The Age of Ignorance

Graying HIVers are writing safe-sex work into the retirement plan

December 1, 1998 By Charlotte Huff

Florida can seem like every aging former frat boy's fantasy. Condo complexes stretch for days, dotted with garden apartments, swimming pools and hot tubs. Enough space to support golf courses and shopping malls, a rich social calendar and, with public transportation handy, no worries about sliding behind the wheel. And a high concentration of women -- widows, divorcees, singles -- seeking affection and attention.

In the late '90s, it's no longer a shameful secret that seniors -- gay and straight -- have sex, or want to. A 1994 University of Chicago study of Americans' sexual habits confirmed that desire does not flicker out as the years march on. Sixty percent of men aged 55 to 59 reported having sex at least a few times every month, only slightly lower than the average across all ages, 73 percent. Women aged 55 to 59 are less lucky -- 37 percent say they have sex at least a few times every month, about half the overall average, 70 percent.

More Americans are living longer. Baby Boomers began hitting the half-century mark in 1996; in another decade, their numbers will have swelled by half, to 38 million. And with the rates of divorce high and adultery rising, more seniors than ever are entering the sexual push-and-shove traditionally viewed as the domain of the young and restless. But in the age of AIDS, frustrated advocates lament, older Americans are doing it with far less prevention knowledge than college kids at a keg bash. "They sometimes call because they went to a potluck, had too much to drink and went home with someone," says Margaret Moore, a public-health nurse-consultant in the Office of HIV/STD at the Arizona Department of Health Services. Many callers are unaware of what constitutes safer sex and why they should even worry about it, she says.

AIDS among the elderly -- a group defined by the Centers for Disease Control and Prevention (CDC) as 50 or older -- is no new phenomenon, comprising at least one in 10 cases since 1981. However, the most common modes of transmission have changed, largely because of the lack of accessible HIV education. Blood transfusions, once a common cause of late-life AIDS, made up just 2 percent of all diagnoses from 1991 to 1996, according to the CDC. New cases among gay men 50-plus were stable across that six-year span. But while still relatively small, the number of older PWAs who got infected through heterosexual sex and IV-drug use have steadily climbed -- up 94 percent and 53 percent, respectively, for men. Among women, the respective increases were even greater -- 106 percent and 75 percent.

“This Old, Wrinkled Face”

“Can an older, Caucasian female, college-educated and still a career woman at 63 -- who was monogamous during a long marriage that combined motherhood and journalism in a conventional lifestyle -- have HIV?” asks the kindly looking grandmother. “Certainly,” she answers brightly, after a beat. Jane Fowler, the 63-year-old co-chair of the National Association on HIV Over Fifty (NAHOF) has stood before some 200 Midwest audiences, laying out her story. “Look at this face -- this old, wrinkled face,” she tells elementary-school students and retirement-home seniors. “This is another face of HIV.” No sex radical (“I was, by choice, a virgin on my wedding night in ’59”), Fowler was abruptly dropped into the early-’80s dating scene after a divorce at 48. “It never occurred to me that I was putting myself at risk by engaging in unprotected sex with an attractive, intelligent, amusing man of many interests,” the former Kansas City Star reporter and freelance writer recalls. “A man who had been a close friend my entire adult life.”

In 1991, Fowler returned from a holiday visit with her son, Stephen, in San Francisco to find a shocking letter in her mailbox. Her health-insurance application had been denied, based on “a significant blood abnormality.” Her dumbfounded family doctor gave her the news that her blood tested positive for HIV. “Stunned, devastated,” she immediately retested. “My hope was that the insurance company had mixed this up -- that this was someone else’s test.” Two weeks later, after sharing the news with family and friends, including her 80-plus-year-old parents (“All were wonderfully supportive, but I have never felt so alone in my life”), a second positive test result shattered this hope. She had just turned 55.

Fowler’s disbelief that she was exposed to, let alone infected by, HIV is no less common among seniors than among their doctors, who tend to dismiss HIV as a possible cause of their older patients’ health complaints. Laura Boston, now 72, after repeated battles with lung infections and other ailments in the early ’90s, asked several times to be tested for HIV. The Indianapolis woman’s physician pooh-poohed her and her AIDS fears. But in 1994, a blood test, mandatory for her enrollment in a drug trial, identified Boston’s CD4 count as 268. Only then, she recalls, did her doctor begin to ask her questions about blood transfusions and possible intimacies with IV-drug users. “I said, ’Not to my knowledge,’’’ says Boston. ”But of course, people’s partners don’t advertise those things."

