REALHEALTH™

3 Degrees of Separation

Meet three individuals leading very different lives who are united by their shared experiences as older women living with HIV.

January 31, 2020 By Kate Ferguson

The Women

Melanie Reese, 67, 20-year survivor

Executive Director, Older Women Embracing Life (OWEL)

Community research advisory council member, Johns Hopkins Institute of Clinical and Translational Research

Courtesy of Melanie Reese

How did you become involved with Older Women Embracing Life?

Older Women Embracing Life was founded in 2004 and began as a support group for older women who were living with the virus. I got involved in 2005 because I knew Dorcas Baker, a research nurse in the Institute of Clinical and Translational Research. She was very interested in older women who were living with the challenge of HIV, and I was infected at the age of 47. In 2002, when I met Dorcas, that was my 50th birthday year, so that's how we connected. She was interested in women over 50.

How does OWEL help women living with HIV to manage, overcome or negotiate their problems?

At Older Women Embracing Life we support each other with our experiences in dealing with stigma, treatment or medication adherence. We support each other to be successful because when you are supported it's easier to deal with any challenge that may pop up on your life journey. OWEL supports women and girls living with HIV and also those who may be at risk, or those who are caretakers of people living with HIV, so you don't have to be positive to be involved with OWEL.

For those of us who are infected, our goal is to live a quality, healthy life. But we also want to prevent others from hearing the diagnosis "You're HIV positive," so we do a lot of work that includes treatment as prevention and support with adherence as prevention. Over the years, new tools and skills evolved that we incorporated into our skill set to help individuals, especially seniors who don't feel they're at risk and who medical providers don't see as being at risk.

We encourage them to get tested and know their status—not to hope or wish. People need to know their status so they can be equipped to be the best at either staying negative or getting virally suppressed or undetectable.

What are some of the major challenges you faced during your personal journey as an older woman living with HIV?

My first experience was stigma. I was 51 and needed to go to the dentist. 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 optimum, so I didn't have a good experience. I avoided the dentist for four and a half years, and that led to gum disease and bone loss. I lost six of my front teeth as a result of fear of being put in that situation again.

I didn't want other people to go through that, so I learned how to be an advocate, first for myself and then for others. I got involved in a training called LEAP; that's an acronym for Leadership, Empowerment, Advocacy and Participation.

I learned that as a person living with HIV, my voice is powerful because I can talk to the medical providers as a member of the team. In addition, I can be at the planning tables in the discussion as to how treatment and care should be provided and learn what the minimum is for the standards of care and removing obstacles so that people can access antiretrovirals early on in their HIV journey.

A lot of these protocols have evolved because now they do rapid testing and they do route to care. It doesn't matter what your CD4 count is, [the priority is to] get people on antiretrovirals as soon as possible because you don't wait until you're sick to get on meds; you treat with medications while you're healthy to prevent getting sick.

I've been able to see the evolution in the treatment and care side of HIV and on the prevention side. Those of us who are living with the challenge can share our experiences about what we weren't thinking about when we got into a situation that got us infected. We can share those things, especially with seniors.

What role do you think care providers have in discussing sexual health with their patients?

This doesn't only affect older women, but medical providers are not skilled in getting—and really don't want to request—an individual's sexual history. They don't want to discuss it, they don't want to know about it and they don't ask.

This is key to knowing who could be at risk for acquiring HIV or hep C or any other infectious disease including sexually transmitted infections. This is why we encourage women to ask for tests—a hep C test, an HIV test. We tell women to learn about their body parts so that if something is not quite right they can ask about it. When women reach the age of 62—through 65—they're not required to have a Pap smear. Women with HIV should never stop [getting these screenings], and women of color should never stop [getting these screenings]. When we get a cancer, it's aggressive and can go from zero to Stage 4 quickly.

Also, women of color should never stop having mammograms and never stop having Pap smears because we're very susceptible [to these illnesses]; and when you have HIV, that's even more so.

