Living With HIV and Limited Mobility

Aging and other conditions often pose additional challenges for those with HIV.

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The summer of Yolanda Santana's 18th year was a party. Laughing, Santana remembers dancing until dawn at Cheetah and other Manhattan discos. She also remembers that part of the fun of it all was walking to those clubs from 181st Street—a distance of about seven miles.

"When you're talking to your best friend, time just goes by and then you're there," she says. "Oh, and then we'd dance all night and go to an after-hours [club]."

Today, Santana's partying looks different. It's more about hot dates playing with Hot Wheels and her grandson on the floor of her Bronx, New York, studio than dancing till dawn. Now 67, she's lived a full life that has included an HIV diagnosis in 1996 and a diagnosis, in 2018, of a degenerative and painful condition called spinal stenosis. Her spine is compressing in on itself, pinching nerves and creating bone spurs that cause their own pain. Now, a seven-mile walk is out of the question.

"I still love to walk," says Santana. "With my walker, I can walk."

Santana's not alone. An analysis of national 2017 data found that 45% of people living with HIV report some form of disability—and that mobility disabilities were the most common. Fully one in four people reported them. And that's among all adults living with HIV. At middle age, men with HIV walked more slowly, and continued to decline faster, than their HIV-negative peers.

By their 50s, Black men living with HIV were nearly three times likelier than white folks with the virus to have a mobility disability. These racial disparities were seen only in people living with HIV, not among the HIV-negative population. And the proportion of people with mobility disabilities rose significantly as people reached 65 or older. For women living with HIV, mobility was lower than it was for men with the virus.

Slow walking, limited movement and difficulty standing from a sitting position are three of the criteria required for a diagnosis of frailty, a condition of aging that can make it harder for people to recover from episodic illnesses. The good news is that mobility aids can keep people moving, which is associated with better overall health as one ages.

Clinicians who provide geriatric care already consider maintaining mobility to be one of the six key

areas of good care for people as they age. The other five are: the concerns that matter most to the client, mind/cognition, medications/polypharmacy, multi-complexity/living with multiple chronic conditions and modifiable factors.

A report issued in 2021 by the O'Neill Institute for National and Global Health at Georgetown University calls for more and better research into the health of women and transgender people aging with HIV as well as translating traditional programs for older people into programs that will work for people living with HIV too. Meeting these needs is essential to ending the HIV epidemic, the authors argue.

"Concerted action," the report states, "is needed to meet the needs of older people living with HIV."

Like many long-term survivors, Santana has seen a lot. Diagnosed in 1996, she has outlived her older sister, her father and a serious romantic partner, all of whom died of AIDS-related causes. She has survived crack addiction and South American drug deals gone wrong. She has survived childhood sexual abuse, domestic violence and a period of "hell" during which she lived on the street and did sex work to support herself. But she has survived, and she has begun to rebuild relationships with the children she lost as a result of her drug use.

"There are so many things—I try not to even think," she says. "It torments me, honestly."

Her sister's death in 2001 hit her especially hard. Here was a woman who was just a few years older than Santana, and she'd watched her become addicted to heroin and begin to sell sex to support her habit. Santana remembers witnessing that and thinking, That's never going to happen to me. But in just a few years, there she was, nearly in the same situation but hustling for crack instead. When her sister died, Santana says, she had already learned that even "good, hardworking people" could become addicted. But something about the death got through to her.

"I always tell people my sister died so I could live," she says. "If I were to go that route [that my sister did], I would be spitting on my children, spitting on my mother, who was really there for me. I told God, 'Take my life or let me begin anew.'"

Something new did start to happen. She began a yearslong process to quit drugs, which she hasn't used since 2009. She's also been getting care through GMHC and other providers, such that today she not only manages her HIV but also maintains an undetectable viral load.

Santana says she never really figured out what caused her spinal stenosis. But whatever it was, the pain didn't manifest until 2005. Back then, it was manageable. She took Tylenol with codeine and went about her business. But as time passed, it didn't let up. In fact, it got worse. Soon, she was accessorizing with a cane to help her do the things she'd always done. Eventually, she went from getting her pain treated at the HIV clinic to working with a pain specialist.

By 2018, she was in so much pain that she cried at doctor's visits, she says. Movement had become much harder. It was only after she collapsed in the doctor's office that the clinician

ordered tests to image her spine. And that's when she received her spinal stenosis diagnosis and learned there was no treatment.

"So my spine is rotting away slowly," she says. "And my pain is getting progressively worse."

She does get some help, though, in the form of monthly epidurals and the addition of morphine and oxycodone to deal with breakthrough pain. As someone with a history of drug use disorder, she's careful about the prescription pain meds. She knows that she can never take too many of them or she'll risk losing access.

