

## **The Over-50 Crowd Relearns the Facts of Life**

HIV infection is a growing fact of life for America's baby boomer population. But it's a fact both the aging and their caregivers are spectacularly unprepared to address.

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April 01, 2008

## Read part one: Aging With HIV



For years, single seniors would find the idea of meeting new people following a divorce, or loss of a partner, daunting at best. But with today's online dating services, success in finding the perfect partner is ostensibly only a click away — all you need is a computer and a little courage.

But Jane Fowler, retired journalist and now HIV/AIDS prevention educator, waves a red flag of caution for older singles. As founder and director of the national HIV Wisdom for Older Women, Fowler says that older single people — "the fastest-growing segment of the dating services" — may put themselves at risk by engaging in new relationships.

"The perception among both the older, public population and providers of health and social services is that seniors are not at risk for sexually transmitted disease, and as a consequence they have low awareness about HIV," Fowler said.

While HIV can pose health problems at any age, there is additional risk of having the virus as an older person. People 50 and over have less vigorous immune systems, and studies report that a majority of older adults have at least one or more chronic, age-related condition such as diabetes, arthritis or heart disease.

Fowler, a vibrant and active senior, has a personal commitment to HIV awareness for women over 50: She was diagnosed HIV positive in the mid-80s, having been exposed to the virus from an unprotected, heterosexual contact following her divorce.

"I am very concerned about women who, like me years ago, may be re-entering the dating scene after an absence of several decades," she said.

## The Myth of Age-Related Immunity

According to Fowler, AIDS cases in women over age 50 are reported to have tripled in the last decade. Furthermore, the findings of the recent landmark ROAH ("Research on Older Americans with HIV") study reported conclusive evidence that heterosexual contact is now the predominant mode of virus transmission.

"It is important to get the message out," Fowler said, "to both women and men over age 50, that unprotected sexual contact is a risk."

She said physicians do not typically discuss sexual behavior with their older patients, and this fosters a false sense of security that age imparts "some special kind of immunity." Plus, as people age and their immune systems weaken, many of the symptoms of age-related conditions, such as fatigue, dementia, weight loss and skin rashes, are very similar to those of HIV.

"When these symptoms are overlooked and attributed to natural aging, people who are HIV positive end up walking out the door," she said. "By the time they are diagnosed, they may be very ill and the window of opportunity to begin a therapy that helps prevent the virus from progressing to AIDS has already passed."

However, the problems of older people affected by HIV are, "much more than physical ones and a regimen of taking pills," said Dr. Stephen Karpiak, lead investigator of the ROAH study. While the latest antiretroviral drug therapies allow people to live longer and healthier, their research data on the quality of life "paints an unsettling picture of the older person with HIV."

"More often than not, these older, HIV-positive adults are not only alienated by friends and family, they are afraid to disclose their status, and have few places to turn to for help," said Karpiak, who described "help" as "the little things that make the big difference."

"We're talking about having someone to help buy groceries, take you to the doctor or to church," he said. "Our study reported just how disconnected these people are from society — not just from their disease and its stigma but also because they are old with this disease."

There's a stereotype of older people as being no longer productive, with failing mental competency and low value to society. "There is this prevailing cultural attitude," recounted Fowler, "of 'so what if old people get HIV and die?' — the assumption being that they have already lived their lives and are no longer productive contributors."

## Need for Community Involvement

Dr. L. Jeannine Burkhardt-Murray, medical director of Harlem United Community AIDS Center, who helped Karpiak write the spirituality component of the ROAH study questionnaire, adds another dimension to the picture of social disconnection.

"Informal care giving by friends and family is provided to millions of people in this country who have chronic illness, disability, are elderly, or just need some day-to-day maintenance help," she explained. "But older people with HIV are often stepped over from potential sources of assistance because of persistent stigma and lingering misconceptions about virus transmission."

She added: "(It is) so unfortunate because we know that people who have outside contact with the community — not just the health arena of their doctors and nurses but with friends and family members — these are the ones who do the best."

Burkhardt-Murray said she has spent time over the years trying to engage local leaders of the religious communities into supporting people with AIDS.

The dilemma, said Burkhardt-Murray, who lives and works in the largely African-American community of Harlem, is that this is a population largely estranged by their family and friends who would turn to their church but find themselves unwelcome.

"For many years our clergy would not acknowledge this disease," she said. But after more than a decade of advocacy, she sees things changing and the church is now more willing to talk openly about HIV with its constituency.

This is good news since one of the ROAH findings, she said, is that many older HIV-positive people "expressed a positive benefit from a religious or spiritual affiliation."

#### An Intergenerational Approach to Breaking Barriers

For Ed Shaw, a tireless, 60-something-year-young HIV educator and chair of the New York Association of HIV Over 50, just "getting people to talk about this disease is an important step and can make a difference, one person at a time, to overcoming barriers."

