as we age, but people with diabetes or high blood pressure are especially prone to loss of kidney function and kidney damage. HIV may also play a role, especially among African Americans, and so may some anti-HIV drugs. Co-infection with hepatitis C also puts PLWH at higher risk for chronic kidney disease.

Kidney damage caused by HIV can be limited by starting HIV treatment as soon as possible after diagnosis. For people who have suffered some kidney damage due to HIV, ACE inhibitors or angiotensin receptor blockers used for treating high blood pressure may be prescribed alongside HIV treatment.

Your physician should monitor your kidney function regularly, along with your blood sugar and blood pressure, and prescribe medication to manage your blood pressure, cholesterol, and blood sugar where needed.

If your kidney function is declining, some anti-HIV drugs should be avoided, especially if you are over 60 and have other conditions that increase the risk of kidney damage. Tenofovir (TDF), atazanavir (Reyataz), and lopinavir/ritonavir (Kaletra) should be avoided. The new formulation of tenofovir (TAF) is less likely to affect kidney function.[24]

Kidney damage caused by HIV can be limited by starting HIV treatment as soon as possible after diagnosis.

LIVER DISEASE

The main cause of liver disease in PLWH is co-infection with hepatitis B or C. Direct-acting antiviral treatment for hepatitis C (HCV) is recommended for all PLWH, regardless of liver disease stage, but HCV treatment is costly and access to treatment depends on health insurance. You can get more information on how to access HCV treatment from HELP-4-HEP, 877-435-7443.

ORGAN FAILURE—THE NEW TRANSPLANT POTENTIAL

When organs are failing, the transplant list is not an easy place to be. Recently however, new hope for people with end-stage organ disease emerged with the news that several research groups in the United States had carried out successful transplants of organs donated by PLWH to others with HIV who needed them. The HIV Organ Policy Equity Act of 2013 permits PLWH to donate kidneys or livers as part of a research study. The National Institutes of Health is running a large trial of kidney transplantation for PLWH, half receiving kidneys from donors with HIV. Heart transplants have also been carried out.

Many of the health problems that face older PLWH are the same as those faced by everyone else but may need HIV specialist input to get the most appropriate care.

CONCLUSION

Many of the health problems that face older PLWH are the same as those faced by everyone else but may need HIV specialist input to get the most appropriate care. See page 15 for more information on care providers.

If there's one action point to take away from this article, it's quit smoking if you can, and get help to quit. Smoking exacerbates many of the problems faced by aging PLWH. Heart disease, high blood pressure, breathing problems and chronic lung disease, gum disease, bone thinning and fractures, reduced kidney function, and cognitive decline are all more common in smokers and likely to be more severe. Medication to help you quit is available and greatly improves your chances of quitting. The National Cancer Institute provides an online tool to help you develop your plan to quit—view it at smokefree.gov/build-your-quit-plan. PA

FOOTNOTES AT POSITIVELYAWARE.COM

KEITH ALCORN is former editor of aidsmap.com. Based in London, Keith writes about HIV, TB, and viral hepatitis. His cat Binks pays close attention.

COMPREHENSIVE GERIATRIC ASSESSMENTS

OR, HOW DO I 'GERI'-RIG MY HEALTH CARE?

BY **THEO SMART** AND **LANCE SHERRIFF**

Older adults with HIV (OAWH) often find it difficult to find medical care that meets the complexity of their needs. Talking to our friends in New York City and online, it seems clear that the standard of care that older people living with HIV receive in this country is extremely uneven. Many have doctors who don't seem to do anything other than treat their HIV, monitor and treat their blood pressure and or high cholesterol, and only react to health crises when they occur. Referrals to specialists, when needed, take months and months—time in which people may become increasingly disabled or, worse, die. We've seen and heard of horrible things happen to too many of our friends who didn't receive the appropriate care soon enough.

Helping one of our older friends, an AIDS activist hero, home one night from an ACT UP meeting, he told us how he had been seeing the same HIV doctor in a small practice since the 1980s. They have grown old together. But it is questionable whether this doc has really been on top of all of his complicated health issues and often there are challenges getting him the timely specialist referrals he needs. As we helped him carry his oxygen tank in the subway (he insisted on taking the subway), he told us that he had had heart attacks that had gone undetected. He said that his heart condition and other multiple comorbidities were only diagnosed when he landed in a hospital in Europe due to a heart attack. It doesn't seem that his care has been up to the same standard since coming back to the U.S. Recently, he suffered a fourth heart attack, winding up in a different hospital here in the city (which, by the way, never seemed to have an accurate list of which medications he was supposed to be taking—but that's another story).

Counterintuitively, we have other friends who don't live in one of the cities with big HIV clinics or HIV 'hero docs.' Instead, they see non-HIV general practitioners, in some cases, even old country doctors. Their HIV regimens may not be the most up-to-date, but they seem to receive better screening and treatment for the complex health conditions typically seen at much older ages. Why is this?

"HIV clinicians who provide care for people living with HIV are not skilled in 'multimorbidity management'—they did not 'sign up' to manage multimorbidities, rather they wanted to specialize in HIV," according to Steven Karpiak, PhD, Senior Director for Research at the ACRIA Center for HIV and Aging at GMHC, which has conducted a number of surveys into the care being received by older people living with HIV. However, he added, older people with HIV "are increasingly aware of the changes in their health status as they age. They expect their providers to exhibit similar awareness."

The truth is that many of us—even at age 50 and older—have more than one or two comorbidities. Some of us have a mix of complicated things going on at the same time, conditions such as frailty, sarcopenia (muscle wasting), polypharmacy, neurocognitive disorders, difficulty sleeping, proneness to falling—which, compounded with weaker bones can lead to injuries and disability, compromised mobility, and problems with the daily functions of life, though the mix of conditions varies from person to person. Many of the syndromes are quite similar to those seen in geriatric patients, though complicated by HIV. In fact, more than half of the HIV-positive population has two or more geriatric syndromes at once, according to a medical paper from aging specialists in France and Italy (including Professor Giovanni Guaraldi, who was mentioned in the Guest Editor's Note). Consequently, the type of personalized care we need isn't exactly geriatric care, but we "might benefit from models of adapted and integrated care developed over the years by geriatricians for the management of their frail and complex patients," the European doctors wrote.

But what really is geriatric care?

