Race Against Time: Activists Call for More Research on Aging and HIV

With the ranks of HIV-positive people older than 50 growing rapidly, AIDS activists with the Coalition for HIV and Aging Research and Policy Advocacy (CHARPA) are demanding that the National Institutes of Health (NIH) devote more attention and resources to the issue of aging and HIV. Will the NIH respond, and will it respond in time?

October 5, 2010 By David Evans

Think of old age. Chances are that various forms of disease and disability come to mind. Brittle bones, the relentless exchange of muscle for fat, weak hearts, and forgetfulness—while all of these conditions are unpleasant and unwelcome when they strike, they are almost expected by the time people reach their 70s or 80s. What if, however, these health issues begin to happen during a person's 40s and 50s? That's exactly what researchers fear is occurring in people with HIV—and we don't fully understand why.

Is It Aging or Something Else?

The data emerging from recent scientific conferences paint a troubling picture—they increasingly suggest that diseases common among the elderly are now occurring at a much earlier age in people with HIV. Rates of heart disease, bone loss, cancer and cognitive decline are many times higher in HIV-positive people in their 40s and early 50s, compared with HIV-negative people of the same age. In addition, several immunological alterations characteristic of HIV infection, notably declines in the immune system's ability to mount effective responses to disease-causing pathogens, are similar to immunosenscence: gradual deterioration of the immune function brought on by aging.

Is this accelerated aging or something else? There are believers that it is, and there are skeptics.

While no one disputes there's a lot more disease and disability occurring in people with HIV than their HIV-negative peers, the skeptics are cautious about calling this accelerated aging. Rather, they argue that what looks like aging is a combination of other factors, including: immune system dysfunction, a higher prevalence of cancer-causing viruses, increased rates of smoking and drug use, toxic effects of some older antiretroviral (ARV) drugs, and constant inflammation due to the presence of the virus. Take away these factors, the skeptics suggest, and a person could probably live a next-to-normal lifespan.

While the believers agree whole heartedly that these factors greatly contribute to the conditions plaguing an aging population of people with HIV, they also insist that many of the diseases are occurring in people who never smoked, or never took the more toxic HIV drugs, or didn't wait too long to start ARV therapy.

Jeff Taylor, a longtime HIV activist from Palm Springs, California, is a believer. He thinks that some type of accelerated aging is occurring, and he's not pleased at the way that some scientists are approaching the problem. "My response to those arguments is, 'If it looks like a duck and it quacks like a duck, chances are it is a duck,'" he says. "That's got to be your best assumption, and you start there, and then disprove it if you can."

Proving the Point

That's exactly how Taylor and a group of activists he belongs to—called the Coalition for HIV and Aging Research and Policy Advocacy (CHARPA)—are hoping that the National Institutes of Health (NIH) will begin to approach the problem: Assume that aging itself plays a role, and then set out to better understand, and then disprove the theory.

The consequences of not following this approach could be serious indeed. The Centers for Disease Control and Prevention (CDC) estimates that more than half of all people with HIV will be older than 50 by 2015. This, activists say, makes them feel like they're in a race against time.

Jules Levin of the National AIDS Treatment Advocacy Project is another CHARPA member who took an early interest in the topic. He experienced an HIV-related bone fracture three years ago and began haranguing researchers about the subject at that time. Levin thinks we are woefully unprepared for an aging population.

Levin and Taylor began pushing researchers more than a decade ago to quickly respond to the body fat distribution problems that were starting to show up in people with HIV. Taylor feels that researchers turned their attention too slowly toward the condition, ultimately dubbed lipodystrophy. By the time we figured out what did and didn't cause it—we're still not entirely clear why people are accumulating such large amounts of fat in their guts—tens of thousands of people had developed the condition.

Taylor laments that there's still no approved drug to treat fat accumulation and the only one near approval, Egrifta (tesamorelin), is "lackluster."

"But at least with lipodystrophy there's now a kind of a checklist of what these things are," he reflects. Not so with aging.

These concerns led Lei Chou of the Treatment Action Group (TAG) and two other members of CHARPA to hand-deliver a letter to Anthony Fauci, MD, the director of the National Institute of Allergy and Infectious Diseases (NIAID)—the institute at the NIH responsible for the bulk of HIV research dollars—at a NIAID council meeting September 20. The letter begs NIAID and other NIH

institutes to boost both the priority and funding of aging-related HIV research.

“Right now [NIAID is] just paying lip service to HIV and aging by given it an ‘awareness day,’” claims Chou, referring to a September 9 press release from the institute dedicating September 18, 2010, National HIV/AIDS and Aging Awareness Day.

In essence, the letter from CHARPA calls on the NIH to take several actions. First, CHARPA would like the NIH to create a new funding mechanism in the 2012 budget that sets aside discrete money to study aging and HIV.

Second, CHARPA asked the NIH to issue a Request for Information and Ideas (RFI) on aging and HIV to the research community and to set up a special review panel that has expertise across all relevant disciplines in order to streamline the grant making process.

Third, CHARPA wants the community to have a prominent role in the research prioritization and review process.

Finally, CHARPA would like the NIH to establish a new cohort study that includes enough older people with HIV and enough HIV-negative people—who are similar in demographics and other key factors to the HIV-positive participants—to answer the most fundamental questions about HIV and aging.

