TuSalud™

Living Longer with HIV

Antiretroviral therapy helped people with the virus add years to their lives, but now scientists must address other issues of longevity.

January 31, 2020 By Kate Ferguson

In 2015, one decade after investigators looked at nearly 1,000 older adults living with HIV in New York City, researchers organized a successor study, the Research on Older Adults with HIV Study (ROAH 2.0), in several sites across the United States.

Findings from the first part of the study documented the challenges of older adults living with the virus in San Francisco. Here Real Health spoke with senior research scientist Mark Brennan-Ing, PhD, from the Brookdale Center for Healthy Aging at Hunter College, a part of the City University of New York, who was a co-principal investigator on the ROAH 2.0 team.

Based on your research, what issues for long-term survivors with HIV seem to distinguish them from people who are more recently diagnosed?

What seems to be distinct between the two groups is that long-term survivors—and I'm generally talking about people who were diagnosed before antiretroviral therapy was widely available in1995—a lot of them are very socially isolated. These are people who lived through some of the worst years of the AIDS epidemic. Many of them lost friends and lovers and had very depleted social support networks. Many of them expected to die; many of them, because there was no treatment, the HIV disease progressed to AIDS, a result of their immune systems being more compromised than somebody whose HIV has been kept under control.

A lot of them have this kind of, I would call it almost an existential crisis because they had to stop working. Many of them went on disability, and now that they're living to an older age, they're thinking this is great, but wondering about still being alive, but for what? They really do not have a lot of meaningful activities; they don't feel like they're participating in society, but they're often held back, say, from finding employment because any kind of extra income would mean a reduction in their disability and medical benefits, and they'd be worse off than if they stayed on disability.

I've heard some people call that situation "like being in golden handcuffs." It's great they're getting the support, but they really don't have any kind of outlet or any way to contribute in a way that they can. A lot of these people are highly educated and have a lot of things that they could give back.

One thing we hear a lot, and which kind of cuts across different demographic groups, is a desire for them to connect with people who are newly diagnosed, whether that be older people or younger people. They want to kind of walk them through the process and support them and share the knowledge and the wisdom they've acquired after living with HIV for many years. They really want to give back to the community. A woman from one of our focus groups who was in recovery—I don't remember from what exactly—was very involved in substances recovery groups and trying to help other women who were dealing with abuse and addiction issues.

In terms of stigma and marital and work-related experiences, what were these experiences like for some older women living with HIV who participated in your focus group?

Unfortunately, stigma is still a very powerful force. A lot of times when people find out the kind of work I do, they say, "Oh, HIV is not a big deal anymore." That's because of the treatments. But folks face a lot of stigma. That, in turn, increases social isolation because people will withdraw because they don't want to experience the stigma and discrimination that also can lead to depression.

Most of the people in our focus groups weren't currently working. But some of those factors did come up in the context of work. There was an older Black man who was very involved with his church and was actually running the HIV/AIDS ministry there. But he hadn't come out as HIV positive to the congregation, and he was afraid to do that. Even though the minister would always route people who he found out were HIV positive to this gentleman for help and support, he still felt so stigmatized by the disease. Even in this congregation he felt very close to he still had trouble coming out.

There was another gentleman, close to 80, who was taking care of his elderly mother. She did not know that he was either HIV-positive or gay, so those stigmas persist. From what I heard from the women, they seemed to be a little more likely to disclose to their family members—I'm not exactly sure why. But a lot of the women's stories were around disclosure to family and how important that was and in terms of getting the support from them.

Another way stigma came up was in terms of relationships—romantic relationships—and there was a real problem there with people avoiding becoming romantically involved because they didn't want to have to disclose their HIV status, which isn't really a good thing because love is a very central part of being a human. It's part of our human experience and to have to kind of shut down that part of you because of fear of disclosure is not a good thing.

But I think one thing that's really changing the landscape in terms of stigma is folks knowing now that people who are undetectable are uninfectious. I think that has remained one of the most stigmatizing aspects of HIV, that you can give it to other people. That people with HIV now can feel that they're not infectious and that they're not a danger to others has been, psychologically, very beneficial and important to them.

In terms of internalized gender roles, what effect does this have on older women with HIV developing successful strategies for healthy aging—physically, mentally and emotionally?

