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Are sexually active older Americans your next high-risk group?

CDC says more older people are contracting HIV through sexual contact

When Jane Fowler, 64, began dating in the mid-1980s, she was a little rusty, having gone through a divorce in 1983 after 23 years of marriage. However, by the end of the decade, the Kansas City, MO, resident knew enough about AIDS to be concerned that she could be at risk. In 1989, Fowler asked her long-time family practitioner if she should take an HIV test.

"Oh no, not you, Jane Fowler," her doctor answered lightly.

Fowler found her doctor's response comforting. She put the possibility of AIDS out of her mind until she received an ominous letter from an insurance company in January 1991. Her application for a new health insurance policy was denied because of a "blood abnormality." She spent a sleepless night and anxious next day until the insurer faxed the results to her doctor. The same doctor who had earlier brushed off her interest in an HIV test now gave her the bad news: "Jane, your insurance company claims your blood tested positive for HIV."

Fowler, who later determined that she had become infected on New Year's Eve in 1985, says she hopes things are different today and family doctors don't brush off a middle-aged patient's request for an HIV test.

"Obviously, if someone starts talking about HIV, then maybe doctors should have a sense that the person has some concerns and there was a behavior that could lead to infection," says Fowler, who now serves as speakers' bureau coordinator with the Good Samaritan Project, an AIDS service organization in Kansas City. "And by all means, the provider should follow through and offer testing."

However, despite the progress made in the field of HIV/AIDS treatment and all the education information disseminated to the public, physicians and others who work with older HIV patients say the health care profession still treats older people as though they are celibate and therefore at no risk of contracting the virus.

"There's a tremendous amount of education needed," says **Mary Lynn Kasunic, MS, RD**, executive director of the Area Agency on Aging, Region One, in Phoenix. "Physicians often don't acknowledge that seniors are still sexually active."

Statistics present a different picture. Until the 1990s, elderly Americans were disproportionately infected by contaminated blood supplies, with a risk factor of 6% for those in their 50s, 28% for people in their 60s, and 64% for those age 70 and over.¹ Now the risk of contracting HIV from blood transfusions is negligible, but increasing numbers of older adults are becoming infected through their sexual behavior, according to the Atlanta-based Centers for Disease Control and Prevention's *Morbidity and Mortality Weekly Report*.

According to 1996 figures, the most recent figures available from the CDC in this category, only 2.4% of HIV-positive people ages 50 and over were infected with HIV from blood products. Another 19% were infected through injecting drug use. About 36% of those infected were men who had sex with men, and 14.5% reported they were exposed through heterosexual contact. This compares with 12.7% of people ages 13-49 who were exposed through heterosexual contact. Because nearly 26% of the older adults reported no reason for exposure, the number of cases relating to sexual behavior could be higher.

About 11% of all AIDS cases reported in 1996 were among people ages 50 and up. The CDC reports that this percentage has remained stable since 1991. However, the CDC notes an alarming trend in that older AIDS patients had a greater increase in opportunistic infections (OI) than did younger AIDS patients. The older age group's OI incidence rate rose by 22%, vs. a 9% increase among the 13-49 age group. The report also says a higher proportion of people aged 50 and above died within one month of AIDS diagnosis.

Older people diagnosed later for infection

The CDC concludes that people ages 50 and above are diagnosed later in the course of their HIV infection than younger people are, and they may not be promptly tested for HIV infection following the onset of HIV-related illnesses.

These statistics seem to confirm the idea that older adults are naive about their risk of contracting HIV and their providers aren't discussing that risk with them. A 1997 study of Texas doctors found that most physicians rarely or never discussed HIV and risk factors with their older patients.²

"I'm concerned that there are older people out there who may have the virus, and no one

is really alert enough or paying attention to the fact that HIV may be a possibility," says **Mary Ann Malone**, CSW, case manager of adult AIDS clients at Mt. Sinai Hospital in New York.

Compounding the problem, AIDS symptoms often are more difficult to diagnose in older people because they mimic some common diseases associated with old age, says **Nathan L. Linsk**, PhD, professor of social work at the Jane Adams College of Social Work in Chicago and the principal investigator for the Midwest AIDS Training & Education Center at the University of Illinois at Chicago. Linsk is a co-founder and co-chair of the National Association on HIV Over Fifty.

"HIV-associated dementia might be confused with multi-infarct dementia or other diseases," Linsk explains.

Physicians should ask about sexual behavior

For these reasons, physicians should keep HIV in mind as a possibility, even with their older patients. Malone and other HIV experts recommend physicians routinely ask all patients about their sexual behaviors during the annual physical or gynecological exam. Or if they are uncomfortable doing so, they could simply add a question about sexually transmitted diseases or sexual risk behaviors on the patient's medical history form.