Forty percent of primary-care physicians report rarely or never asking patients over 50 about HIV risk factors, while only 7 percent don’t ask patients under 30, according to a survey of 330 Dallas, Texas, specialists published last year. Sue Dodd-Adams, an HIV educator in Phoenix, once startled a Gen X-aged doctor during a routine gynecological exam. “She didn’t ask me one thing about my sexual history,” says Dodd, then a single mother in her 40s. “I said, ’How do you know if I don’t play around with every man in town or do drugs?’” All motion ceased on the other side of the sheet, Doss recalls, and a pair of eyes peered over the top. "She said, ’Should I ask?’’’

Risk Reduction For Retirees

Whether you’re 16 or 60, age-appropriate HIV prevention is a necessity. In her deep, booming

voice, Sue Saunders, 65, gives presentations for the Senior HIV Intervention Project (SHIP) in South Florida, explaining why condoms can't be tossed out with menopause. She and other activists say the extent of denial and misunderstanding among their audiences never ceases to amaze. "After 20 years, some still think it's through blood transfusions and casual contact -- like breathing and spitting and coughing," Saunders says.

Dozens of interviews with educators, social workers, clinicians and PWAs identified no more than the occasional pocket of prevention and outreach aimed at older Americans among the nation's myriad gay rights, AIDS and seniors' organizations. In 1996, for example, the American Association of Retired Persons (AARP) produced 500 copies of a prevention video, "It Can Happen to Me," which continue to circulate through retirement communities. It's a rare bright spot that AARP -- and other groups -- have yet to duplicate. Every June 27, the National Association of People With AIDS targets several risk groups on its National HIV Testing Day. So far, older Americans have not made that list. But lined faces will soon figure more prominently in the group's agenda, policy director Mike Shriver says. "This is a population," he says, "that we have not done a good job targeting."

SHIP, launched last year by the Florida Department of Elder Affairs and the Florida Department of Health, targets a three-county coastal stretch from West Palm Beach to Miami. Saunders and other senior activists give presentations at synagogues, churches, health fairs and assisted-living facilities.

Condominium complexes, so ubiquitous in South Florida, are a much harder sell. "They say, 'That subject doesn't pertain to us because we don't have anyone who is infected,''' says John Gargotta, SHIP's project coordinator. But once begun, the presentations rock along with skits describing sexual communication and a crop of multicolored condoms. "They love to talk about sex," Saunders says. Prostate problems, heart medications and other erection deflators make oral sex a popular topic. Last April, SHIP sailed into its version of Broadway, speaking to a large condo complex in Pembroke Pines. "We had a couple of people walk out, but 200 stayed," Saunders says. SHIP's supply of 1,000 condoms flew off the table.

HIV can also be found at the end of a senior's dirty syringe. It was traditionally thought that IV-drug users "aged out" of their addiction, either because they quit or died -- stereotypes that are not upheld by the recent CDC report. Registered nurse Kathy Nokes, cochair of the New York Association on HIV Over 50, worries about the seductive link between drugs and sex, which can occur when an older man falls for a younger, drug-using woman, or vice versa. "I have clients who start using heroin at 53. And they'll say, 'I met this woman and we started hanging together.'''

Like straight seniors, older gay men have been overlooked in prevention efforts, but mainly due to the mistaken assumption that they already learned these lessons firsthand, says Richard Elovich, director of prevention at Gay Men's Health Crisis (GMHC). "Essentially, older men have lived the AIDS crisis," he says. This fall, GMHC launched a prevention campaign focused specifically on sexuality and the older man, including discussions of relationships, aging and self-esteem. According to Elovich, these men over 50 are, in a sense, a "lost generation" who -- miraculously, it

may seem to them -- have survived uninfected. "If we want them to feel it's important that they *stay* uninfected," Elovich says, "we have to help them feel that what they have in their lives is worth holding onto" -- a project made problematic by survivor guilt.

"He Still Plays Around"

Society prefers to pretend that older people -- gay and straight -- are dead from the neck down, says Ron Stall, an associate professor at the University of California at San Francisco and the lead author of a 1994 *Archives of Internal Medicine* study on HIV risk behaviors among the 50-plus. "I'm struck," he says, "by phrases like *little old lady* and *dirty old man.* Little old ladies are clearly not sexual. And dirty old men clearly are and shouldn't be."

Stall's research indicates that, at most, only 10 percent of all older people are at high risk for HIV. But those who are remain far less likely to use protection than most members of other groups at risk. High-risk heterosexual adults aged 50 and over were one-sixth as likely to use condoms during vaginal or anal sex, and one-fifth as likely to get tested, as a comparable group in their 20s -- recipients of a decade-plus of safe-sex messages. But this schism doesn't exist among gay or bisexual men, Stall adds.

Risk among older people is often exacerbated by age-specific conditions and situations. Physically, time thins the vaginal walls, reducing natural lubrication and making HIV transmission easier. And once back on the dating scene, older women face stacked male-female odds that may make them more likely to take risks in an effort to meet a man. "The women come up to me and, pointing to the one seemingly eligible man in the place, want to meet the Casanova over there,'' says Gargotta, the SHIP educator.