"One of the criticisms of geriatrics is that no one really knows what we do," said Dr. Alison Moore, head of the Division of Geriatrics and Gerontology at the University of California, San Diego at the most recent HIV and Aging Conference in New York City. Geriatric

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COMPREHENSIVE GERIATRIC ASSESSMENTS

MEDICAL VISIT
(AT LEAST TWICE A YEAR)

Medical history: Check medical problems, hospitalizations, allergies, adverse events, substance use, sexual habits

Centralized medication history: Check prescription medications, over-the-counter and alternative remedies

Physical examination: Vital signs, body mass index.

Routine tests: Blood/urine tests; viral load and CD4/CD8 and T cells when required

SPECIAL APPROACHES
(AT LEAST ANNUALLY)

Age-appropriate assessment of **comorbidities** (e.g., cancer, cardiovascular disease, bone)

Evaluation of **geriatric syndromes** (falls, incontinence, sleep disorders, confusion, vision/hearing problems, sarcopenia)

Update **vaccines**

Screen for hepatitis C/B and other **sexually transmitted infections** (STIs)

Physical function/frailty measurements (e.g., four-minute walk, time to rise from a chair, or grip strength)

Nutritional assessment

Neuropsychological and psychological evaluation (e.g., depressive symptoms, quality of life, neuropsychological test)

Evaluation of **social** problems

KEY ACTIONS

Prevent chronic conditions or ensure early detection and control

Check **drug-drug interactions**

Stop unnecessary drugs (STOPP/START criteria)

Choose the most **appropriate antiretroviral** regimen according to the patient's conditions

Reduce risk factors and encourage health behaviors. Counseling on **diet and physical activity**

Intervention for **sensory and physical** problems

Maintain **muscle mass** and **bone density** through exercise and nutrition

Treat the underlying **causes of decline** in capacity

Cognitive remediation if neurocognitive impairment

Psychology/psychiatry if psychological problems (e.g., anxiety, depression)

Social workers if social problems

Capacity enhancing **behaviors**, strengthening personal skills, and building **relationships**

ADAPTED FROM NEGREDO *ET AL.* AGING IN HIV-INFECTED SUBJECTS: A NEW SCENARIO AND A NEW VIEW, IN *BIOMED RESEARCH INTERNATIONAL*, 2017

ISTOCKPHOTO

‘One of the criticisms of geriatrics is that no one really knows what we do.’

care, she explained, is focused on “5 M’s”: what **matters most**—**mind**, **mobility**, **medications**, and **multicomplexity**.

Matters most means knowing and acting upon each person’s own health outcome goals and care preferences.

Mind is identifying and managing cognitive impairment, depression and mental health, and in some cases dementia and delirium.

Mobility: geriatricians try to identify impairments in gait and balance, implement an individualized fall prevention program, and create an environment that enables mobility for each person.

Medications: As we age, we tend to accumulate prescriptions and on top of that self-medicate with over-the-counter medications. Too many, in fact, and they often interact and have cumulative unanticipated effects. For instance, many cases of delirium are the consequence of taking too many medications, including over-the-counter sleep aids, that have an anti-cholinergic effect (small but cumulative effects on brain function or chemistry). The use of multiple medications is actually considered a syndrome called polypharmacy. Geriatricians look at optimal prescribing: watching for adverse medication effects and medication burden, adjusting doses, and de-prescribing in order to reduce polypharmacy.

Multicomplexity: Identifying and managing multi-morbidity, and complex biopsychosocial situations—including stigma, psychosocial problems, changes in living situations/environment, social support, spirituality, sexuality and intimacy, employment, and food and housing security.

Essential to the geriatrician’s approach to care is something called a comprehensive geriatric assessment (CGA), which is a diagnostic process that evaluates these multiple dimensions that affect our overall health. The goal of the assessment is to develop a comprehensive plan for prevention, treatment, and rehabilitation that meets the needs of each person.

Here’s the rub though: this CGA can be somewhat complicated and time-consuming. It involves a host of standardized screening tools, some that can be performed in the standard clinic and some that cannot. For instance, the most common method for assessing frailty involves a questionnaire, a timed walk test of 15 feet to measure gait, and a grip strength test using a specialized handheld device that most doctors don’t have (though they aren’t expensive). In other words, it would require someone trained and with the proper tools and space to perform the assessment. It would be interesting to hear if anyone is routinely doing such assessments in the middle-aged and elderly people living with HIV who they treat.

“The assessment often, *if you’re lucky*, employs a multidisciplinary team,” Dr. Moore conceded. Nevertheless, she told the doctors in the audience that the assessments could be adapted to the available resources. “It can be done by one person if you have to, it can be done by five people if you are fortunate. It can take an hour if you need to. It can take several visits, if you are able… The particular methods one chooses to conduct the CGA can be individualized to your practice.”

Note: There are many guides on CGA tools online available for doctors. Dr. Moore made reference to *Geriatrics at Your Fingertips*, from the American Geriatrics Society, which is available as a book or mobile app at: geriatricscareonline.org.

After the assessment, the geriatrician shares the findings and concerns with their patient, and a shared decision-making approach is used to decide upon next steps. These may involve stopping certain medications that may be causing problems, understanding and addressing unresolved pain issues, referrals for physical and occupational therapy, and securing assistance from social workers. Whatever the individual agrees is needed. They are then given written instructions (in their own language) explaining everything, and scheduling follow-up visits to review or reassess the care plan or continue evaluation if necessary.

For many of us, this seems a far cry from the existing managed care approach which has the laudable goal of treating all people living with HIV, but in many places seems to strip care to its bare minimum. It’s HIV care on a conveyor belt. Many of our loved ones going to the large HIV treating facilities have complained of being treated like an annoyance whenever they have a complication and treated with suspicion about substance use or abuse if they ever complain about pain, lack of sleep, or muscle wasting, leaving them humiliated. This occurs in a context where “the system” seems to do everything it can to disempower patients. Demanding more and better care from a downtrodden position can be extremely difficult and becomes more difficult the more problems that develop and care that is needed.

In addition to the handful of activists working on these issues, our best advocates may be some of the researchers. In another pivotal medical paper, Dr. Eugenia Negredo of the University of Barcelona and other aging specialists make a powerful case for changing the HIV care model.

“The geriatric literature suggests that care of the older patient with multimorbidities is best managed with the assistance of a multidisciplinary team,” Negredo and colleagues wrote.