"And secondly, providers should educate the population over 50 about possible exposures to HIV and safer sex practices," Malone says.

One of Malone's clients is a 72-year-old HIV-positive woman who probably contracted HIV through sexual intercourse, although her partner had not been diagnosed before he died of an ear infection. The woman began to develop a few symptoms of HIV infection, and her physician suggested that she be tested. "He was more alert to the fact that this could be a possibility," Malone says. "So there are always these very hopeful signs that the message is getting through."

Some agencies that offer support services to older people and the Washington, DC-based American Association of Retired Persons (AARP) now try to get the word out to their audience about HIV and safe sex. AARP has a video about HIV titled "It Can Happen To Me," and the Phoenix agency distributes HIV brochures titled "AIDS is Ageless - Practice Safe Sex" and "Don't Gamble with HIV/AIDS."

But there's little federal support for these efforts.

“When you apply for national grants for HIV prevention education, the government is focused on groups like teenagers or men having sex with men,” Kasunic says. “In the last five to six years, when we’ve applied for grants, they always send it back and say, ‘This is not one of our targeted populations.’”

Meanwhile, the few agencies that are trying to get the word out to older people face an uphill battle.

The Phoenix Area Agency on Aging has sponsored four free suburban HIV testing sites that were marketed to seniors in the same way as a blood pressure or cholesterol screening, but these offered anonymity. In all, 40 people showed up for tests.

“It’s been real disappointing, because we were hoping we’d have a groundswell from the community saying, ‘I want to be tested,’” Kasunic says. “We’d thought some of the problem was older people didn’t want to go to the county health department, and they didn’t want to drive into the city, so we thought we’d take it out there to them.”

The stigma of HIV is still so high among the elderly that even when people have engaged in risky behavior, they often are afraid to be checked. **(See related story on treating older HIV patients, at right.)** For example, Kasunic recalls that one woman who came to a portable testing site said she and three other women in her apartment complex were having sex with the same man. The woman had lost a straw draw and was selected to come down to the site for testing. The four women figured that if one of them tested positive, they would all have something to worry about. Her test was negative.

Kasunic says she can understand an older woman’s reluctance to demand that her partner use a condom. “If you’re in your 60s or 70s, and the ratio of men to women is not so good, and you finally find someone to become intimate with, I don’t know if you’d want to demand the man use a condom,” she explains. “If you get too demanding, he might move on to another woman because he has lots of choices.”

References

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Older HIV patients require special considerations

Older people with HIV offer their advice

It’s difficult being an older person in America, where the culture is permeated with messages of youth, beauty, and vitality. Having an additional burden of a socially unacceptable disease like HIV can further stigmatize and alienate an older person, according to HIV experts and people who are infected with the virus.

Society can be hard on people with common frailties, **Bill Rydwels** has found. Rydwels, 66, who lives in Chicago and was diagnosed with HIV in 1985, is treated with antiretroviral drug therapy. The gastrointestinal side effects from his drugs, compounded by the aging process, often cause him considerable discomfort and embarrassment.

“I’ve walked into stores and said, ‘Please may I use your bathroom?’ and they say, ‘I’m sorry, but the toilet is only for employees,’ so you end up messing yourself,” Rydwels says.

These types of discomforts can wear down people’s self-esteem and erode their independence, but providers may see these as minor problems.

“The medical community seems to say, ‘Well, look, it may cause those side effects, but look how well you’re doing right now,’ and you want to say, ‘Gee, thanks, but you should be in my position and have the embarrassments I have when I can’t control everything all the time,’” Rydwels says.

Providers who have older patients with HIV need to consider a wide variety of health and psychosocial issues, some of which overlap with the problems experienced by their younger patients and others of which are unique to that population.

Rydwels and others familiar with what it means to have HIV over age 50 offer these suggestions:

- **Encourage patients to find support to prevent their isolation.**

Older people with HIV often become isolated, partly from a fear of disclosing their disease to family members or friends, says **Nathan L. Linsk**, PhD, a principal investigator for the Midwest AIDS Training & Education Center in Chicago.

“They might not find other people their age who have HIV, and many HIV services are not equipped to deal with the special needs of older people, so they become more isolated,” Linsk says.

Jane Fowler, 64, has become very active and vocal in advocating for services and support for older people with HIV in recent years, appearing on the covers of magazines and being quoted in major newspapers about her HIV status. But Fowler admits that she wasn't always this open. After she confirmed her HIV diagnosis, she only shared her problem with very close family and friends, and for four years she retreated from her former life. She quit her journalism career and spent her time avoiding potentially painful social circumstances. Fowler even drove 90 minutes out of town to see movies so she wouldn't see anybody she knew.

