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Issues - Groups-Older Persons

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National Institute on Aging

AgePage

HIV, AIDS, and Older Adults

Everyone talks about AIDS (acquired immunodeficiency syndrome), but few talk about how AIDS affects older people. No wonder so many older adults think they are not at risk.

The truth is that 11 percent of all new AIDS cases are now in people age 50 and over. And in the last few years, new AIDS cases rose faster in middle age and older people than in people under 40.

What is AIDS?
AIDS is a disease caused by a virus called HIV (short for human immunodeficiency virus). HIV attacks the body's immune system. When the immune system is hurt, it can no longer fight diseases the way it used to.

People with HIV seem to be healthy at first. But after several years, they begin to get sick. Often they get serious infections or cancers. When this happens, they are diagnosed with AIDS. The most common cause of death in people with AIDS is a type of pneumonia called pneumocystis carinii pneumonia or PCP.

How Do People Get AIDS?
HIV is spread when body fluids, such as semen and blood, pass from a person who has the infection to another person. For the most part, the virus is spread by sexual contact or by sharing drug needles and syringes.

In older people, sexual activity is the most common cause of HIV infection. Second is blood transfusions received before 1985. Since 1985, blood banks have been testing all blood for HIV, so there is now little danger of getting HIV from transfusions.

Otherwise, HIV is not easy to catch. It is not spread by mosquito bites, using a public telephone or restroom, being coughed or sneezed on by an infected person, or touching someone with the disease.

Is AIDS Different in Older People?
The immune system normally gets weaker with age, but this decline is faster in older AIDS patients. They usually become sick and die sooner than younger patients.

It may be harder to recognize AIDS in older people. Early symptoms of AIDS--feeling tired, confused, having a loss of appetite, and swollen glands--are like other illnesses common in older people. Health professionals may assume these are signs of minor problems.

Prevention
Medical experts predict that a cure or vaccine to prevent AIDS will not be found in the near future. So stopping HIV depends on each person's actions. You can prevent AIDS by thinking about the risk of infection before sexual contact. Use condoms if sexually involved with someone other than a mutually faithful, uninfected partner.

Treatment and Help
Treatment for AIDS usually involves medicine, such as AZT (azidothymidine). AZT does not cure AIDS but many patients use it to stay healthier longer. Other promising drugs are being tested. Doctors are also learning how to treat the diseases, like PCP, that strike people with AIDS.

People with HIV infection should stay in touch with a doctor who knows about the latest research. For help finding the name of an expert, call a local medical school's department of infectious diseases or the National AIDS Hotline (1-800-342-AIDS).

Older AIDS patients often may not have anyone to take care of them. Help is available from local groups in some cases and from the Social Security Administration (1-800-SSA-1213).

Resources
In most cities, health agencies or centers offer HIV testing, counseling, and other services. In addition, the following national organizations offer information:

National AIDS Hotline
1-800-342-AIDS
1-800-344-SIDA for Spanish
1-800-AIDS-889 (TTY)

The hotline operates 24 hours a day, 7 days a week. It offers general information and local referrals.

National AIDS Clearinghouse
P.O. Box 6003
Rockville, Maryland 20850
1-800-458-5231

The clearinghouse offers free government publications and information about resources.

National Institute of Allergy and Infectious Diseases (NIAID)
Office of Communications
Building 31, Room 7A32
Bethesda, MD 20892

One of the National Institutes of Health, the NIAID will respond to written requests for information on AIDS research and clinical trials of promising therapies.

Seniors in a Gay Environment (SAGE)
208 West 13th Street
New York, NY 10011
212-741-2247

SAGE provides HIV/AIDS information and referrals for people age 50 and over.

Social Security Administration
Contact local office or call:
1-800-SSA-1213

Social Security has two disability benefit programs that provide financial assistance to eligible AIDS patients.

American Association of Retired Persons (AARP)

Social Outreach and Support (SOS)
601 E Street, NW
Washington, D.C. 20049
202-434-2260

The AARP/SOS program has information on HIV and AIDS and their impact on midlife and older adults.