There aren’t enough geriatricians even to meet the existing needs among the elderly in this country, but the paper calls for doctors to consider being guided by these principles of geriatric medicine.

“Among HIV-infected persons aged 50 years or older, both general and HIV-specific management considerations can be taken into account and CGA programs should be considered to be incorporated in the HIV clinics in the following years,” they wrote (see next page).

“Providers should seek to understand the future health needs of [OAWH] and modify the goals of care to meet these needs,” the article concludes.

This may be a tall order for our country, which prioritizes spending health dollars on pharmaceuticals, but not in developing the pool of health care providers that are needed.

“There is no evidence that this approach will occur. Structural changes in care delivery require shifts in standards of care as well as the number of specialists being generated by the medical education system,” Karpiak writes in his position paper—though he suggests considering how nurses might be better utilized to integrate such elements into care. More of Karpiak’s recommendations about how to address the needs of older adults with HIV are in his article on page 20. PA

In the 30 years since joining ACT UP in 1988, **THEO SMART** has been an HIV medical writer all over the world, including 13 years in South Africa, where he met his husband Lance Sherriff. Now back in New York, he currently works for ICAP at Columbia University.

LANCE SHERRIFF is a medical reporter and assistant editor with a background in HIV care and counseling in South Africa.

THE ACTIVISTS

ILLUSTRATION BY DAVID MASTERS

Three advocates on developing resilience for communities of people living and aging with HIV

BY **THEO SMART**
AND **LANCE SHERRIFF**

There are serious challenges ahead for people aging with HIV who have a potentially high number of comorbidities, and heightened risks of serious complications and disabilities—but our health care and social services systems are not prepared to respond to the more complex needs of people living with HIV (PLWH) as we age. Our goal is to explore how to build resiliency in ourselves, in our health care, and in our community.

One way to build resiliency is through community building, mobilization, and activism, so we sought input on what should be done from three activists working in this space: Jules Levin of the National AIDS Treatment Advocacy Project (NATAP), Jeff Taylor of the HIV & Aging Research Project-Palm Springs (HARP-PS), and Waheedah Shabazz-El, the Organizing Director of Positive Women's Network-USA.

Each of these activists are contributing in their own way to raise the profile of the unmet needs of OAWH. Nevertheless, as Jules says, the larger community of people living with HIV need to hold our community-based and advocacy organizations accountable. They need to engage in activism for OAWH in a much more substantive >>

VOICES OF RESILIENCE
FROM LEFT: JEFF TAYLOR, WAHEEDAH SHABAZZ-EL, AND JULES LEVIN.

and effective way. On page 20, Stephen Karpiak makes some recommendations for HIV-service organizations to provide more relevant and useful services, and to represent our agenda to the national policy makers.

Jules Levin

NATIONAL AIDS TREATMENT ADVOCACY PROJECT (NATAP)

Jules Levin is the most tenacious AIDS activist one could ever hope to meet. We met in the early ’90s, when he was just learning about treatment—before the advent of effective antiretroviral therapy (ART). There is arguably no one more knowledgeable about HIV and treatment literature than Jules. However, he is frustrated by what he sees as the lack of engagement on the part of the community and research establishment to respond to the needs of older adults living with HIV (OAWH). The following is a compilation of a number of statements Jules has made publicly and in online discussions about HIV and aging.

“It’s the number one problem that’s getting no attention. Everybody’s talking about ‘cure’ and ‘PrEP,’ and they’re all-important—but no one’s paying attention to aging.

“I’ve been working on the aging problem for more than 15 years. Well, it’s 15 years later now and so everyone’s older, and a lot of older people with HIV don’t even realize what’s going on. Every comorbidity is worse in people aging with HIV.”

- We have more comorbidities (three to eight on average) compared to HIV-negative people the same age.
- We have fifty percent more heart disease (cardiovascular disease, myocardial infarctions, and stroke rates are much greater among people living with HIV).
- We have higher rates of death from stroke.
- We have a much greater prevalence of kidney disease.
- HIV-positive people are at greater risk for fatty liver/non-alcoholic hepatic steatosis (NASH) as we have all the risk factors: diabetes, heart disease, lipid abnormalities, hypertension, metabolic abnormalities—it’s estimated NASH will one day be the greatest cause for liver transplantation.
- We have twice the rate of osteoporosis, fractures, and falls.
- Women aging with HIV face more health challenges than men.
- Depression, anxiety, and insomnia are three to seven times higher among OAWH.

> ‘It’s the number one problem that’s getting no attention. Everybody’s talking about cure and PrEP, and they’re all-important—but no one’s paying attention to aging.

- We have a greater burden of polypharmacy, more disability, more cognitive impairment, and a loss of daily independent functioning.
- A recent study from London reported that 77% of deaths among PLWH were due to comorbidities—AIDS-related conditions were the cause of death in only 15–25% of deaths.

There are only two HIV and aging/geriatric clinics in the U.S.—at Cornell and the University of California–San Francisco—but the problem extends far beyond those two clinics. Jules says we need clinics everywhere that provide special support services for OAWH and that offer better education for clinicians and expanded broader research.

Many people who are stuck in overwhelmed HIV clinics do not get the attention they deserve. One study last year found that 50% of OAWH in Washington, D.C. did not get treatment for comorbidities. In New York City, a significant number of OAWH are already homebound, depressed, and socially isolated. They do not have the wherewithal to seek out expensive treatments—which may or may not work.

Jules explains that special care and better coordination are vital to ensure that patients see the specialists they need and receive necessary treatment and services. These include better patient contact and follow-up, detailed in-depth attention, homecare, food shopping, and household maintenance. “We need to address social isolation and the fact that many are emotionally and physically impaired. With increasing disability, the need will also increase for housing and institutionalizing of those who are unable to care for themselves at home. Integral to the HIV epidemic is a population who are often living alone—having lost friends and family, unlike the HIV-negative general population, who are more likely to have family and children to assist who can care for them as they age.” As he points out, many OAWH do not have this.

Jules says that some older patients are so cognitively impaired they are unable to stay in follow-up; they don’t even recall what their specialists recommended. Moreover, their primary care provider does not have the time to address this either—which is why he says we need extended visit times, care coordination, and special support services.

Jules feels that the large community-based AIDS service organizations in major U.S. cities and Washington, D.C. policy groups have done little to influence federal or local officials to address these needs.