It’s complicated because most of the older women with HIV are women of color, and so it’s kind of hard to disentangle what’s going on. Also, sociological research in poorer communities shows that gender roles tend to be stronger in those situations. Honestly, I haven’t really heard women talking about gender roles, but I did hear a lot of them talking about their roles as mothers and caregivers and that was really a central part of their identity. I didn’t hear so much about them necessarily taking care of older parents, but in terms of feeling restricted in their gender role in any way, that wasn’t something that really came up.

In your opinion, what are the most critical areas concerning HIV and aging that need to be addressed by research?

Short of a cure for HIV, we’re going to have an increasingly older population that is not only going to be dealing with the long-term effects of HIV disease but also just what everybody else deals with in terms of aging. This is why I think we really need to figure out how we’re going to provide care and support for these people who don’t have the same kind of resources that many people who are going into old age have. You have high proportions of individuals who are living alone.

My research has found about one third of people aging with HIV are very socially isolated and about another third have what we call these friend-centered social networks that we typically associate with LGBT adults. But these are common among heterosexual adults as well.

While those kinds of networks are good in providing emotional support, when you look at the kind of instrumental help with tasks of daily living, caregiving support and that kind of thing, they really don’t make up for what people are not getting from family members. I think what’s encouraging in some other research that I’ve done where I’ve looked at just older gay and bisexual men and social supports and the impact of HIV, there did appear to be some activation of family support for the men with HIV that we weren’t seeing for the HIV-negative gay and bisexual men. But I think that’s really going to be the key. It’s both medical care in terms of how you manage HIV disease in aging along with an average three or more other comorbid conditions. How do you support folks in the community? I don’t think we’ve figured that out.

The second study on older adults with HIV was really designed as a needs assessment to develop programs, policies and services for this group because if you look right now there’s very little in terms of services that are targeted toward older adults with HIV. And a lot of them don’t feel comfortable in settings where it’s primarily younger people. In fact, we’ve had focus groups talk about this kind of ageism they’ve experienced when they try to access mainstream HIV programming.

For example, one guy went to some program, and it was with a bunch of younger people, and they called him a grandpa, and he never went back. I think that’s a real challenge now, and a lot of these people have complex needs in addition to the HIV if they've had a substance use history or a history of incarceration—and all the baggage that goes with that. So I'm not sure what the answer is.

I know a lot of older people with HIV would benefit from the kinds of services we generally provide the older adults, but the median age of this group now is up to about 59. So more than half of them are not eligible for any programs that are funded under the Older Americans Act. This means there could be things going on at the senior center down the street, like a meal program or recreational programs—things like that they could benefit from—but they're not old enough to be eligible. So those are some of the issues.

There's also a real reluctance, I think, of social providers who aren't in the HIV domain to engage this population.

And why is that?

It goes back to stigma and that people aren't really out about their HIV status. There's that and also the fear of, I think, people who end up getting those kinds of services disclosing their status and then being ostracized, and we've heard about cases of this happening. So there's not a lot of cultural competence out there around serving older people with HIV. There are still a lot of myths about how easily the virus could be transmitted, that just casual contact can put you at risk for HIV, so there's still a lot of misinformation and prejudice out there when it comes to HIV.

I've heard that physicians rarely take a sexual history or address sexual health issues with an older patient because of discomfort in doing so or because doctors automatically assume older patients no longer engage in sexual activity. What about medical schools providing their students with the skills to address these issues?

That's a really good point. I did some work on this geriatric fellows consortium in the NYC area, and at one of the hospitals, they asked me to present on sexual health and aging at the symposium they were having. A geriatrician and a health educator was there, and they did a skills-building session on how you take a sexual history from an older patient, and that went over really big

But when we talked to the fellows, as well as the program directors, we found out that sexual health is not considered one of the core competencies at medical school, so medical students get very little training on the topic. One of the ways to address that would be to make some changes to medical education and elevate sexual health into being a core competency. But then you'd get the pushback from the medical schools because there are already 60 core competencies they have to cover in their curriculum, so they're really reluctant to add to that.

The fact is that unless you're going into urology or ob-gyn, you're not getting a lot of training around sexual health.

Is there something you'd like to add that you think needs to be said?

Well, we've been focusing a lot on the problems facing older people living with HIV, but I think it's really important to talk about their strengths and resilience as well. A lot of these people were long-term survivors. There's something in them that's allowed them to survive and for many of them to thrive as they've gotten older. They've had to cope with a lot of things, and I think it's important to remember that.

In addition, antiretroviral therapy is such a huge success story, and so many people are living longer—and in many cases, happier and healthier—lives because of that. That's why I believe we need to think about how we can support that breakthrough in research as well.

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.