Like Fowler, Shaw's mission for more than a decade has been to bring awareness to the risks of HIV in older people.

"I think that what we really need now is a bold, new vision, some real 'out-of-the-box' thinking," he said, explaining that his mission is to "tear down the wall" of barriers in communicating about HIV.

He developed what he calls the "intergenerational approach" to communicating about the virus. "What we need to do is connect whole families to start talking about health in general," he said, explaining that young people who are more likely to talk about sensitive issues like sexually transmitted diseases and AIDS can break down the barriers to talk candidly with the "older generations."

"I think when you get different generations to all sit down together — parents, kids, grandparents, aunts, uncles, whomever — you can all learn from each other, and this is key to breaking down traditional taboos of discussion," Shaw said.

Diagnosed HIV positive more than two decades ago, Shaw spends a lot of time in New York's community senior centers spreading his enthusiasm and "tearing down the wall" on HIV discussions. He says his "soft-sell approach works well" — using raffles, screenings and health fairs to promote senior attendance to his programs.

"Telling this story to older people is more than renting a space and handing out brochures," he said. "If you advertise 'come and learn about HIV in the elderly' you'll be talking to an empty room! I get people together to talk about aging and health from a wellness approach, then, we can introduce HIV as a discussion point."

### Public Policy Recommendations for Unmet Needs

Based on the findings of the 1,000 participants of ROAH, the first study of an HIV-positive population age 50 and over, Karpiak and his colleagues have outlined policy recommendations that are needed to address the multiple social and health delivery issues of this marginalized population.

"There needs to be action on three fronts," he explains, "health care, and clinical research, and social policy." The shorthand message is to educate physicians and advance an awareness of this aging population with HIV, to conduct research to learn about physiological effects, and develop programs to address unmet social needs.

"We need to address the problem of stigma and conduct public education and outreach awareness that targets the general public, and to also create prevention messages that targets older people," Karpiak said. "The medical community needs to realize all patients are at risk, and that those older people who have the virus need a different kind of care than someone who is in their 20s or 30s."

Karpiak calls for amendments in the Older Americans Act and its Caregiver Support Program elements. "We'd like to see HHS make specific provisions in programs and services and fund the Agency on Aging to pay for education and training," he said.

The researchers also envision local AIDS service organizations as the ideal resource who can provide specialized training to Area Agencies on Aging, to home health services and to other community outreach services who may have contact with older HIV-positive people as well as their typical client population.

The ROAH team also recommends more research on the medical and health needs of older HIV-positive people, including them in clinical trials, and implementing curricula in medical and nursing schools that address the specific needs and challenges of older people with the virus

## **Challenges of a New Frontier: Aging with HIV**

People living with HIV are living longer, but a new study stresses that few preparations have been made to address the future health and social services needs of the aging group.

### **Read part two: The Over-50 Crowd Relearns the Facts of Life**



Two decades ago, living to reach "old age" was not considered a likely prognosis for people with HIV. But with the tremendous success of better and more well-tolerated HIV drug therapies, people with the virus are living longer.

Dr. Stephen Karpiak, associate director of research at the New York-based AIDS Community Research Initiative of America, said that more than half the population with HIV is over 40, and one-third of those in that pool are age 50 or over.

"We have data that tell us that there will be large numbers of seniors living with HIV and AIDS, but we also see the incidence of infection growing in this older population — this is a huge concern," he said, adding that few, if any, preparations were made to address the future health and social service needs of this population.

The process of aging brings its own challenges — how will aging affect people who are HIV positive, many of whom have taken antiretroviral therapies for more than a decade?

"Up to now, there has been no comprehensive research that investigated HIV and older adults," Karpiak said. This uncharted territory and his goal to "identify a public health problem before it happens," became the basis for the landmark ACRIA study, "Research on Older Adults with HIV."

Karpiak said the primary purpose of the study was to find out "just who is the older adult with HIV? What is their background? How do they take care of themselves? Where do they get care? Who are in their networks? How do they feel about themselves? In other words, who are they?"

He said a thorough understanding of this current population's status was the necessary link to bringing recommendations to the research, social service and public health policy sectors addressing the needs of this marginalized population.

"The results of (the ROAH study) are enormous and present an alarming picture of the challenges facing HIV-positive people over age 50 as they age over the next decades," Karpiak said.

### Groundbreaking Survey

The ROAH study is a landmark undertaking both for its size — 1,000 participants — and its 11 components (sets of questions) in six primary areas: demographic profile, health status, sexual behaviors, social networks, stigma and psychological resources. Twenty-one academics, physicians and social scientists oversaw the project, self-funded by ACRIA; the questionnaire and methodology were reviewed by Copernicus, an independent review board, to ensure ethical treatment of its participants.