He points to the work being done in Europe, where the community has formed an aging coalition and meetings have been held across the continent to influence government officials. “The European AIDS Treatment Group (EATG) and many other advocates are leading this movement, but there is *nothing* like this in the U.S.,” says Jules.

As determined and tireless as Jules is, he can’t affect these policy changes on his own. His call to action needs an engaged community response. We asked Jules what we need to do.

“Please tell U.S. government officials and advocates that we need to better address this ‘new’ HIV epidemic.”

- We need special support services for those aging who need them in their clinics.
- We need more education for clinicians regarding prevention, care and treatment for key comorbid diseases including heart disease; brain, neurologic and cognitive impairment; and depression and social isolation—reaching out to the homebound.
- We need broader and expanded research, including more patient-focused research. NIAID [National Institute on Allergy and Infectious Diseases] priorities list aging/comorbidities in the top five, but this is a red herring. In reality NIAID and OAR [Office of AIDS Research] have made it clear to researchers that funding is severely limited in this field. Many study funding requests are denied. Requests to NIAID, the Department of Health and Human Services, and OAR to begin addressing these problems are ignored. Long-term care and living plans are not even discussed.

Jeff Taylor

HIV & AGING RESEARCH PROJECT, PALM SPRINGS (HARP-PS)

"Palm Springs is a beautiful place, but it is more than just palm trees, swimming pools, and fabulous mid-century architecture. I like to call it, 'God's Waiting Room for Older Gay Men Aging with HIV'," Jeff Taylor of the HIV & Aging Research Project-Palm Springs (HARP-PS), said at the HIV and Aging Conference in New York City last September. He explained how the coming together of a particularly large community of OAWH has created a unique environment for patient-focused research into HIV and aging.

According to epi-data from the Ryan White program in Riverside County, 78% of PLWH in Palm Springs and the surrounding cities are over 50 years of age; nearly 40% of those are over age 60; 10% over 70; and 1% are over the age of 80. There's even one individual who is 92 years old. Given the high rate of migration to the valley, there are many more people who are unaccounted for in the available epi-data. Extrapolating from the HIV caseloads of the top three HIV providers in the valley, and factoring in the Veterans Administration, Kaiser, and other health systems, it is estimated that there are approximately 10,000 PLWH in the region with a similar age distribution.

The story of this community was depicted in a 2015 documentary *Desert Migration*, which examined the phenomenon of HIV-positive gay men moving to the desert.

"It was mostly because they had been priced out of expensive coastal California cities like San Francisco, because we have a very welcoming LGBT community, and an embarrassment of riches in terms of competent HIV providers (many are HIV-positive and aging themselves), and HIV services," Taylor said. "As a result, Palm Springs has one of the highest prevalence of HIV-positive people over age 50 in the nation—we estimate that to be about twelve times the national average."

Recognizing that this demographic represented an opportunity, about five years ago a group of Coachella Valley HIV providers and PLWH collaborated to create HARP-PS, a non-profit community-based initiative.

"We have received a two-year capacity building grant from the Patient-Centered Outcomes Research Institute (PCORI)," Taylor said. During those two years, the organization is tasked with bringing together all the community-based groups, care providers, and activists interested in this issue and developing the organizational structures and capacity to conduct research on an ongoing basis—and "most importantly," said Taylor, "to identify and explore key topics for future research."

A series of focus group meetings identified key health issues, resiliencies, and research priorities within the community.

"Cognitive function, dementia, and memory loss are a huge concern for people living with HIV," said Taylor, though isolation and depression and financial strain were highlighted as important health issues or health considerations. "We can treat people medically, but they have a lot of psychosocial issues that are holding them back and those need to be addressed," said Taylor.

'We can treat people medically, but they have a lot of psychosocial issues that are holding them back and those need to be addressed.'

"Secondly, and really important for us, is the concept of resiliencies. Many people are aging healthily with HIV and we want to identify what those resiliencies are, what the resources are that can help people achieve those resiliencies, and what choices people have that they can make to live healthily," said Taylor.

Finally, Taylor said that OAWH in Coachella Valley are also living with inflammation and comorbidities and see those as research priorities. They would also like to see interventions affecting neurologic function studied.

A scientific retreat was held to come up with study ideas or concepts to evaluate—among which was the establishment of a cohort study on inflammation.

"We're very acutely aware we have a unique population of aging people, and that one of the deficits in research is we don't have a lot of data in people over 65, especially in their 70s, 80s, and 90s—and that can obviously serve as a platform for a lot of other research interventions."

Among the ideas to evaluate are investigating the role of the flora and fauna in our gastrointestinal tract on cognitive function, the effect of diet and exercise on cognition, and methamphetamine interventions. They also want to evaluate the comparative effectiveness of community programs to address isolation and depression in OAWH.

California also provides a unique context to study the effects of cannabis use in the community. Another study will evaluate the use of a single dose

of psilocybin (the active ingredient in "magic mushrooms") in a controlled setting on the post-traumatic stress disorder (PSTD) that many long-term survivors are experiencing as a result of having lived through the HIV epidemic.

Currently, HARP-PS is performing a study on the effect of tesamorelin on both visceral fat and HIV-associated neurocognitive disorder (HAND), conducting a survey to measure resiliency factors in the community setting, and performing an evaluation of the effectiveness of group cognitive behavioral therapy for people with HIV-epidemic related PTSD—with the involvement of the grassroots organization Let's Kick ASS (AIDS Survivor Syndrome).

CREATING A FRAMEWORK FOR HIV SURVIVAL

Another nationwide grassroots organization that Taylor is involved in is The Reunion Project (TRP). Now in its fifth year, TRP is led by a national steering committee made up of PLWH, including many who are long-term survivors. TRP conducts single-day seminars in various cities across the country to bring people together to combat isolation and build community. TPAN, the publisher of POSITIVELY AWARE, serves as fiscal agent for The Reunion Project, and recently joined TRP in a three-year collaboration called Positively Aging. Positively Aging will allow TPAN to increase direct services to older persons living with HIV in Chicago, and The Reunion Project to expand its support network through its unique "town hall" programs. Information about the project and issues surrounding aging with HIV will be shared with the national POSITIVELY AWARE audience.

"We get people together, acknowledge and spend a lot of time dealing with the psychosocial impact of the epidemic, addressing the trauma that people have been through," said Taylor. "It's also meant to be educational; there are breakout workshops where people can learn more about clinical aspects of research, such as what's available in their community. Usually there's a keynote speaker and a very strong social aspect with meals and events."