While Fowler eventually broke through her self-imposed shame and isolation, many seniors do not.

"When you can't share this with people in your lives, you end up isolated and lacking support," says **Erica Aeed TeKampe**, MSW, case management supervisor for the HIV Care Directions program of the Area Agency on Aging, Region One, in Phoenix.

TeKampe recalls a particularly poignant case of a couple in their 70s who discovered when the husband was having some unrelated health problems that he also was infected with HIV. The wife was not infected. "They'd just moved to Arizona to be near their family, but staying there after the diagnosis ended up being too much for them," she says.

The man heard his siblings and nieces and nephews discuss AIDS in a very derogatory and judgmental fashion, and he decided he couldn't share his problem with them.

"The husband became very isolated and really shut himself off from his wife, and that was difficult for her because she needed someone to talk to, and she couldn't talk to her family," TeKampe says. "She needed the support of social service providers, but she didn't want to go that far, because what if someone in her family saw her car at an AIDS agency or if they saw a brochure in her house?"

As far as he knows, they never found a solution to their social isolation. Instead, they moved away from their family and from the retirement life they had planned.

• **Differentiate between geriatric and HIV symptoms, while treating both.**

When Fowler began to experience hearing loss, she wasn't certain if it was due to aging or HIV. Her physician reassured her that this was a normal part of growing older.

Older HIV patients often have multiple health problems, such as heart conditions, high blood pressure, and diabetes, says **Mary Ann Malone**, CSW, case manager of adult AIDS clients at Mt. Sinai Hospital in New York.

"All of these things combined make them somewhat different from someone who is younger and doesn't have the problems associated with growing older," Malone says.

Be aware of drug interactions

Clinicians need to be aware that their older HIV patients may be on multiple medications that could be contraindicated with their antiretroviral drugs. For example, Pfizer recently published a warning that the impotence drug Viagra should not be combined with the protease inhibitor ritonavir because the protease inhibitor can boost the maximum levels of Viagra in the body to dangerous levels. Saquinavir also caused Viagra levels to rise, although to lower levels.

Some of the side effects from antiretroviral drugs, such as increased cholesterol levels and hyperglycemia, are already a problem in older people.

"The HIV cocktails may cause more rapid progression to other conditions," Rydwels says. "I'm dealing with diabetes, which was not a condition I had before I took protease inhibitors."

Fowler struggles with lipodystrophy as a side effect of her HIV drug regimen. She says the mid-section roll of fat is hard to deal with because when she looks in the mirror, she's reminded of how she looked 35 years ago while pregnant with her son.

Rydwels says he's encouraged that health care professionals are beginning to recognize the need for clinicians who specialize in both geriatrics and HIV. Rydwels says he knows a nurse who works with older patients and now is returning to graduate school to study HIV. And he has a therapist who is studying both HIV and aging.

• **Acknowledge the person behind the disease.**

Fowler offers a good example of how not to handle the first consultation with an HIV-positive person, older or not: "The first doctor I went to was a male, and I would be his second female HIV patient," she recalls. "The first thing he did was draw a time line showing me how the infection progresses and how in 10 years of infection you're dead, meaning I would have five more years to live."

She never returned to that physician's office, although he was considered one of the leading HIV specialists at the time.

Clinicians should be aware that confidentiality, while important for anyone with HIV, is an even bigger issue for older people with the disease, TeKampe says.

"There's even more stigma related to being positive within their own generation," she explains. "And it's such an oddity that they have much bigger issues of privacy and keeping it a secret."

They might not want to tell their children, for fear of what their offspring will think of them. "They've tried to be role models all their lives," Malone says.

Fowler told her adult son about her diagnosis soon after she learned the bad news, and she says his support has been extremely important to her acceptance of the disease. She also told her parents, and while they were supportive and non-judgmental, it has been difficult news for them to bear. Her father has since died, and her 89-year-old mother now lives in a nursing home.

"My mother teared up," Fowler says. "Her greatest fear in these last eight years has been that I will get sick and die before she does, and she will have to witness the death of her only child."

Probably the most important emotional service a clinician can provide to an older HIV patient is being open and willing to listen, Rydwels says.

"Just recognize that this is a human being who operates like all other human beings in this world and has needs, and some of those needs are for attention, love, support, and sexuality," Rydwels says. "And approach that individual from that point." ■

'THE Course' helps keep HIV patients on meds

Washington, DC, clinic finds program works

Convincing HIV patients to stay on their protease inhibitors requires more than a little TLC. However, participants in a compliance program called the Tools for Health & Empowerment (THE) Course receive a healthy dose of self-esteem reinforcement with every lesson geared toward giving them skills to manage their disease successfully.