This last point is particularly vital. It is perhaps one of the only ways to determine whether accelerated aging is part of the problems that researchers are beginning to document—and that many people with HIV are suffering through.

If research fails to illuminate how much various factors are contributing to the increased rates of diseases and disorders in people with HIV, the prospects aren’t good for the people Taylor knows.

“I live in Palm Springs,” he says, “which is kind of the epicenter of aging gay men who have survived long enough to tell the tale.” When asked to explain the ailments some people are already suffering from, he says, “It’s everything, the whole gamut: cancer, heart disease…the whole lipodystrophy spectrum…and neurocognitive decline.” This last item, he asserts, “that’s what terrifies the average aging person with HIV more than anything. Nobody wants to lose their mind.”

A Step in the Right Direction?

“NIAID’s research priorities are tightly focused on prevention, a vaccine and the cure,” Chou says. “Of course we want all of these things, but the medical complications and comorbidites of people living and aging with HIV seem to have been put on a back burner.”

Levin agrees: “They did not notice it. It got past them. They were preoccupied with everything else.”

Levin hears regularly from researchers who are interested in doing work on aging and HIV but who say the NIH turns down their requests for funds. When he asked “a top government official” about the accusations, he recalls, the response he got was, “Oh these researchers, they complain about everything. They just want their studies funded.”

A spokesperson for the Office of AIDS Research (OAR), which coordinates the HIV research programs across the different NIH institutes, insists that the OAR has actually been focused on the issue for quite some time and that NIH funding has already begun to bear fruit, including a large cohort study out of the Veterans Administration.

What’s more, the spokesperson said NIAID is currently working on a letter responding to CHARPA’s concerns, and that OAR would be glad to meet with the community at any time.

This echoes the experience of Sharon Maxwell, an activist from Kansas City who attended the NIAID council meeting along with Chou. “After we gave the letter to [Anthony] Fauci and Carl Dieffenbach [the director of the Division of AIDS at NIAID], Carl came back and said, ‘You all have some very good points in this. I do want to have a meeting with you,’” Maxwell recounted.

“From the time that we handed him the letter it was only 15 or 20 minutes before he was back saying, ‘Yes, let’s have a meeting,’” she continues. “I was very pleased with that.”

When asked what he would consider to be a sign of progress, Chou says, "I think one early indication that they are taking this seriously would be demonstrated by the research network recompetition process that’ll end by Feb. 2011. The new network leadership must include experts outside of virology, and be composed of researchers from other…disciplines as well as more emphasis on immunology. That would be a good indication.”

The OAR representative pointed out that the office has sponsored two meetings dedicated to the topic in the past year, and further stated that, “We are in the midst of the development of the fiscal year 2012 budget, and OAR plans to set aside funds to stimulate additional research in this area.”

What Comes Next?

CHARPA was born at the HIV Research Catalyst Forum, a conference held in April 2010 to rebuild and reinspire an activist community focused on HIV research advocacy. The conference was supported by funding from OAR and the pharmaceutical industry and cosponsored by TAG and other advocacy groups.

Though CHARPA has no official leaders and belongs to no specific agency, TAG has continued to sponsor the group’s activities and has dedicated the time and energy of its staff, including Chou. He hopes that the letter to NIAID, and the research it could inspire, will be just a first step in addressing the needs of an aging population of people with HIV.

In addition to the letter to NIAID, and plans for how to get the most out of a meeting with the staff of NIAID and OAR, CHARPA also intends to work on other areas, such as disease prevention and care guidelines. It will also explore how Ryan White programs and health care reform will affect the aging HIV population and whether or not safety nets will be there as people's needs for ancillary care grow.

The group currently has more than 50 members across the United States. "I've been very encouraged by the community response to CHARPA so far, and I think there is a lot of interest and motivation out there," Chou says.

Maxwell's motivation for joining CHARPA was two-fold. While she's been involved in HIV research advocacy for years, it's also personal.

She was diagnosed with HIV in 1994 and had just 40 CD4 cells at the time of her diagnosis. She says she's been remarkably stable ever since. At 63 years old, however, she is beginning to experience the effects of age and HIV. "The frailty, the weakness in the legs, the lipid disorders…all of that is starting to show up now."

Bob Munk, an HIV-positive activist from Santa Fe, says he's not a "sky is falling" type of activist, but the issue has particular urgency for him. While he's deeply grateful for the extended years that ARVs have given him, he insists that quality of life is equally important—and something that research has not yet conquered. "I have osteoporosis. I have CNS symptoms. And routinely those get kind of shrugged off as, 'Well you're aging,'" he complains.

"Yeah right!" he responds. "I'm almost 60, and I deserve better."

**David Evans is a member of CHARPA. CHARPA is a coalition of activists and people living with HIV that has formed to: 1.) expedite research about the intersection of aging, inflammation and HIV; 2.) ensure that the community has a voice in developing an aging and HIV research agenda; and 3.) advocate for policies that improve clinical care and social safety nets for older people with HIV. Members meet via monthly conference calls to share information and develop advocacy strategies. CHARPA is not affiliated with any other group. If you have health research advocacy experience and would like to learn more about the group,* click here*.*

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