The Reunion Project recently hosted a national roundtable in Rancho Mirage, California with HARP-PS, to bring together grassroots advocates from around the country who've been addressing this at the local level.

"We acknowledged that there's a lot going on in local communities, but people don't really know what's happening elsewhere, and we thought it valuable to bring people together. We called it 'Creating a Framework for HIV Survival,' and created a document that's been posted on the TPAN website (tpan.com/reunion-project)," said Taylor.

'We acknowledged that there's a lot going on in local communities, but people don't really know what's happening elsewhere, and we thought it valuable to bring people together. We called it *Creating a Framework for HIV Survival.*'

Several main themes emerged at the roundtable that advocates want to explore:

- More research into both medical and clinical care as well as socio-behavioral research.
- Programs: What kind of programming can community-based organizations offer to long-term survivors in their communities?
- Community building: How do we build community both locally as well as nationally so we can do more in this area?
- Advocacy: How do we go to the national level and make sure that we get the funding and the services we need to help people age healthily as the epidemic progresses?

Taylor and HARP-PS are also engaging with the AIDS Clinical Trials Group (ACTG) to prioritize research into aging and on the long-term effects of HIV treatment (not just in the U.S. but also globally). Taylor is pushing for the ACTG to gather more data on OAWH over the age of 65 years, and to form an ACTG Aging Working Group.

Other items on HARP's agenda:

- To develop collaborations with other large cohorts of OAWH.
- To advocate for more behavioral and social science research to design and measure the kind of interventions that can improve the lives of people as they get older.
- To find ways to incorporate HIV into geriatric care, including training a new generation of providers in both HIV and geriatrics; and
- Collaborate to develop clinical recommendations and guidelines for the care of OAWH.

"And, of course, as we did since the beginning of the epidemic, both the research and provider communities need to partner with people living with HIV to advocate for what we need—such as research, services, and funding. We did this 30 years ago. I know we're old and tired now, but this is a problem that's not going to go away. If we don't address it now, it's just going to get worse. As 'cranky' and old as are, we need to 'ACT UP' and advocate for what we need," Taylor concluded.

SHABAZZ-EL: HOLLY CLARK

Waheedah Shabazz-El

POSITIVE WOMEN'S NETWORK–USA

We asked Waheedah Shabazz-El, the Organizing Director of Positive Women's Network–USA, to tell us about her background and her activist priorities to build resilience into the community of people aging with HIV.

LANCE SHERRIFF: **Can you tell us a little bit about**

yourself and your experience as an activist living with HIV?

WAHEEDAH SHABAZZ-EL: I came into the world of HIV as an older person. Diagnosed with AIDS at the age of 49, having taken my first HIV test, I was told not only did I test positive for HIV, but that I already had AIDS. My activism took off rather quickly in 2003, through amazing mentors placed in my path, including ACT UP/Philly's John Bell, Project TEACH's Laura McTighe, CHAMP's JD Davids, and University of Johannesburg's Farid Esack, to name a few.

SHERRIFF: **What do you think are the chief challenges for people aging into their 50s, 60s, and beyond in your community?**

SHABAZZ-EL: Health care is an issue for all people who are aging. Those aging with HIV are in need of health care from providers and other specialists that have the very latest information and education around HIV. High quality geriatric care ought to be available, accessible, affordable, and non-discriminatory. Developing a "Standard of Care" for people aging with HIV—so folks do not "fall out of care." That care ought to include transportation, because as people age generally their mobility decreases. People aging with HIV need stable, affordable, and safe housing options that are non-stigmatizing.

SHERRIFF: **How can our community better respond to depression and isolation among older people living with HIV?**

SHABAZZ-EL: By creating opportunities for people aging with HIV—not just to gather, but to assist with the planning of an event where they can share their own stories of survival and resilience. Aging people are holding the history of the HIV/AIDS movement. We need to find ways to consult older people living with HIV and document their stories of survival. These programs ought to be held in places that offer a safe and nurturing environment. Next steps must also be guided by those who are most impacted—meaning we support people aging with HIV with transportation as well as the use of technology such as video chatting and Zoom so they can continue to engage and be engaged.

SHERRIFF: **Surveys in several cities suggest that financial hardships, housing insecurity, and even food insecurity are leading concerns in the aging population with HIV. How do we as activists best respond to these challenges?**

SHABAZZ-EL: Surveys and listening sessions are always good ways to gauge the needs of specific communities. In the early days, as a result of stigma, many people living with HIV were forced out of their jobs, their livelihoods. An HIV diagnosis also condemned many to a life of poverty. As people age many find they have specific dietary needs—our providers are all too aware of this. Geriatric-based case management is a service that may help alleviate some of the barriers to nutrition and housing for people aging with HIV. Supplemental food vouchers, and fresh and cooked food delivery services, are very much needed. For those who own their homes, people aging with HIV need services that help to ensure we have functional heating and cooling and general maintenance. Homeowner insurance and warranty services are often extremely challenging on fixed incomes. And so, [we need] case management that understands the pressures and challenges of aging with HIV. Those who may need assisted living and identify as gay ought to have access to housing services that are not homophobic and forces people back into the closet in order to be safely housed.

