Embracing Life

New challenges for women aging with HIV require more research.

February 24, 2020 By Kate Ferguson

Melanie Reese had been living with HIV for about a year when she visited her dentist for a routine checkup in the early 2000s. “Oral health care is so important if you have a chronic illness or are just aging,” she says.

“When they learned I was HIV positive, they dressed up in what looked like space suits and tried to look in my mouth from a yardstick distance away, which was humiliating, degrading and just not an optimal experience,” explains Reese, who is now 67. “After that, I avoided the dentist for four and a half years—didn’t go for anything—so that led to gum disease and bone loss. I lost six of my front teeth as a result of fearing to be put in that situation again.”

But the incident didn’t crush Reese’s spirit. Instead, she became an advocate—first for herself and then for others.

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In 2005, Reese joined Older Women Embracing Life (OWEL), an HIV support group cofounded by a woman she knew named Dorcas Baker, who was at the time a research nurse at the Johns Hopkins Institute of Clinical and Translational Research. OWEL members are mostly from the Baltimore and Washington, DC, area.

“We support each other by sharing our experiences dealing with stigma, treatment, medication adherence and [through] group and individual support of women and girls living with HIV, those who may be at risk for the virus or those who are caretakers of people living with HIV,” Reese says.

Today, Reese, Baker and other OWEL members are building a coalition called HIV Aging and Long-Term Care in order to fill the gap in information on how HIV affects older women. “Because no one expected us to still be here, nobody thought about what a quality life would need to be like for women with HIV as they aged,” says Reese.

Much like other people who are aging, these women may find themselves undergoing medical procedures, such as hip or knee replacement surgeries, that land them in rehab centers or day care, or they may one day need to relocate to an assisted living facility or nursing home. But these otherwise normal transitions can pose additional challenges for older women with HIV.

“The professionals at these places are ignorant, for the most part, about how we who are living with HIV need to be treated and that we’re not infectious,” Reese says. “Most of them have the old group-thought process that happened in the beginning of the epidemic when nobody wanted to touch, clean, feed or go near somebody who had HIV.

“The people in these industries haven’t kept up with scientific advances and knowledge about HIV, so we’ve had women—and also men—who’ve had horrendous experiences in nursing homes and assisted-living and rehab facilities, and we don’t want that to happen,” Reese continues. “That’s why we’re organizing the coalition—to build policy; make policy changes, curriculum changes and licensure changes; and support use of the five Ms of geriatrics.”

The Geriatric 5Ms is a five-part standard of care protocol that providers use to treat older adults. It encompasses the diagnosis and management of older adults’ minds, mobility, medications, multi-complexity of their conditions and matters most important to them regarding health outcomes, goals and care preferences.

All medical professionals ought to follow this protocol, Reese says. “We are whole human beings who happen to have HIV, and the whole person must be treated.”

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For more than a decade, Tonya Taylor, PhD, an assistant professor in the College of Medicine and the Special Treatment and Research (STAR) Program at the State University of New York (SUNY) Downstate Health Sciences University in Brooklyn, has been conducting research on the understudied effects of menopause in older women with HIV. Her goal is to identify effective strategies to promote physical and psychosocial healthy aging in this population.

“I’m using the menopausal transition as a moment to reengage this particular priority population,” she says. This is because menopause among women with HIV may be associated with a long list of health problems, including co-occurring illnesses as well as a higher risk of hypertension, cardiovascular disease, diabetes and osteoporosis.

“There are also higher rates of anxiety and depression in women with menopause due to normal social losses from death or relocation of family and friends or changes in relationship status (married or partnered, widowed or divorced) and combined stigmas of ageism and HIV,” Taylor adds.

She believes that many older women aging with HIV may not understand how menopause can affect their health. “First and foremost, women don’t know that their menses [menstrual flow] changing over time has a profound impact on other things,” she explains. “And they may also not be aware that women with HIV undergo an earlier onset of menopause, often with more severe symptoms, compared with women who don’t have HIV.”

Taylor has been studying sleep disruption and insomnia during menopause and their damaging effects on cognition and mental health. “Insomnia among people living with HIV—of all ages—is really high,” she says. “Often, people will dismiss problems with sleeping as being minor or just a factor of aging, especially with older adults, and they think there’s nothing we can really do about it.

“But we can do something about it,” Taylor adds. In her new research, she plans to explore the uses of evidence-based strategies, such as cognitive behavioral therapy, “to help menopausal women manage nocturnal hot flashes, which commonly interfere with sleep during menopause,” she says.