National Institute on Aging

U. S. Department of Health and Human Services
Public Health Service
National Institutes of Health
1994

Back to Brochures and Fact Sheets for the Public

Back to the Health Information Home Page

National Institute on Aging Back to NIA Home Page

12/3/98

To: Todd
From: Jack
Re: 1. HIV/Older Adults briefing paper
2. Mailing lists
3. My schedule

1.HIV/AIDS and older adults:
There appears to be very little policy or media focus regarding HIV/AIDS and older adults. The National Institute on Aging fact sheet on the internet is dated 1994. AARP issued a recent press release re the topic, and has produced a video for older adults. A CNN/AP report on January 22 this year also focused on older adults as an overlooked part of the AIDS epidemic. The report quoted Dr. Kimberly Holding of the CDC. There was a study in 1994 at UCSF, funded by NIA and NIMH, on high risk behaviors of the age 50 and older group. One book on the subject is HIV/AIDS and the Older Adult, Kathleen Nokes, ed. As the population with HIV and AIDS ages, along with society in general, older adults should receive increased attention.

Data request:
Adults age 50 or over now account for approximately 10% of all AIDS cases in the U.S. It would be very helpful if CDC could provide the following data to us:
--Percentage, and numbers, of AIDS cases among all adults age 50 or over, for each year, 1993-1997
--Percentage, and numbers, of new infections among adults age 50 or over for each year, 1993-1997
--Percentage, and numbers, of infections among adults age 50 or over, 1993-1997, by method of infection
--Percentage, and numbers, of infections among adults age 50 or over, 1993-1997, who died within one month of diagnosis, with comparisons to other age groups
--All of the above, by gender
--All of the above, by race/ethnicity
--All of the above, for adults ages 65 and older

Key players:
Would you like for me to follow-up with specific contacts at NIA, UCSF, CDC, AARP, AIDS Action Council, etc. for further information and consultation?

Older adults with HIV/AIDS face many of the same issues and concerns as younger adults, but there are a range of differences which will affect policy recommendations:
Prevention:
Older adults may consider themselves at less risk, and may not be adequately protecting themselves.There are dramatic increases in rates of infection due to unprotected sex and to IV drug use, with the number of new cases related to these causes more than doubling between 1991 and 1996 among older adults.

Health care:
AIDS related illnesses may mimic other illnesses of aging. For example, AIDS related dementia could be mislabeled as Alzheimers, and weight loss could be attributed to depression among the elderly. Fatigue, loss of appetite, swollen glands can all be connected to other illnesses common in older people. Per the CNN report, older people may be diagnosed with AIDS in the later stages. In 1996, 13% of people 50 and older died within a month of diagnosis, compared to 6% of those between 13 and 49. Dr. Holding at CDC is quoted as saying "Physicians who are caring for older people should discuss HIV risk factors with them and look for these diseases. They need to be included in AIDS education. You don't see any messages targeted to them."

Policy outlines:
The current discussion of older adults, limited as it is, has very broad outlines. The issues affecting those over 65, and particularly, the very elderly, will vary from those affecting a working person in his or her 50's. The socioeconomic, racial/ethnic and sexual differences among older adults will also vary considerably, as they do with any other age group. Any discussion of "older adults", i.e. all adults over 50, needs to be refined accordingly. Further, many of the concerns of older people with AIDS will parallel those of older people in general, such as adequate health care, psychosocial stressors, housing, and longterm care issues.

2.Mailing lists:
Could you suggest some of the organizations/contact persons you would like for me to talk with regarding access to their mailing lists? Also, do you want a mailing list that will target AIDS service organizations or include a wide range of individuals as well?

3.My schedule:
I would like to work for you on Wednesdays and Thursdays, 10:00--4:00. I will be working for Tom Sheridan on Mondays and Tuesdays. This is a realistic volunteer schedule which still allows me time for my permanent job search and other responsibilities. On occasion, I may be able to come in on Fridays here to complete necessary work if needed. Also, I need to let you know that I will be out of town next Thursday (my partner's grandmother died and we are going to the funeral in Florida).

I am delighted to have this experience in the White House Office of National AIDS Policy and am very grateful to you for the opportunity.

Jack

12/9/98

To: Todd
From: Jack
Re: HIV/Older Adults

Todd,

Could we meet briefly on Wednesday morning next week? I will not be here tomorrow due to my trip to Florida, but will be back next Wednesday at 10:00 a.m. I'd like your input on how I should proceed with the HIV/older adults project.

-- CDC statistics. Can we get their latest stats regarding adults over age 50? What is the procedure for this?