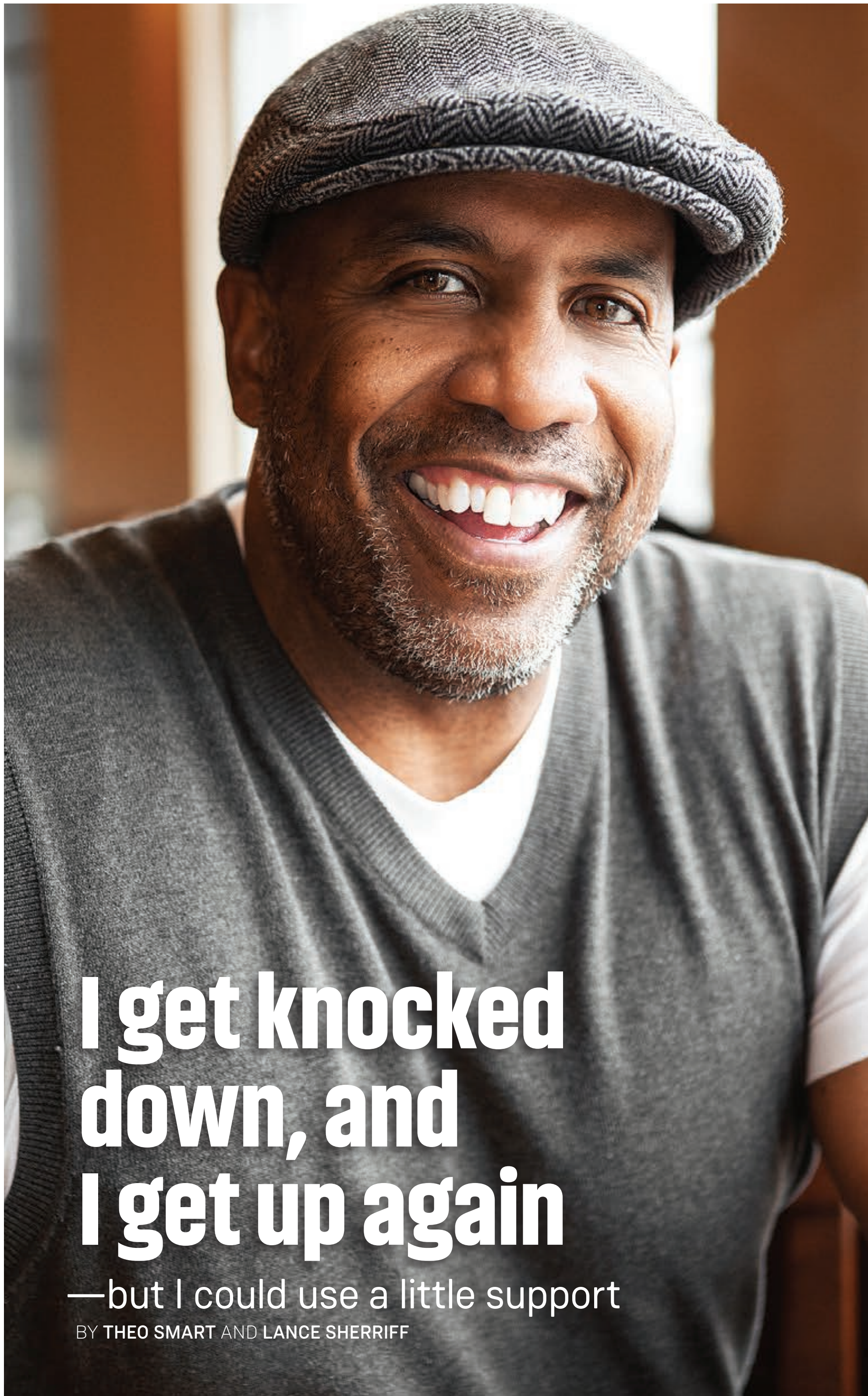
> 'Geriatric-based case management is a service that may help alleviate some of the barriers to nutrition and housing for people aging with HIV.'

SHERRIFF: **We've heard about your participation in The Reunion Project (TRP). Can you tell us about your role in it and about other activists working in this space?**

SHABAZZ-EL: I am a TRP Steering Committee Member as well as a member of TRP's Core Management Team. I was attracted to TRP because I am a long-term survivor of the AIDS epidemic. I was asked to join the Steering Committee to help develop TRP's diversity plan of inclusivity. I was excited to bring the voices and perspectives of women and black people to TRP. The epidemic today looks strikingly different than it did 35 years ago and TRP recognized that reality. TRP's Core Management Team meets weekly to ensure the growth and reach of TRP. We are very intentional about our grant deliverables, rolling out TRP events in the most impacted areas in the U.S. Our effort is to combat isolation and provide spaces for long-term survivors where they find a sea of calm knowing their hearts are being held by other long-term survivors—this happens through the sharing of our experiences of survival and resilience. TRP events are designed to hear from our community members.

SHERRIFF: **Any other issues close to your heart about HIV and aging?**

SHABAZZ-EL: The lack of social safety nets for people aging with HIV is a great concern: The constant attacks on Medicare-protected classes of (one-pill, once-daily antiretroviral) drugs. The classification of HIV as a chronic condition has put psychosocial services in danger without taking into account that there is still so much stigma to deal with (unlike with other chronic conditions). Homeowner's insurance (which would pay off a home mortgage upon the homeowner's death) is denied due to pre-existing conditions. Barriers to life insurance due to pre-existing conditions. Finally, there is a lack of geriatric case management services that leaves people aging with HIV with challenges of access to transportation, food, safe housing, and technology as well as geriatric specialty health care. PA



I get knocked down, and I get up again

—but I could use a little support

BY **THEO SMART** AND **LANCE SHERRIFF**

"When we think about aging, what we usually picture is a gradual decline in physical function—but it's not always like that," Dr. Todd Brown of Johns Hopkins University told the audience at a recent forum in New York held by the National AIDS Treatment Advocacy Project (NATAP). "These drops in physical function are often precipitated by health events."

He described the story of an older adult living with HIV (OAWH) who was doing well until the age of 52—then the person had a heart attack, and a decrease in physical function—and never quite got back to the fitness level they operated at before. Then, weakened, they contracted pneumonia and were hospitalized. Before they fully recovered, they suffered a hip fracture—leading to a major effect on their quality of life and mobility. The ability to perform the routine activities of living plummeted. The person grew even weaker and frail until something even more serious happened—they had a severe stroke.

"The important thing is to get back to your previous level of function after that event," said Dr. Brown. "When people are hospitalized, it is important that they can get physical therapy or occupational therapy so that they can bring back their level of function. It's vital to have that as a goal of recovery."

Physical and occupational therapy are indeed critical so that one can safely get physical activity back up to previous levels, though it may be a challenge to get insurance or managed care plans to pay for all the visits needed. Even in Canada, where access to these services is more readily available, a web-based national survey found that very few people living with HIV (PLWH) were accessing formal rehabilitation services: Only 17% had visited a physio or physical therapist in the past year, and only 6% had seen an occupational therapist. A little over one-third did report exercising regularly. However, while people should be motivated to get back into good health, the responsibility for rehabilitation should not be placed solely on the person who has had a health setback or who is in great pain. Health care services should be actively seeking out people who are falling through the cracks after a health emergency as well as retaining such clients.