What are some of the psychological and social factors that older women living with HIV face?

Loneliness, isolation and mental health issues—primarily depression—but there are others that could be present. Depression is very prevalent in women with HIV and anyone with a chronic disease. In addition, as you get older, you're apt to get arthritis, bursitis or other immobility issues. Those conditions hurt more when it's cold outside, so you tend to stay inside and not communicate with anyone because you're feeling sad. If you don't go to church, you may just be watching the TV, and it's so important to break that cycle in any way, shape or form because isolation shortens the life span. This is why we encourage women to go to a support group or to get involved in senior center activities. These facilities have all kinds of activities, usually at a small cost. But the long-term benefits are priceless.

What are some of the current projects you're working on that are meaningful to you?

Well, Dorcas Baker, who is the president and cofounder of OWEL, myself, our treasurer—a lot of us in OWEL—we're building a coalition called HIV Aging and Long-Term Care. No one expected us to still be here; nobody thought about what a quality life would need to look like for us as we aged. Signs of aging happen earlier for women with HIV because of the chronic inflammation the virus creates. Additionally, we develop cardiovascular, diabetes, renal and liver issues. A lot of times we even have to go to a rehab center after to get back on our feet after a surgical procedure like knee or hip replacement, or we need to recover from a stroke and some have to go to assisted living facilities or day care, or some need to be in a nursing home.

For the most part, the service professionals in these places are ignorant about how people living with HIV need to be treated [and don’t realize] we’re not infectious. But 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.

People in the nursing home and assisted living industries haven’t kept up with the scientific advances and the knowledge about HIV. Both women and men have had horrendous experiences in nursing homes, assisted living and rehab facilities, and we don’t want that to continue happening, so we’re building a coalition to build policy, make policy changes, curriculum changes and licensure changes.

We support these places using the 5 Ms of geriatrics, a best practices protocol for diagnosing and managing the care for older adults. This procedure focuses on their minds, mobility, medications, the multiple complexities of their conditions and what matters most in their personal treatment plans to ensure good health outcomes.

Everybody who is in any kind of helping or assistance services in the medical field needs to know that we are whole human beings who just happen to have the disease of HIV. We have to treat the whole person, and we’re more than HIV, and you don’t have to be afraid of us. We have to get good at helping people live a high-quality life, not be isolated, not be lonely, and so we’re building that coalition and doing work that has to get addressed.

We’re also informing Health Resources & Services Administration, Centers for Disease Control, and the Substance Abuse and Mental Health Services Administration that they need to hear from us and they need to listen to us. We’re a part of ending the epidemic and we’re still going to be here, so they still have to focus on what our needs are and how well we are living and how well we are being viewed, handled and taken care of in that part of the health care community.

Michelle Lopez, 53, 29-year survivor

Case worker, Gay Men’s Health Crisis (GMHC)

HIV/AIDS activist and advocate

Michelle Lopez pulling paper pulp to make handmade paper valentinesitive for Love Positive WomenCourtesy of Visual AIDS

What primary concerns and challenges do you have about aging while living with the virus?

The biggest concern I have with aging while living with the virus is that the health care system is not meeting our needs. You can pull up so many different articles that talk about the health disparities, but our medical system is not geared to fix this.

Right now, one of the things that has made me so displeased and disappointed is that some of our decision makers just held a summit in New York state—called “End the Epidemic”—they’re big funders. My question is, How come there was no priority talk about aging when more than 60% of all of us who are living with HIV in New York state are all over the age of 50? We’re all aging in New York and San Francisco. I can tell you that there are many big cities that have a large aging population.

Yes, we’re long-term survivors, but we cannot end the epidemic if we do not also prioritize those who are living and aging with HIV. The government’s priority right now is PrEP [pre-exposure prophylaxis for HIV prevention], and I’m not saying that there’s anything wrong with that. But New York state has to understand good public health is also about parallel care—for those infected and for those who are affected—alongside prevention efforts.