THE Course's gentle touch seems to work. A recent study showed that participants at a six-month follow-up assessment had significantly fewer reported number of missed doses during the prior four weeks than a control group did.

The program is very effective, says **Steve Geishecker**, MSW, LICSW, a clinical social worker at Whitman-Walker Clinic in Washington, DC. The clinic has taught THE Course to clients twice and also continues to use some of the program's modules for educational materials.

"The amount of information provided to instruct this program is very thorough, and it gave us a nice structure and framework in which to teach these different modules," Geishecker adds.

Building self-esteem and coping skills

Presented to patients in one to 12 module sessions, THE Course is designed to build HIV patients' self-esteem and coping skills, as well as teach them about their disease and why medication adherence is crucial to their survival. The program was launched in early 1997 at 12 sites nationwide, and now has been implemented in 16 states and the District of Columbia. THE Course has had more than 1,000 participants and about 100 trainers.

"Knowledge doesn't necessarily change behavior," says **Maddy Rice**, BSN, ACRN, associate manager of HIV/AIDS program development for Glaxo Wellcome Inc. in Research Triangle Park, NC. The pharmaceutical manufacturer has a separate care management division that developed THE Course for use with HIV patients who are at risk for discontinuing their medication treatment.

"So even though this is an educational program where people will improve in their knowledge base, we focus on behavioral objectives," Rice adds.

"We analyzed the data six months after intervention, and we've seen statistically significant increases in adherence to antiretroviral therapy, statistically significant increases in knowledge, and an improvement in patients' quality of life," says **Dana Bonas**, MOH, outcomes manager for HIV/AIDS at Glaxo Wellcome's care management division.

"What interested me in THE Course was the emphasis on behavior change and behavior management specifically related to medication compliance, increased quality of life, and the opportunity

for participants to gain valuable innovative knowledge about how to better live with the virus,” says **Lisa Porto**, MSW, LICSW, LCSW, LCSW-C, a behavioral therapist and the former clinical program manager for addiction treatment services at Whitman-Walker Clinic.

“I taught the original 10 modules twice,” Porto says. “It brings people together with others who are HIV-positive, and they learn new information and skills in an environment that fosters learning.”

During the first 10-module session, all 10 HIV-positive participants and their 10 caregivers completed the training. The clinic had required caregivers to attend as well, and that probably helped with attendance and compliance, Porto notes.

However, when the clinic used the course’s 10 modules a second time, enrolling 18 HIV-positive people without their caregivers, the results were less successful. Only 11 completed the sessions, Porto says.

Incentives improve program attendance

“The first time around, we had more incentives for attending, like medication materials, a free meal, gift certificates for grocery stores, movie tickets, and we’d help out with transportation and give each participant \$10 for each session attended,” Porto explains. “The second time around was a different story because the clinic offered it as a psycho-educational group program, and we had some incentives but not the cash incentives.”

Still, both sessions were a success from Porto’s perspective because of the changes she saw in clients.

One man, for example, had been HIV-positive for three years, but he was opposed to taking medication despite his deteriorating health. “He had had bad experiences in the past and had seen a lot of friends die,” Porto recalls. “He began the medication management module with a lot of resistance, but soon he began to open up and share his experiences.”

Then, when other participants began to talk about medication side effects and food and drug interactions, the man began to learn different strategies for reducing medication problems. By the time the session ended, the man decided to try his medications again, and he has since successfully stuck with his medication regimen, Porto says.

Geishecker has another HIV-positive client who gained motivation to take better care of his health after attending THE Course. “Afterwards, his compliance with his treatment improved, his self-esteem improved, and one wonderful by-product is that his health has improved,” Geishecker says.

THE Course initially focused on empowerment

When Glaxo Wellcome first began to develop the program in the mid-1990s, researchers weren’t focusing as much on medication adherence. Until the extensive use of protease inhibitors, HIV infection was not considered a chronic illness, Rice says.

“There was only one protease inhibitor approved at that time, and we weren’t thinking about adherence,” she explains. “We were looking at behavior change theories and built our program on self-empowerment and self-management of the disease.”

That’s why the initial studies of THE Course focus as much on participants’ changes in such indicators as “avoids negative coping,” “empowerment,” and “total coping,” as they do on medication adherence.

THE Course’s focus is on giving HIV-positive individuals the skills they will need to cope with and successfully manage their disease. Trainers assist in these goals through positive reinforcement, building group camaraderie, and showing participants how to communicate with their health care providers. **(See a description of THE Course’s 12 modules, p. 91.)**

In the pilot study, only health care professionals were allowed to become trainers. But the trainer program later was opened to anyone who had a strong HIV knowledge base and some peer teaching skills, Rice says.