ISTOCKHPHOTO

Furthermore, these crises are never solely physical. According to one physiotherapist and researcher, Kelly O'Brien of the University of Toronto, Canada, speaking last year at the HIV and Aging Conference in New York City, PLWH of all ages experience episodic disabilities that "may involve physical, cognitive, mental, and emotional symptoms and impairments, difficulties carrying out day-to-day activities, challenges to social inclusion (the ability to take part in society), and uncertainty about the future—worrying when the next illness might arise and what the consequences of that illness might be," she said. Even in the absence of any existing physical or cognitive problems, this uncertainty about the future can have a powerful effect on one's mental and emotional health. And, said O'Brien, studies specifically looking at OAWH have shown that these uncertainties only increase as we age.

Non-physical disabilities such as the depression that many of us experience often precede the physical setbacks that Dr. Brown described and, notably, can have a major influence on whether PLWH keep physically active, which in turn, affect the likelihood of additional episodes of disability and declining functional abilities as we go on.

Additionally, the context within which the disability occurs may affect the ability to fully recover. Aspects of your social, physical, and financial environment "may exacerbate (or alleviate) the disability... and one's ability to engage in sustained physical activity over time," O'Brien said. Stigma, for example, has consistently been shown to have a toxic effect, while certain living strategies, such as maintaining a sense of control over life and seeking social interaction with others, improve one's chances of recovery. Social support is critical: support in terms of accessible health care services and health care providers, program and policy support that help to maintain income and housing security, and support from friends, family, partners, pets, and the community.

"Selfcare may be difficult for those OAWH who lack the support of family and friends. The majority of OAWH are not partnered or married, with 60–70% reporting living alone," according to Stephen Karpiak at the ACRIA Center for HIV and Aging.

People with a disability, whether physical or emotional, need social support to recover and stay active. As Karpiak and the HIV and aging activists point out, it is critical that we engage our community-based organizations to develop effective interventions to address the isolation experienced by OAWH. We must do this before we experience a disability, to make certain that those services are there for us, as well as one another, when we need them.

The benefits of exercise

Another critical task for our community organizations would be to make certain that middle-aged and OAWH have easy access to exercise interventions (such as supervised aerobic and resistance exercise) that have been shown to have rehabilitative and protective effects against disability in people living with HIV.

O'Brien presented the findings of some systematic reviews (in mostly young and middle-aged PLWH) indicating that such exercise programs led to statistically significant (and potentially clinically meaningful) improvements in heart and pulmonary fitness, and in the case of resistance exercise, improvements in body composition (decreases in body fat), muscle mass, and upper and lower extremity strength.

In addition, a few of the studies looked at quality of life measures, and saw major improvements in a number of areas including mental and emotional health and physical function. Studies have also shown that consistent exercise can offset a decline in neurocognitive health among OAWH. There are also metabolic benefits—reducing insulin resistance, triglycerides, and inflammation. Other studies show that regular physical activity improves the quality of sleep in PLWH—and one study reported a reduction in fatigue.

> Physical and occupational therapy are indeed critical so that one can safely get physical activity back up to previous levels, though it may be a challenge to get insurance or managed care plans to pay for all the visits needed.

Even moderate exercise can have some benefits, but higher intensity exercise leads to the most significant cardiopulmonary benefits and improvements in stamina and physical function.

O'Brien and other colleagues in the field synthesized all of this research and published guidelines for rehabilitation professionals working with OAWH online (go to bmjopen.bmj.com/content/4/5/e004692.full).

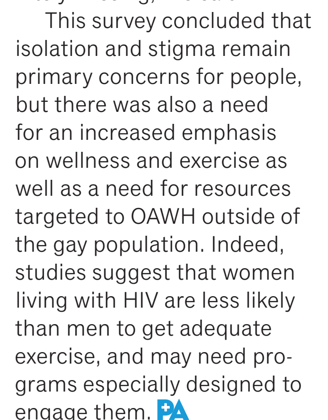
But studies suggest that about half of us (and according to some studies up to 70%) are not getting the recommended 150 minutes of moderate to vigorous physical activity each week—and fewer are getting in the recommended 10,000 steps per day. Factors such as pain, depression, and physical illness are major barriers to engaging in regular exercise, so it is something of a vicious cycle.

Of note, O'Brien reported the results of a community-based exercise intervention (including a weekly coaching session with a personal trainer), which found that the major factors influencing whether people initiated and stayed engaged in the program had mostly to do with the complexities of living with an episodic illness, including mental health or complex personal and environmental factors (e.g., relationships with others, stigma, and financial insecurity). O'Brien said that after the research study concluded, only those "with the financial means" kept to personal training even though it was found to be associated with the most benefit.

This point was highlighted by Jules Levin of NATAP who was in the audience: "There's no question that the benefits of exercise are widely known," he said. "The problem is scaling up and implementing something like this in major cities. It is difficult to get clinicians to buy into—to get patients to buy into, because PLWH tend to be so sedentary. And then there's reimbursement and paying for it all. These are all issues that are difficult to address. It is not on the radar of federal reimbursement, like Ryan White. This is not on anyone's radar, except in New York where it is under discussion."

Indeed, in New York City, gym service fees were cited as a significant barrier to initiating an exercise program by OAWH. At a recent community forum, Scott Spiegler of the New York City Department of Health reported that "over 80% of survey respondents indicated that community fitness programs were either not meeting the needs of the population, or their needs were being somewhat met but there was something definitely missing," he said.

This survey concluded that isolation and stigma remain primary concerns for people, but there was also a need for an increased emphasis on wellness and exercise as well as a need for resources targeted to OAWH outside of the gay population. Indeed, studies suggest that women living with HIV are less likely than men to get adequate exercise, and may need programs especially designed to engage them. PA



Addressing the needs of older adults living

Embracing a too often abandoned population

BY **STEPHEN KARPIAK, PhD**

The ACRIA Center for HIV and Aging at GMHC investigates, defines, and seeks to address the unique needs and challenges that older adults of diverse populations living with HIV face as they age. Through research, education, and advocacy, the Center fosters the open exchange and dissemination of information within the lay and scientific communities and among both older adults and AIDS service providers.

Stephen Karpiak, PhD, GMHC's Senior Director for Research at the Center for HIV and Aging, on faculty at New York University and director of the soon to be launched National Resource Center on HIV and Aging, recommends the following to be part of advocacy efforts by the community and its institutions.