I’ve been around for too long, and I’ve seen a lot of stuff happen from the beginning that makes me feel like, no, where are our decision makers? Once again, it’s like the band is playing on. In New York, they’ve already done a disservice to women where it seems like they want to give the impression that PrEP is about gay men. That’s such an insult to women. They’re trying to clean up that impression, but it’s a day late and a dollar short.

Why do you think older women living with HIV seem to be largely invisible when it comes to funding and research about the virus?

The government has politicized our care. The only time women were the priority here in New York was when we were of reproductive age and having babies. I feel they wanted to save the babies, but they didn't care about the women. I was part of that fight because I have a child who was perinatally infected in 1990. When I delivered that child, the baby protocol was in place.

[Editor's Note: The "baby protocol" Lopez refers to here is the blinded newborn screening program in place in New York state in 1990. This policy did not mandate that newborns who were screened and found to carry the anibody for HIV be identified and a parent notified.]

I didn't have an HIV test; I wasn't counseled about HIV. For those of us who survived through that when our children were born back then—some are males, some are females—the females are having kids now, and their babies are being born negative. So when I think of aging—and I've looked up where we came from—many of us as aging women who were positive were really affected by the disparities that were allowed.

Now that we're living longer and aging, we really have to have a strong ally to get our health care needs prioritized if we're supposed to get good care. Yes, we're aging, but we're aging with a virus that did some damage. These are preexisting conditions so they have to be addressed.

You're involved in a pilot study for an intervention called CHANGE. Can you tell me about this program and the role that you have in its development?

Through word of mouth a friend of mine told me that this investigator named Tonya Taylor was about to do some research work with women and her focus was about sexual health and menopause, so I went to the sit-down meeting that night. I was so intrigued because what she was talking about wasn't just looking at clinical information. The research was about women getting access to care that is making a difference in their lives.

We didn't realize that in our 40s we would be entering menopause, so doctors had no idea about what to tell us to do. Some of us would be really miserable; some of us had mental breakdowns or started back using drugs and alcohol.

For the study, Tonya gave me and a woman this intense training and had us deliver an educational intervention where we would bring other women like ourselves in to talk to them about menopause, give them some information and have these discussions. Then, we would identify how to take leadership roles.

We noticed that these women started opening up to us because they felt a level of comfort, and they started sharing things with us as peers. At the time, I was not working permanently. I was doing consulting work, so I had the flexibility of really taking some extra time to take the ball and run with these women. They'd say, "Michelle, come over and sit and talk with me."

I literally wrote this up and asked Tonya what she thought about me going to their homes to talk to them. I just wanted to put aside any kind of bias and go visit them as Michelle, their peer. I'd go there to talk. And some of the things that I identified from the women was that they weren't taking their meds at all or they would take their meds only a day or two out of the week. Some of them were drinking, or some of them were using their drugs right in front of me. But I did not judge them. I allowed them to be themselves, and I said to them, "Look, I did all of that."

What I learned is that if I got, like, a good 10 more Michelles, we would have really done some serious, serious work and intervention over there with Tonya at SUNY [State University of New York] Downstate.

But [Tonya] keeps getting denied funding, and we need the monies to pay the peers. People said to her, "Tonya, what Michelle is doing, that's Michelle Lopez. That's what Michelle does." But I can train other peers; I can train other women. There are other women who have said to me, "You know, Michelle, I know I'm not you, but how can you help us do some of the things that you do?" These were all older women living with HIV, and every one of them was over 50. I had just turned 50.

Some women can go into perimenopause—going a full year without menstruation. Some women haven't even had an opportunity to get the blood workup that determines they're in this phase of life. So they don't know why they're experiencing certain things and feeling certain ways. It's really sad.

What did you learn from this experience about loneliness, mental health problems and all the things that go hand in hand with older women living with HIV?