Recently, SHE went for what is now a long walk for her—six city blocks, from 42nd Street in Manhattan to a street fair on 36th Street. With the help of her walker, Santana wound through the stalls, admiring the handicrafts and enjoying the aroma of food for sale. The walker also enables her to go to the market and pick up food. And, even though she knows it will cost her later, she still gets down on the floor with her grandson to play with those Hot Wheels and trucks.

"Lately, my grandson has noticed that I have a hard time getting up from the floor, so he's taking my elbow and helping me," she says with a smile. "I have to lie down after that, until the pain goes away. But I don't care. My grandson is my healing tool."

In addition to the walker, she says the bariatric surgery she had around the same time she was diagnosed with spinal stenosis has improved her mobility. Without that weight on her, Santana says, she moves better.

Still, she can't sit or stand for too long anymore, and she can't wash more than one dish at a time.

Today, she shows some signs of age-related impairment. In addition to mobility differences, she struggles with some activities of daily living—namely, feeding herself well. If she doesn't feel good enough, she doesn't go to the grocery store. She skips meals sometimes. And since she lost her dentures in December, she's been off solid food. An aide has started going to her apartment every day to help her out, but she isn't a fan of having strangers in her home.

For Santana, mobility isn't as important as eating well, she says, but they are connected. Sometimes she's in so much pain that she can't get out to the market. When she does, she buys mostly microwaveable meals, since standing long enough to cook rice and beans or other favorite Puerto Rican dishes has become too difficult for her. At least her aide makes a mean mangú, a Dominican breakfast favorite of mashed green plantains and onions. She wants to get a slow cooker so that when she does have the energy, she can prep and cook food without having to worry about burning it.

She hasn't advanced to a wheelchair yet. But that's also an option.

Today, life is much slower, she says, and revolves around her sunny apartment.

"The back of the building has enough space that we get the full sun all day," she says. "I can sunbathe. Last summer, I bought a pool for me and my grandson. We were in it all summer. I

didn’t go anywhere. I wasn’t going to jeopardize my health. I maintain my T cells usually over 1,000.”

At 28, Nick Melloan-Ruiz was 90 pounds and so weak from opportunistic infections that he couldn’t stand in the shower. He received a walker along with his AIDS diagnosis and antiretroviral medications, and he’s never looked back.

In fact, at one point, he had to sit his doctor down and tell him to stop asking him when he was going to start physical therapy to learn to walk without it.

“The walker is here to stay,” he remembers saying. “I will go to physical therapy just to be strong, but I’m not doing it to wean off the walker because the walker needs to be here. It’s a part of me.”

To use a therapy term, it was a breakthrough. Growing up, Melloan-Ruiz was an enthusiastic kid. As a teenager, he got a subscription to Seventeen magazine but put it in his dog’s name, and he saw Paula Abdul as his first concert. Growing up, he could be all parts of himself in his Bloomington, Indiana, home. But when he left his house, he says, people only saw one thing about him: his uneasy gait caused by cerebral palsy (CP). He wasn’t ashamed of being gay, he says. But he was ashamed of his CP.

“There was so much to focus on when I left the house, it was like, What am I going to deal with today?” he says. “I really chose to bury CP and not focus on that.”

And that meant that after a childhood of orthotic leg braces and physical therapy, he refused to use a mobility device. Just before his AIDS diagnosis, Melloan-Ruiz would walk around unaided, but he sometimes fell. And he coped with people reducing him to just his physical differences by becoming the funniest, best-read, most articulate version of himself, by putting others at ease, by doing the additional work of putting others’ comfort before his own. He needed to be good, he says. He needed to be liked. That was the case with his high school friends. That was the case with CP. That was the case in sexual situations.

“I just wanted to be liked and would do whatever people wanted—that may not have been my choice—to be included, to be valued, to be desired,” he says.

He knew what he was doing sexually. He knew he might have HIV. But he says he avoided getting tested the same way he had avoided dealing with CP. In fact, as he developed the fatigue, the cough, the stomach ailments—all the signs of progressive HIV infection—he says he rationalized that they were probably because of his CP and not really anything he had to deal with. That is, nothing he had to deal with until it was unavoidable.

Then came the hospital, him at 90 pounds and unable to stand. And that’s when he realized, “I didn’t have another 28 years to do the same thing.” He had to face reality.

So when he was given a walker, this time he took it. At the same time that he confronted his long-avoided HIV diagnosis, he decided that he no longer needed or wanted to hide his mobility

differences. He began to volunteer and then work at HIV organizations.

His goal now, he says, is to help other people overcome whatever shame they face and live their lives and pursue their passion—whatever that may be. And he tries to show them by his own actions that it’s safe for them to speak their truths too. And part of that is embracing using a walker.

“It was a great integration for me,” says Melloan-Ruiz, now 35. “I needed to admit that I had CP, and I needed to make it 100% visible to people.”

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