Older adults living with HIV (OAWH) are the majority in the HIV epidemic in the U.S. These older adults include long-term survivors. Yet even for the casual observer of programs based in AIDS service organizations (ASOs) or community-based organizations (CBOs) that target people living with HIV (PLWH), the number of programs aimed at these older adults are scarce. This needs to change. In fact, the activism that characterizes the first decade of the HIV epidemic produced the large networks of ASOs in the U.S. Many OAWH who had once accessed services at these community-based organizations have since abandoned them. They encounter programs where the emphasis on prevention of HIV in high-risk youth and young adult populations often dominates. Such much needed programs are "sexy," aging is not. Welcome to ageism. We live in a society where youth receive the highest premium. Aging is seen as a disease rather than an inevitable process of living.

As OAWH age and exhibit significantly higher rates of multimorbidity (having two or more chronic conditions), the need to optimize their medical care and supportive services is clear. The HIV treating provider now spends most of their time managing non-HIV conditions. The delivery of medical care to OAWH is a structural issue that can best be addressed by shifts in health policy and the underlying standards of care. This is especially true as health care moves toward a community base. For OAWH, their care needs begin where the HIV Treatment Cascade ends.

> Women account for almost 25% of OAWH. They are too often forgotten. They share common needs with older men, but also confront challenges that are unique.

Some might argue that AIDS exceptionalism is no longer operative for these OAWH. They confront the same challenges of aging and managing multiple health issues that are common in the general aging population.

But they are also burdened by toxic levels of stigma and lack of economic supports, as well as poorly managed mental health issues. And, they live each day with an infection that is fatal if not treated relentlessly.

OAWH exhibit 3–5 times higher rates of depression, which is reinforced by their often self-imposed social isolation as a reaction to the fear of disclosing their HIV status—fear of rejection as well as physical harm.

Many observe that as gay activists won the right to marriage, the "glue" of the gay community has been lost. Men who have sex with men (MSM) account for more than half of all OAWH. The slow dissipation of gay communities due to economic intrusions, the web, and shifts in culture have in part caused those communities to be "absent" as OAWH seek their support, especially to meet their need for socialization and caregiving.

Women account for almost 25% of OAWH. They are too often forgotten. They share common needs with older men, but also confront challenges that are unique. Research shows that they are more often far more empowered than their male counterparts and exhibit high levels of resiliency.

RECOMMENDATIONS

■ **As ASOs and other CBOs seek** to provide appropriate services for OAWH, they need to bring their OAWH clients into their decision making, but also people from the aging arena. Who knows more about aging and its challenges than those who have worked in, conducted research on, and provided services in aging for nearly a century? HIV hubris must be put aside to make the path clear for those who are most knowledgeable about aging as programs are devised. SAGE and the SAGE network, which focuses on providing supportive services and advocacy for LGBTQ seniors, is an experienced resource in aging. The same applies to AARP as well as

with HIV

Older adults living with HIV comprise a resource that needs to be activated. We can learn from them their remarkable levels of resiliency.

the U.S. Department of Health and Human Services' ACL (Administration for Community Living). Engaging the ACL network by connecting with their local programs, which include sustaining relationships with providers of care and support for those aging, is a logical and economically viable step. There are extraordinary resources that should be joined.

■ **ASOs and CBOs need** to create a welcoming environment for OAWH. This can result in reducing ageism as well as bridging the chasm between younger and older PLWH as well as engendering their participation in programs. Is the membership of the much-touted local Community Advisory Board (CAB, part of research trials) reflecting the present epidemiology of those living with HIV? Are older adults represented? These same considerations need to occur on local Ryan White Councils (Eligible Metropolitan Areas, or EMAs) and Prevention Planning Groups.

■ **Cultural competency** regarding OAWH necessitates training of staff, including those at ASOs and local health departments. Many curricula exist that address this need. Targets for such trainings include long-term care facilities as well as other residential programs for older adults.

■ **The total sum** of resources that support PLWH/OAWH as well as those aging is large. OAWH cannot be connected to available services unless those services have been identified. A simple referral of an OAWH to an agency program is not sufficient. The referral must be made to a person(s) within that agency where the target program or service exists. Platforms have been developed (like One Degree and NowPow [supported by millions of dollars invested by the Centers for Medicaid and Medicare Services]) that are electronic bridges between health care and social service providers. These are partnerships of traditional health care with innovative technology. The programs enable information and services to be identified and made available to clients. These platforms connect patients to community resources that will provide support to manage chronic health and social conditions. Such programs leverage local social support services that can address social determinants of health. ASOs do not need to reinvent the wheel in order to provide supportive services in their community. It has been done—develop partnerships with service providers helping aging populations.

The HIV treating provider now spends most of their time managing non-HIV conditions.

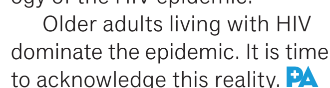
■ **Buddy programs** (visiting programs) that connect people are needed. It is important to recall that those buddy programs of the 80s and early 90s provided support for people living with HIV who had received an AIDS diagnosis. Prior to antiretrovirals, supporting them was a short-term effort. In fact, with the advent of highly effective HIV treatments, the buddy programs disappeared. Today such programs are needed to provide a human connection, often for many years given the course of most chronic conditions that comprise multimorbidity. New buddy programs need to show efficacy as well. Can they replace the informal caregiving the aging person with HIV needs?

■ **OAWH comprise** a resource that needs to be activated. We can learn from them their remarkable levels of resiliency. They are a significant resource that can help guide ASOs to develop programs that address their unique needs. Such programs will vary by locality, gender, age group, etc. It is likely that some groups will be small and others larger. Small funding for peer-initiated efforts, using a structured monitoring system, could yield an unexpected array of effective supportive programs.

■ **Develop a** local or national speaker's bureau on HIV and aging. Speakers can include long-term survivors and OAWH peers. Care should be taken to assure that the content of speaker presentations is valid and universal.

Lastly, an HIV and Aging Conference is needed where OAWH and those who provide clinical and social care are joined. A conference where there can be a frank and safe exchange of ideas is needed. Too often OAWH are relegated to a "guest" appearance. This is unacceptable and needs to be redressed. Such a conference will generate new ideas, validate present efforts, and bring OAWH into the dominant role they deserve based on the present and near future epidemiology of the HIV epidemic.

Older adults living with HIV dominate the epidemic. It is time to acknowledge this reality.



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