“We use adult learning principles and do not lecture participants,” Rice says. “We tell trainers, ‘Don’t be the expert — you have a group of adults with a large amount of experience, so use the session to be an open discussion.’”

Modules are designed to facilitate group discussions as well as role-playing and other activities. These different educational techniques help keep participants attentive and open to learning.

Glaxo Wellcome sells THE Course at cost to AIDS service organizations, public health clinics, and other organizations that work with HIV patients who are at risk for noncompliance with

their medications. The program's cost, which varies according to how many modules an organization purchases, ranges up to \$3,000. Most of the organizations pay for THE Course out of Ryan White funding, says **Monique Anderson**, MBA, manager of HIV/AIDS program implementation for Glaxo Wellcome's care management division.

Once an organization orders the program, Glaxo Wellcome care management staff work with the organization to recruit HIV patients, using referrals, posters, and other methods, Anderson says.

Then Glaxo Wellcome staff will spend two days training two to four trainers, who may include people who already work for the AIDS organization. Finally, the organization receives a trainer guide and module materials, including videos, 20 minutes of activities, and hands-on practice guides.

Program redesign accommodates illiteracy

The activities are designed to enable illiterate participants to learn through hands-on experiences. "At first, the program was very literacy-intensive, so if you couldn't read, you'd have trouble," Anderson says. "But we redesigned it so you could participate if you were illiterate, and now it's a flexible program that could meet the needs of anybody with HIV."

For example, one simple activity involves a little homework. The trainer asks participants to bring their medications to class and then teaches them how to put their pills into different compartments according to when they need to take the medication.

"They learn that certain medications need to be taken on an empty stomach and some with food, and why it's important to take them like that," Rice says.

The program gives participants all the tools they need, including an HIV log book that they are encouraged to take home and use to keep track of their viral loads, CD4 cell counts, and other important information.

All of this patient education takes place in a group setting, partly because the group model gives patients certain benefits, such as having a safe place to discuss their emotions about having HIV.

Geishecker says he has continued to use various parts of THE Course as reference materials for clients and staff. These materials include a

manual listing various medications and side effects and a book describing different opportunistic infections and their causes and warning signs.

Also, the clinic has held three workshops based on modules from the program. Because holding a 10- or 12-week program requires a large commitment of staff and client time, the Whitman-Walker Clinic has found that brief one-subject workshops focusing on medications or basic HIV education also can help clients learn about HIV and improve their compliance, Geishecker says.

Finally, THE Course gives trainers ideas for how to reinforce participants' positive behavioral changes. "Positive reinforcement is constantly woven into everything, and not only from trainers, but also from other participants," Rice says.

Rewards may be as simple as a compliment or acknowledgement that a participant has reduced his or her viral load. The program offers ideas for actual prizes, such as coupons to stores or tickets to events, or certificates and buttons. For instance, some organizations have given out buttons that say, "I'm taking charge."

"If everyone has an undetectable viral load, then let's applaud them," Rice adds. "There are a lot of rewards and gifts to make participants feel good, because even though they have this horrible illness, they're doing something about it, and so they should get a pat on the back." ■

Here's 'THE Course' program in a nutshell

Research Triangle Park, NC-based Glaxo Wellcome Inc. has developed a behavioral modification program that consists of 12 two-hour modules to help HIV-infected people improve their medication compliance.

Called Tools for Health and Empowerment (THE) Course, the program includes the following modules:

- **Who's in charge here?** This introduction to the program shows participants how to be active members of their health care teams. It includes scenarios for role-playing in which a participant has a discussion with his or her physician, and it provides an introduction to patient rights and the stages of HIV infection.

- **How does HIV work?** This module gives participants an introduction to the pathogenesis of HIV/AIDS. It imparts information on primary and secondary prevention and modes of HIV transmission and lists common household prevention techniques, such as hand washing, using gloves, and making a bleach solution. It also introduces participants to lab tests, home testing, viral load, and CD4 cell count.

- **Emotions and HIV: Taking control.** The module covers the four stages of adjusting to and accepting an HIV diagnosis. Group discussion is encouraged, and trainers teach participants positive and negative coping strategies. Plus, they cover caregiver emotional issues, and they show HIV-positive individuals how to get emotional and behavioral help from members of their health care team and community resources.