Gay men who came of age in the pre-Stonewall days may be more likely to hide their orientation behind a marriage. Some of these men seek counseling from Howard Warren, a 64-year-old Indianapolis minister diagnosed with HIV in the mid-'80's. Recently, he fielded a not uncommon call from a man in his mid-50s struggling with guilt over his double life. "He still plays around a bit," says Warren, who inquired about the man's HIV status. "He hadn't even thought of that -- that he could even be HIV positive."

In the openly gay community, many older men are victims of burnout, with little energy to lead prevention efforts. Bob Green, Los Angeles resident, is, at 61, left to explain the early days of gay rights and HIV to men half his age. For 15 years, this survivor has lived with HIV, watching the virus take first his lover more than a decade ago and then, one by one, his mentors and contemporaries. "They are all gone."

Without intensive HIV education, neither older men nor older women are likely to discuss risk with sex partners, especially once menopause has removed the possibility of pregnancy. "Back in my days," says 71-year-old Miami resident Joe Kostick, "a condom was for birth control."

Kostick and his wife, married nearly 30 years, had already raised four children when they divorced in 1985. "I was living all by myself in the same house and I went berserk," Kostick says. He

became a heavy beer drinker, frequenting bars, picking up both men and women. He was 60, near death in a Miami hospital bed battling tuberculosis, his children at his side, when a hospital physician leaned over and whispered that he had HIV. “I was so sick I couldn’t walk,” says Kostick. "I had to be carried to the bathroom. Every day, I would wake up and say, ’Why am I alive?’’’

The Invisible 11 Percent

CDC officials say it’s difficult to determine the number of older people living with HIV, given the lack of data from state and federal agencies. And what about missed diagnoses? Dementia, lung problems, unexplained weight loss and other symptoms of HIV can be easily mistaken for ailments related to the general aging process. One January 1995 *Archives of Internal Medicine* study tested 257 New York City patients, aged 60 and older, who had died without any recorded history of HIV. Five percent were positive.

Nearly 391,000 Americans have died of AIDS since the epidemic’s start, according to the CDC’s 1997 data. One in 13 was at least 54. Despite these numbers, older Americans with HIV typically have less support -- financially and medically -- than do younger people. They are more likely to face HIV with fixed incomes and options. Standard Medicare plans don’t cover prescription medicines. Even if they did, age-specific treatment information is nearly nonexistent.

Long-overdue research into seniors with HIV -- everything from longevity to medication side effects to risk-taking behaviors -- requires money, and that remains scarce. “What research there is comes through our unit,” says Marcia Ory, chief of social science research at the National Institute on Aging. Often lauded as a leader in geriatric AIDS research, the institute nevertheless devoted just $1.8 million in 1997 to funding AIDS-related studies, including the sexual behaviors of middle-aged women and the risk profiles of older drug-users. Even the much-touted University of Chicago study limited its examination of adult sexual behavior -- with age 59 the upper limit.

Compare these figures with those of pediatric AIDS -- responsible for roughly 2 percent of cases since the early 1980s. In the 1998 fiscal year, the National Institutes of Health expects to divvy up about $174 million for pediatric research. Does society value its kids that much more than its grandparents?

Meanwhile, older Americans now account for 11 percent of existing AIDS cases, according to the CDC. About 36 percent of this total are gay men, while nearly 15 percent were infected through heterosexual transmission and about 19 percent through dirty needles.

The Shame Game

How they got HIV may differ, but how older Americans live with it is distressingly similar. Most describe an acute sense of isolation that only pluck and luck can cure. Even Sue Saunders, the well-known South Florida educator, still longs to find another local HIV positive woman to meet for lunch -- someone her age who has learned to stare down that look from strangers, even some health professionals, when they find out she has the virus. “People thought I was a dirty old slut because I got it through sex,” says Saunders, diagnosed at 58. “If I had gotten it through a blood

transfusion, it would have been all right." She initially tried local support groups, but they were filled with young gay men who, she says, often seemed uninterested in her concerns.

Or consider Jane Fowler. "Immediately following my diagnosis in 1985, I decided to call myself 'retired,' to reduce stress and protect my immune system" she recalls. "But that wasn't the only reason I withdrew. I did not have the courage to put myself in painful situations -- where I might experience rejection, prejudice or intolerance." A Kansas City, Missouri, resident since her early 20s, Fowler describes driving many miles from familiar neighborhoods to go the movies -- her "one solitary escape" -- without bumping into a casual acquaintance and the requisite idle chitchat. "I didn't want to answer the question 'What are you doing?' with the statement 'Waiting to die from AIDS,'" she says. "But alone, I could almost forget that I perceived myself as tainted and 'dirty' because of my infected blood."