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Beyond ensuring that they’re getting their zzz’s, however, older women with HIV experiencing menopause must negotiate other issues that affect their health and quality of life.

To that end, Taylor has teamed with Michelle Lopez, a colleague who works with GMHC, the storied provider of HIV/AIDS prevention, care and advocacy based in New York City, to create an intervention called CHANGE—named after the euphemism for menopause—which is now a pilot study.

The program identifies basic lifestyle behavior modifications to help older women with HIV improve their health, such as eating more nutritious food, boosting physical activity and reducing the number of cigarettes they smoke. In addition, the intervention focuses heavily on positive sexuality as women age.

Taylor trained Lopez to lead the educational intervention and participate in peer group discussions. “We would bring in other women like ourselves and talk to them about menopause and give them some information,” Lopez says.

Lopez would visit the women at home and listen to them as they talked about what was transpiring in their lives and whether it was helping or hindering their efforts to get and stay healthy. “I allowed them to be themselves,” Lopez says. “They were all over 50, and I had just turned 50.”

Now 54 and living with HIV for 29 years, Lopez taught herself everything she could about the disease so she could better advocate for herself. “I’m not just depending on a doctor to give me a pill,” she says. Case in point: “I really had to put up a fight for my HIV doctor to give me a referral to see a geriatrician [a physician specializing in aging issues].”

Similarly, at OWEL, Reese cultivates behaviors that empower older women with HIV to discuss their sexual health with their doctors, a skill that’s crucial to their efforts to age well. She encourages individuals to educate themselves about their medical needs and to override the social conditioning that would have them believe doctors always know best.

Reese wants women to reframe the way they think about their relationships with their doctors and to view them as people whose job it is to develop a treatment plan tailored to their unique health needs.

“When we get through talking with [the women], they’re pretty amazed to realize that they do have power,” Reese says, “and can ask their medical providers for certain additional screenings they need, such as a test to check for hepatitis C.”

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Another conversation that postmenopausal women should have with their doctors concerns their increased risk of contracting sexually transmitted infections because of the decline in their estrogen levels.

“This change results in the thinning of the mucosa of the vaginal walls, so it creates vaginal dryness,” Taylor explains. “Less lubrication in the vagina means that tears are more likely to occur during intercourse,” she says, “which allows HIV to enter the body.”

However, many older women—and men—don’t consider themselves to be at risk for HIV.

“When postmenopausal women no longer have to be concerned about becoming pregnant, they may not think of things like birth control or condom use or sexual health,” notes Mark Brennan-Ing, PhD, a senior research scientist at the Brookdale Center for Healthy Aging at the City University of New York’s Hunter College.

“I know from some other work that I’ve done that very few women talk to their doctor about sexual health issues after menopause, and yet they remain sexually active, so that’s a problem. And on the other side of that, physicians rarely take a sexual history or address sexual health issues with an older patient,” he says.

Mark Brennan-ingCourtesy of Mark Brennan-ing

Brennan-Ing, one of the principal investigators for the study “Research on Older Adults with HIV 2.0,” presented his findings at last year’s annual scientific meeting of the Gerontological Society of America in Austin.

The takeaway from Brennan-Ing’s talk? Not only will the increasingly older population with HIV be dealing with the long-term effects of the virus, but these individuals will also have to contend with all the other health and social problems elderly people face.

“I think we really need to think about how we’re going to provide care and support for these people,” he says, noting that members of the aging HIV population often don’t enjoy the same resources as others.

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In 1993, the National Institutes of Health established the Women’s Interagency HIV Study (WIHS, pronounced “wise”), the world’s largest and oldest ongoing longitudinal prospective cohort study of women living with and at risk for HIV.

Deborah Gustafson, MS, PhD, a principal investigator and researcher at SUNY Downstate Health Sciences University, uses data from WIHS—now the MWCCS (MACS/WIHS Combined Cohort Study, which also includes men)—for her studies.

She notes that as women with HIV age, they increasingly find themselves on a slew of different drugs, not counting their HIV meds.

“They’re on lipid-lowering medications, antihypertensive agents, or they might be taking type 2 diabetes medications,” she says. “One of the questions they’ve asked and that we’ve been trying to address in WIHS is what influence polypharmacy [taking multiple pills for chronic diseases] has on aging-related outcomes in the women.” These older women with HIV also tend to be more frail and are experiencing cognitive decline.