Emphasizing development of drug resistance

- **Attacking the virus.** This section gives a review of the HIV reproductive cycle and introduces participants to antiretroviral drugs. It provides an understanding of how antiretrovirals work on the HIV reproductive cycle, and it goes over the benefits and risks of combination therapy. It also emphasizes the significance of viral load and CD4 cell count and their relationship to therapy, survival, and disease progression. Trainers also reiterate the importance of medication adherence and the relationship between skipping doses and the development of drug-resistant HIV. Finally, this module shows how to track lab values and introduces the concept of managing one's medications.

- **Preventing opportunistic infections.** Trainers discuss the relationship between CD4 cell count and the risk of acquiring opportunistic infections. This section gives participants primary and secondary prevention strategies and prophylaxis, with a special emphasis on PCP, toxo, MAC, and CMV. It also covers early recognition of signs and symptoms of opportunistic infections along with treatment options and immune reconstitution.

- **Managing your medications.** The module provides an understanding of which members of the health care team can help with planning and managing medications. Trainers help participants make a plan for medication adherence. And they tell participants what questions must be answered when receiving a new prescription. Trainers show participants the meaning of special instructions

associated with medication schedules, and they provide opportunities for role-playing with pharmacists and providers regarding medications.

- **When to call for help.** This module describes how to recognize the common signs and symptoms associated with HIV and how to decide which ones need immediate attention, which ones can wait for a provider visit, and which ones can be treated at home. There's a focus on fever, cough, weight loss, and fatigue.

- **Choices in health care delivery.** Trainers discuss the variety of health care delivery systems available and what each facility provides. They show participants how to best utilize health care resources in one's community, and they discuss the different types of managed care plans.

- **HIV: Your new part-time job, Part 1.** This module has participants discuss returning to work and life issues. Trainers discuss funding sources, including Ryan White Care Act and ADAP, and they explain access-to-care requirements for managed care and Medicaid coverage. This session also covers problem-solving, adherence to medications on the job, and how to prevent discrimination in the workplace, along with an introduction to the Americans with Disabilities Act. Trainers also explain insurance, financial issues, employment concerns, housing issues, and disability requirements.

- **HIV: Your new part-time job, Part 2.** Trainers discuss patients preparing for end-of-life issues, such as wills, living wills, medical and advance directives, and durable power of attorney. They encourage participants to think about legal issues for their children and how to find allies and resources in the community. The group discusses emotions about death and dying and how to leave a legacy.

- **Women and HIV.** This module covers how to recognize the signs and symptoms of HIV specific to women, including how to access medical and emotional care and how to pay attention to one's own needs. They discuss parenting, pregnancy, and contraception, and prevention of sexual transmission and reducing the possibility of maternal-fetal HIV transmission.

- **Sex and drugs: Making choices.** Trainers explain the primary, secondary, and tertiary prevention of HIV transmission and how to assess risk behaviors. They cover harm-reduction strategies and how alcohol and drug use relate to HIV transmission. They also provide information about resources in the community. ■

MACS passes 15-year mark and is still going strong

Long-time participant reflects on study's meaning

One of the richest sources of AIDS research information will keep up its work, thanks to a recent government grant.

The Bethesda, MD-based National Institute of Allergy and Infectious Diseases (NIAID) recently awarded a five-year grant to extend the research work of the Multicenter AIDS Cohort Study (MACS), which reached a milestone of 15 years this spring.

MACS research has resulted in more than 600 published papers, and it's the longest continuous study of HIV-infected people. Volunteer participants are men who have sex with men and who are willing to be evaluated every six months through a questionnaire about their health status, a physical exam, and blood samples. All of these data are processed through the Center for the Analysis and Management of the Data from MACS under the direction of an investigator at the Johns Hopkins School of Public Health in Baltimore.

Since 1984, the study has followed 5,622 homosexual and bisexual men nationwide to determine if, when, and how they contract HIV. The MACS sites are located at Johns Hopkins School of Public Health, Northwestern University Medical School Howard Brown Clinic in Chicago, the University of California Schools of Public Health and Medicine in Los Angeles, and the University of Pittsburgh Graduate School of Public Health.

The study originally enrolled 1,150 men, and more than 100 of those have attended all 30 MACS visits.

Program identified primary risk behaviors

"MACS made a big contribution to understanding the primary risk behaviors of spreading HIV," says **Joseph Margolick**, MD, PhD, associate professor in the department of molecular microbiology and immunology at the Johns Hopkins School of Public Health. Margolick, who is the director of MACS, has been involved in the study since its inception.

"One of the ideas people had in the 1980s was that you couldn't change people's sexual behavior,

but it turned out that when people found out that a specific type of sexual behavior was communicating the disease, they did change their sexual behavior," Margolick says.

For example, once research showed that unprotected anal sex resulted in a high HIV transmission rate, men in the gay community began to use condoms during sex more frequently.