Then, four years ago, Fowler decided to "liberate" herself -- and try to help others do the same -- by becoming a public PWA and, eventually, an activist. She began by signing up as a speaker for Good Samaritan Project, Kansas City's oldest and largest AIDS service organization, spreading treatment and education information at schools, churches, social clubs and corporations. That, along with her work as NAHOF cochair, keeps her beyond busy and able to deal daily with the complex psychological effects of having HIV.

Life experience can provide older people with HIV a wider palette of coping skills, including the essential ability to take one day at a time, says Richard Levin, a mental health specialist at AIDS Project Los Angeles. But fear and confusion is still part of the package. Support systems, common among young people with HIV, are hard to come by for their older counterparts. Parents, if alive, are usually weak and dependent. Children, likely grownup, may be unprepared for an abrupt window into their parent's sexual behavior or drug use. Statistically, the descent to full-blown AIDS appears steeper in seniors for reasons that remain unclear. A 1996 study, published in the *American Journal of Medicine,* showed that nearly 12 percent of people 50-plus die within two months of HIV diagnosis, compared with 2 percent of younger Americans. In 1998, New York State's North Shore University Hospital reported that 37 percent of people over age 80 die within a month of their HIV diagnosis.

But despite these numbers, ignorance and denial remain endemic in the HIV community, Fowler says. Last summer at the 12th World AIDS Conference in Geneva, she wandered among the thousands and thousands of posters, searching for research focused on HIV in the over-50 crowd. She found three abstracts; two involved her own association.

Although disappointed, Fowler persists, aware that fighting ageism is no easy task. And some days she even sees signs of progress. Soon after she began peddling prevention, Fowler served up her story to some suburban Kansas City middle-school classes, adroitly fielding delicate questions. Until this one: "Look," a girl shot at Fowler, then 60, "we all know we're going to die some day. And you're old, so what does it matter?" "She wasn't," says Fowler slowly, "putting any value on my life." But recently she got a thank-you letter from another middle-schooler that makes up for all the grief. "Dear Jane Fowler," the girl began. "Well, I sure never knew anybody over 50 had

sex.”

GRAY MATTERS

Brain drain on standard of care for seniors

Seniors alternately laugh and cry over their image as perpetual pill poppers who deal with various illnesses, many related to the general aging process. But the rigors of treating HIV can stymie even the most committed drug-taker, says Yvonne Wind-Vazquez, a physician’s assistant who works with PWA Joe Kostick, a 71-year-old Miami resident.

Soon after testing positive in the mid-’80s, Kostick began taking a human growth hormone to help reverse wasting. But it played havoc with his diabetes, requiring additional medication to bring his blood sugars under control. Kostick dropped the hormone entirely earlier this year after a series of heart attacks; his daily regimen now includes several cardiac medications as well as an AZT/d4T/Invirase combo.

Despite these ailments, Kostick has rebounded fairly successfully from 1989, when the five-foot-six-incher’s weight plummeted to 90 pounds and his CD4 cells to 47. Now 142 pounds with a CD4 count of 304 and an undetectable viral load, he credits faithful adherence to his combo. He has exchanged his kick-back-with-a-six-pack habit for hours in the small gym he set up in his Miami carport.

Sad to say, Kostick’s rebound is unusual. As a rule, HIV positive people over 50 tend to get sick and die faster than their younger counterparts, according to Daniel Skiest, MD, an assistant professor at the University of Texas Southwestern Medical Center in Dallas. Delayed diagnosis is a likely key, he says. But other factors certainly play a role, including the toll aging, other illnesses and the medications used to fight them all take, especially on the immune system.

Amy Justice, MD, worries that some physicians may avoid adding such potent drugs as protease inhibitors if the patient is already carting a heavy medicine chest that can heighten drug-interaction risk. The AIDS researcher and staff physician at Veteran’s Administration Medical Center in Cleveland suggests triage based on the most pressing medical concerns. “Once you get beyond six to eight kinds of medications,” she says, “the patient’s ability to take them goes way down.”

And older people don’t seem to tolerate the protease inhibitors as well, says Kathy Nokes, a registered nurse and cochair of the New York Association on HIV Over 50. The elevated triglyceride levels associated with the protease class are a particular concern among those with pre-existing heart disease. Body changes, such as “protease paunch,” appear to be no more common among older people than other PWAs. But in the absence of clinical trials, all such feedback is only anecdotal.

Abbott Laboratories, Glaxo Wellcome and Merck have apparently done no studies looking at side

effects or metabolic differences among older protease takers. “The numbers are so small that we’ve never cut the data to look at it specifically,” Glaxo Wellcome spokesperson Mary Faye Dark says, adding that the issue may be revisited given the rising incidence of late-life AIDS. “But we don’t expect any differences.”

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