But WIHS hasn’t filled all the gaps in research, policy and advocacy targeting women’s long-term experiences with HIV. These gaps must be addressed in order to improve the quality of life of older women living with the virus.

The Well Project, a nonprofit community organization devoted to women with HIV, is helping identify these areas of concern through its Women’s Research Initiative on HIV/AIDS (WRI), a multidisciplinary group of advocates, researchers, policy makers and providers inclusive of women living with HIV—many of whom are long-term survivors—which has published an issue brief on the topic.

“Throughout the epidemic, women have been underrepresented in clinical research, and it’s important that women’s unique needs and issues be addressed in the context of aging with HIV,” says Krista Martel, the executive director of The Well Project. “Two other key gaps are research on women who were born with HIV and the impact of long-term exposure to the virus on the aging process.”

Krista Martel Courtey of Krista Martel

Martel is also concerned that the national discussion about the HIV epidemic—notably the federal initiative “Ending the HIV Epidemic: A Plan for America,” rolled out in 2019—focuses too heavily on prevention and may neglect the health and well-being of those who are living and aging with HIV.

“One of our key outcomes from the WRI meeting was that women really needed to be included in each stage of the plan,” she says. “It’s extremely important that the multitude of women’s lived experiences are heard by researchers, clinicians and policy makers.”

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For instance, transgender WOMEN aging with HIV—a population disproportionately affected by the virus—face special issues connected with the nature of their transition, hormone replacement, conditions resulting from previous diseases or injuries and stigma.

“The life expectancy for most transgender women of color is significantly lower than that for their cisgender counterparts,” Martel says. “So that’s an area where there’s almost no exploration and a huge gap to be filled in terms of research and policy.”

Cecilia Chung, 55, the director of evaluation and strategic initiatives at the Transgender Law Center, has been an advocate for transgender people for more than 20 years.

“Being a transgender woman living with HIV means that in addition to battling the stigma of being transgender, I have to deal with the stigma of being HIV positive and all the traumas in my life that led me to seroconvert,” she says. “The mental health impact of living with HIV intensifies as I am growing older, and it seems that there is another level of stigma I have to struggle with—being older and alone.”

Cecilia ChungCourtesy of Cecilia Chung

Then there are Chung’s experiences with providers in the health care system to consider.

“I am probably one of the lucky ones who have a regular health insurance plan, meaning that I have more choices to determine if my primary care doctor is a good match,” Chung says. “Sadly, even when I have an exceptional doctor, I still am in a health care system whose health screening process failed to recognize transgender patients, resulting in awkward interactions such as this one when I was asked, ‘Are you pregnant?’” Chung’s reply? “No. I am transgender.”

“It might surprise you how often this type of exchange happens in health care settings,” she adds.

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Trauma negatively affects the health and well-being of women aging with HIV, which has led advocates to urge health care workers to provide trauma-informed care.

This approach moves beyond getting people on HIV meds and helping them attain an undetectable viral load. It seeks to cultivate a safe, affirming and empowering environment.

As Carol Dawson-Rose, a professor at the University of California San Francisco School of Nursing and a researcher at the International Center for HIV/AIDS Research and Clinical Training in Nursing, puts it, “Medication is amazing, but there’s a whole other piece to health that isn’t being addressed,” by which she means the aftereffects of such trauma as violence, addiction, racism and poverty.

“I have a higher need for other services in addition to HIV care, such as behavioral health support and a better understanding of health changes that may be typical to aging adults,” Chung says. “There is evidence that trauma and HIV accelerate the aging process among adults.”

From her perspective, if the epidemic is to be brought to an end, then all older women aging with HIV must be included in these strategies. “I think it is egregious that my own government still actively erases my existence,” Chung says. “There is research, but there are not enough data on the survival rate of older trans women living with HIV.”

Despite a report from the Health Resources & Services Administration that showed trans women over 50 living with HIV are more likely to achieve viral suppression, Chung says many questions remain.

“Does the data represent older trans women who survived and lived longer because they were retained in care? Or did they survive because of better health care access? Or simply because they transitioned after their viral loads were under control?” she asks.

“There are so many questions that need answers, but our government and census seem not to be very keen on learning more about us,” Chung says. “Without allocating adequate resources, I fear that any end-the-epidemic strategies will be in vain.”

It’s a viewpoint shared by many others, both women and men, trans and cisgender, who are aging with HIV.

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