A lot of these women didn't have any kind of connection socially. Here's something I found interesting. When my boss asked the aging gay men who come here for services, they said they don't want that type of stuff. But when he spoke to the women who were positive, they wanted to have a Bingo night! They said, "We want people to organize activities that are accessible to us."

One of the things that I'm doing as a staff person now at GMHC is a healthy aging program. It's called the National HIV and Aging Resource Center. I work on one component, which is screening LGBT clients who are aging with HIV and 50 and older for depression, mental health, substance abuse, that whole component. And I'm doing in-house referrals because we have a mental health program and mental health services on-site.

Now, people started walking around again, so I go upstairs, and I sit, and I interact with clients and have lunch with them in the lunchroom. Every single one of them has considered suicide; they've just lost their connection socially. Some of them, guess what their social activities are? When they come there to have lunch. And you should see how they take to that. I've not just seen but heard how they respond. And I see that more men come to the lunch program and the dinner program than women.

When I interact with the women in GMHC's different service areas, you hear from them how much they feel so alone. I’ve really seen that a whole lot of people are walking around depressed or with mental health issues, and part of it is because social isolation is affecting their lives.

Well, guess what? I’m gonna be that peer because I’m not a social worker. I’m a certified alcoholism and substance abuse counselor, so at least I have a skill, and I’m going to do the screening, and we’re going to have a discussion with people about it. I want to hear how you’re coping or if life is bringing you down, and then we take it from there. Because Michelle today can say it: I’m on treatment for mental health, yes. And you wouldn’t know unless I share it with you. I function very well.

So the mental health aspect is a huge part of an intervention program like CHANGE. What else would you like to say about older women living with HIV?

I’d like to say that I think that older women who are aging with HIV feel a sense of displacement or estrangement that happened to us, which really came from the health care system. I would like to see methods and mechanisms developed that are informed by the feedback we give concerning whether their system is meeting our needs. Another thing is that people are not paying attention to us as women aging with the virus. That’s why I use the term displacement. I would like to see our peer needs become a priority within advocacy and health care.

That’s going to take having us at the decision-making table but also, too, having women who are aging with HIV still understand that they have a right to speak up if their needs are not being met.

Cecilia Chung, 54, director of evaluation and strategic initiatives

The Transgender Law Center

Community activist and advocate for transgender people

Cecilia Chung Courtesy of Cecilia Chung

As a transgender woman living with HIV, what challenges to your physical, mental and emotional health have you experienced as you’ve grown older?

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. The mental health impact of these issues 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.

What have your interactions with traditional health systems and HIV care systems been like in terms of the expertise, competency and compassion shown to you while trying to access the health care services you need?

I am probably one of the lucky ones who have a regular insurance health plan, meaning that I have more choices to determine if my primary care doctor is a good match. 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, like the one I briefly describe below:

Health care provider: Are you pregnant?

Me: No. I am transgender.

It might surprise you how often this type of exchange happens in health care settings.

In what specific ways would you say trauma has affected your health through the years and impacted your physical, mental and emotional well-being as an older woman living with HIV?

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. I think there is more evidence that trauma and HIV accelerate the aging process among adults living with HIV.

As a transgender woman, what are your thoughts about the Trump administration’s “End the Epidemic” plan for 2020—in terms of its strengths and deficiencies—as far as its scope, focus and ability to bring us closer to achieving this goal in the United States and abroad?

I think it is egregious that my own government still actively erases my existence. There is research, but there are not enough data on the survival rate of older trans women living with HIV.

From a Health Resources & Services Administration report, we learned that trans women living with HIV over the age of 50 are more likely to achieve a higher viral suppression rate. Even so, we are still trailing behind cisgender white gay men in achieving an undetectable viral load.

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 are under control?

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

This article was written with the support of a journalism fellowship from the Gerontological Society of America, the Journalists Network on Generations and The Commonwealth Fund.