MACS research has helped public health officials develop prevention strategies, says **Chris Camp**, MA, chair of the Community Advisory Board of the Study to Help in AIDS Research Effort, which is part of the Baltimore MACS. Camp also works for the state of Maryland's Department of Health and Mental Hygiene in the AIDS Administration as a training specialist.

Camp, who is HIV-positive, is a participant in the study. (See related article on Camp's personal story, p. 94.)

"As part of the interview process when you come in every six months for a visit, they go through a whole series of questions about different behaviors you might engage in and what efforts you're taking to reduce your risk of transmission to both yourself and others," Camp explains. "The study is divided between HIV-positive and -negative men."

Camp actually found out about his HIV status because of another government study. In 1982, he was involved in a hepatitis study in Texas. Researchers kept his blood samples, and then the government decided in the mid-1980s to do a retrospective study of the blood samples from the earlier study to see how many also showed antibodies to HIV. Camp, unfortunately, had the HIV antibodies, and was notified in 1986 of his infection.

"I've never been sick with anything HIV-related — not ever," he says. "I've had the joys of side effects from HIV drugs, but never had anything AIDS-related."

Camp became involved with the study in 1988 along with his partner at the time, who also was HIV-positive. They were part of a concordant couples group and were identified by the numbers 13218 and 13219, he recalls.

Camp's partner died in 1992, his but participation with MACS has continued posthumously. "Even though he has passed away, they can go back and use his blood cells, culture from them, and take into consideration his samples," Camp says.

Margolick counts among MACS' greatest accomplishments these two developments:

• **MACS researchers quickly learned the levels of T-cell counts that indicated a person was at risk for AIDS-defining illnesses.**

“The question was, at what point are you so compromised that you’re at risk for getting this stuff?” Margolick says. Because of drug side effects, clinicians don’t want to treat everyone with prophylactic antibiotics, so it’s helpful to know the point at which the benefits outweigh the risks.

“We found that when the CD-4 cell count was 200 cells per milliliter of blood, that’s when a person started being at risk, and now that’s when they start taking prophylactic antibiotics to prevent pneumocystis pneumonia,” Margolick explains.

• **MACS research has influenced guidelines regarding the use of viral load as a treatment criterion.**

Using MACS blood samples from the early years of the HIV infection, researchers measured the virus in plasma to categorize them as low-load, intermediate-load, and high-load. Then they compared these viral load findings with what they knew of how quickly the disease had progressed in the people who had provided the samples.

“It turned out that the higher your viral load, the greater your chance of getting AIDS,” says Margolick. “That influenced national guidelines that say when your viral load reaches a certain level in your blood, you should start taking [antiretroviral therapy].”

MACS research also has contributed to the study of people who have been infected with HIV but do not progress to AIDS. “There are a few people who have been infected the whole time, and we’re still trying to figure out why these people don’t progress to AIDS,” Margolick says.

Another mystery MACS researchers are trying to unravel has to do with how T-cells are produced in response to HIV infection and why the immune system collapses.

“We’ve learned a lot about suppressor responses that inhibit the virus, but we need to learn much more,” Margolick says.

As the study heads toward its 20th year in 2004, AIDS researchers have more cause for optimism than they did in the mid-1980s, Margolick notes. “Until 1995, when the protease inhibitors came along, people were dying at a pretty high rate, and we thought the study would end because there would be nobody left.”

(Editor’s note: For more information about MACS, visit the Johns Hopkins School of Public Health Web site at www.statepi.jhsph.edu.) ■

MACS volunteer describes life with HIV infection

Even with protease inhibitors, fear of death exists

The experiences of 43-year-old **Chris Camp**, MA, illustrate the continuing emerging trends that front-line AIDS caregivers face every day.

The Baltimore resident has been active in AIDS work since 1982, which coincidentally is also the year he believes he may have contracted HIV, although he didn’t know his HIV status until four years later.

One of Camp’s most enduring impressions of AIDS involves his experience with a friend in Dallas who was in robust health.

“He had problems with allergies, and I’ve had allergies since I was a kid,” Camp says. “So this friend went into the hospital for what he thought was bronchitis, and two weeks later he was dead with pneumonia, and that so shocked me.”

When you receive news that you are infected with HIV, your fears in 1999 are no less than they were in the mid-1980s when Camp first was given the bad news, he says.

COMING IN FUTURE MONTHS

■ Is the band still playing on? Here’s the latest on federal funding

■ What’s being done about the HIV problem among minorities?

■ Some states are starting medication compliance programs

■ Combination therapy combats AIDS wasting

■ HIV-infected women need regular OB/GYN check-ups

"I think the first thing on your mind is that you're going to die, and that's still the same today," Camp says. "You're reeling from that initial shock, and you have to work through that shock before you can be helped."