With their longstanding research relationships in the New York City area — more than 100 AIDS service organizations, regional hospitals and clinics — Karpiak said ACRIA "was uniquely positioned to collect comprehensive data on the largest sample ever of people who are over 50 and are HIV positive."

Because of ACRIA's extensive community presence, its outreach and word of mouth within the HIV/AIDS population drew a pool of volunteers representing a diverse and rich cross section of the population from more than 25 study locations across the New York City region. People who were HIV positive, age 50 or older, could participate. Volunteers had an average age of 55.5 years and more than half were between 50-55, said Mark Brennan, senior research scientist at ACRIA.

For several months, these volunteers filled out questionnaires at the study sites or at ACRIA. "The survey covered a lot of ground," Brennan said, "and the over-600 data points for each person were mostly yes/no or multiple-choice questions, but there were some open-ended items as well."

It turned out that the education level of the volunteers was "similar to the general population of New York City," Brennan said, with more than half graduating from high school and nearly one-fourth having some college, while 13 percent were college graduates and a few had a graduate degree.

Brennan said 264 women, 640 men and 10 transgender persons participated in the study with the majority of people (83 percent) having been born in the U.S. Half identified themselves as black, a third Latino and about 14 percent white. The remaining 4 percent identified themselves as Asian/Pacific Islander, American Indian or multi-ethnic.

The data found that the older adults in this study have been living with HIV an average of 13 years, ranging from three months to 26 years since diagnosis. The majority of people rated their overall health as "fairly good," another indicator, Brennan said, of the successful drug therapies of the last decade.

"The majority were not working and were either on disability, retired or not employed," he said, adding that more than half described their income as "just enough to get by," and nearly one-fourth said they "do not have enough to make ends meet."

Karpiak said these findings reinforce his and other experts' belief that "it's important to realize for older people with HIV/AIDS, living well and aging successfully is more than just taking pills."

#### Behavior and Risk Factors

"We also asked about incarceration and substance abuse as these are important factors in virus transmission," Karpiak said. "There is much evidence of increased rate of infection when people are incarcerated."

He said that nearly half of the male participants and slightly more than a third of the female respondents had, at some point in their lives, been incarcerated. More than half of the respondents reported abusing alcohol or illicit substances and were now in a recovery program, but a third of the people still engaged in substance abuse that included use of crack, heroin, cocaine or marijuana.

"While sharing needles is a mode of transmission for HIV, non-needle substance abuse is also a high risk and potentially dangerous behavior," Brennan explained. "People under the influence — whether it's drugs or alcohol — may engage in unsafe sex practices and increase their risk of exposure."

Karpiak said that of all the 11 components studied, the questions on sexual behavior are the most revealing, and one of the key findings on this population to date.

"This is the first study ever conducted to assess the sexual behaviors of an older population that is living with HIV," he said. "In our sample," which he explained represents the current HIV epidemiology in the U.S., "less than one person in four identifies as gay or lesbian (21 percent and 3 percent respectively) and 9 percent as bisexual."



Karpiak cited the respondents reported sexual activity from the previous three months of study participation: "Half of the subjects reported having no sex, and of those that did, 83 percent reported having oral sex, 60 percent vaginal sex and 39 percent anal sex."

"This report on sexual behavior is a significant finding," he said. "Where this virus was once almost exclusively transmitted by male-to-male contact, we now see heterosexual sex as the primary mode of transmission."

### Living in Isolation

To date, there has been no research to investigate what happens to people with HIV as they age and experience typical age-related conditions such as depression, arthritis, hepatitis, neuropathy or hypertension. Nearly all the study volunteers said they had at least one other chronic condition in addition to HIV, and more than three-fourths said they had two or more.

Brennan said those are important statistics as "many of the medications commonly prescribed for these ailments taken by older people can make depression worse."

With almost 70 percent of the respondents reporting they live alone - and as a group, scoring fairly high on both the loneliness and feeling-stigmatized evaluations — it is not surprising that the psychological well-being of this population is challenged on a daily basis. Many reported limited access to transportation services and little or declining contact with friends and family.

### Breaking New Ground

ACRIA investigators said the results of the study provide a critical mass of evidence needed to press policymakers for further research, and to determine how to optimize delivery of medical and social services. Investigators conclude that older people with HIV/AIDS do not currently have the family and community support that they need now, and especially as they age. These older people experience feelings of isolation, which are largely due to the persistence of stigma — in many cases they also face racism and age discrimination.

"Successful aging is about having the networks in place," Karpiak said. "What we see happening in HIV is symptomatic of the larger population in general, in health care."

He emphasized, "How we see ourselves and how others see us as a people, and as a nation, is how well we take care of our older people — that goes for those both older adults with HIV and other older members of our community."