Camp understands, not only because of his personal experience, but also because he works as a training specialist for the State of Maryland Department of Health and Mental Hygiene. His job is to train people to become HIV prevention counselors, and he often hears the personal fears and testimonies of HIV-positive people.

While the public may have become lulled into believing scientists have licked the HIV epidemic through newly developed protease inhibitors and combination therapies, Camp and other HIV-positive people know better. "Now people are becoming infected with strains that are resistant to drugs, and that's pretty frightening," he says.

'I didn't want to accept the idea'

Camp also has experienced the heavy denial that is common in people diagnosed with HIV. For more than a year, he refused to believe he had the virus, and had no interest in taking drugs like AZT.

"That was about the time when they didn't know the proper dosage to give to people, and they'd give AZT every four hours, and so you'd go to concerts and hear everyone's [drug dosage reminder] alarms going off," he recalls. "But my CD4 cell count levels were so high that I didn't want to accept the idea that I was HIV-infected."

Camp moved to Maryland in 1987 and requested another HIV test. While his CD4 cell count still was high, the test came up positive.

Finally the reality sunk in. Camp, along with his lover, became involved in the national Multicenter AIDS Cohort Study (MACS). Camp met AIDS researchers through the study, including Mary Lou Clements Mann, who worked on the AIDS vaccine until she was killed along with her husband, AIDS researcher Jonathan Mann, in a recent Swiss Air accident over Nova Scotia.

"I met a lot of people in the field of research who had a true compassion for people living with the disease," he says. "They took an interest in their patients beyond drawing the lab specimens; they wanted to know how things were going with you, and they would ask questions about your families and took time to interact with patients."

Camp, who has been infected with HIV for most of his adulthood, has practiced safe sex for nearly as long. But it wasn't an easy philosophy to embrace, he says. "Initially, when people were given information about what they had to do to protect themselves, I don't think any of us had any idea that we were talking about a lifetime practice, and not just a brief intervention," Camp explains.

Maintaining safe sex practices over the years is difficult, and now Camp sees an even bigger generation-gap problem in which younger gay men are misinformed about the disease. Some younger men believe the current drug cocktails are a magic bullet that will kill the virus, and others can't imagine the death and destruction that AIDS caused only 10 years earlier because

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they might not know anyone who has died from AIDS.

“For me, I’ve lost over 400 friends, associates, and loved ones to this disease,” Camp says. “I have an address book you wouldn’t believe with three-quarters of the names crossed out with the dates when they died, and I have cities all around the world that are like ghost towns to me.”

Punitive attitudes resurface

Another unpleasant new trend is a resurgence of the punitive attitude that has been associated with HIV since it was first identified as being a “gay men’s disease.” It took nearly 10 years and movies like “Philadelphia” for the public to begin to have empathy for HIV-positive people, Camp says.

Now, because of well-publicized cases, such as the New York man who was convicted of purposely infecting assorted girlfriends with HIV, the public is beginning to think of HIV-infected people as predators who will take other people down with them, Camp says. “It’s scary to see how the attitudes have changed.”

While Camp considers himself lucky to have survived so long with the virus and have had undetectable viral counts for the past four years, he still has envy for people who appear resistant to the virus. So far, Camp hasn’t had any opportunistic illnesses, but he worries that they might not be far off because his CD4 cell count has fallen to about 200.

Camp also lives with all of the discomfort associated with drug side effects. He began drug therapy in 1994 when his CD4 cell count first began to fall. He signed up for drug trials in order to obtain the latest and most potent medications.

His current list of drugs reads like a library card catalog: “An indinavir that is the blue chalky stuff that dissolves in your throat if you’re not careful”; Stavudine (d4T); hydroxyurea; an efavirenz, Sustiva, at night before bed; several drugs to fight side effects, enhance appetite, and relieve anxiety; plus steroids because he’s lost 40 pounds of muscle mass in the past year.

“I carry the pills around with me and make sure I have them at all times, so I’m not stuck someplace without them and have to miss dosages,” Camp says. “I’m excruciatingly compliant.”

Soon he’ll probably have to add some prophylactic drugs to the list to stay one step ahead of the opportunistic diseases. ■

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CE objectives

After reading this issue of *AIDS Alert*, CE participants should be able to:

- identify the particular clinical, legal, or scientific issues relates to AIDS patient care;
- describe how those issues affect nurses, physicians, hospitals, clinics, or the health care industry in general;
- cite practical solutions to the problems associated with those issues, based on overall expert guidelines from the Centers for Disease Control and Prevention or other authorities and/or based on independent recommendations from specific clinicians at individual institutions. ■