-- Key players:
Searching the Internet today was more forthcoming (I have no idea why!) regarding individuals and organizations involved with HIV/older adults, including the National Association on HIV Over Fifty, various urban task forces, academic centers, and service providers. Do you want me to contact these people for further information?

If you prefer, I can probably put together a tentative briefing paper for you now, or I can proceed with more in-depth study of this issue. I would say that currently the most prominent concern is **prevention** and the need for more efforts in that direction.

Thanks,
Jack

1/6/99 Wednesday

Todd,

A draft of the briefing paper re HIV/AIDS and older adults is attached for your review.

We had talked about my possibly putting together a mailing list for Sandy. I can begin working on that, but have a couple of questions as to procedures. Alternatively, if there is anything else I can do that would be helpful to you or other staff, let me know.

I will be out of town tomorrow, but will be back next Wednesday.

Thanks,
Jack

HIV/AIDS and Older Adults

Scope of the problem

Census:
Approximately 11% of all AIDS cases in the U.S. reported through December 1997 were people 50 years old and older (11% of men, 9% of women). Many people with AIDS will age into the older category. 27% of men, and 21% of women, were 40 years old and older through December 1997.

Among new infections reported for the year 1997, 6% of men, and 4% of women, were 50 years old or older.

In 1996, 6400 AIDS cases were diagnosed in the U.S. among people 50 and older, up 22% from 5,260 new cases in 1991, according to the CDC. AIDS cases for the 13 to 49 age group rose 9% for the same period, from 46,000 to 50,300.

Most older adults with AIDS in the early days of the epidemic probably contracted it from blood transfusions, but now more are being infected by unprotected sex and injection drug use. Among older women, new AIDS cases linked to unprotected sex more than doubled between 1991 and 1996, from 340 to 700. Among older men, numbers nearly doubled, from 360 to 700. Similarly, new cases among injection drug users increased 53% for older men and 75% for older women.

Health Care:
Older adults may be more likely to be misdiagnosed. Many of the symptoms of AIDS--dementia, respiratory problems, weight loss--can be mistaken for other age-related illnesses. A January 1995 article in the "Archives of Internal Medicine" reported tests of 257 New Yorkers, 60+ years old, who had died without any recorded history of HIV. 5% tested positive.

Physicians may discount HIV among older adults. A survey of 330 Dallas primary care doctors found that 50% of the doctors rarely or never asked patients over 50 about HIV risk factors, compared to 7% for patients under 30.

Morbidity among older adults may be more severe. A 1996 study in the "American Journal of Medicine" noted that nearly 12% of 50+ adults died within 2 months of HIV diagnosis, compared with 2% of younger Americans. In 1998, the New York North Shore University Hospital reported that 37% of 80+ years old people died within 1 month of HIV diagnosis. Such rapid decline may relate to delayed diagnosis, but also to other multiple debilities of older age and co-infection with other illnesses. Further, there may be complications regarding the interaction of HIV medications with other medications taken by older adults for chronic medical conditions.

Prevention:
Very few HIV prevention efforts target, or include, older adults. There are a few isolated program outreach efforts, and AARP produced an at-risk video in 1996. Older adults may have extensive denial and misunderstandings regarding HIV and AIDS. A 1994 article in the "Archives of Internal Medicine" notes a UCSF study which concluded that perhaps 10% of all older adults are at high risk for HIV. They appear far less likely to protect themselves as compared to other high risk groups. High risk heterosexual adults were 1/6 as likely to use condoms during sex and only 1/5 as likely to get tested, as comparable groups in their 20's. No such disparity emerged among gay/bisexual men.

Research:
Minimal research has focused on issues specific to older adults. In a recent article in "POZ" magazine, it was noted that the National Institute on Aging, a leader in geriatric research, allocated only $1.8 million in 1997 for AIDS-related studies (including sexual behaviors of middle-aged women, and risk profiles of older drug users). By comparison, in 1998 fiscal year, the National Institutes of Health allocated $174 million for pediatric AIDS research. Pediatric AIDS cases have accounted for about 2% of AIDS cases. One current study underway at the Medical College of Wisconsin is examining quality of life needs and issues of older adults living with HIV/AIDS.

Key Participants

The existing AIDS service network assists clients of all ages. There is question as to how optimally focused the system is on the specific needs of older adults. For example, in the area of prevention, every June 27, the National Association of People With AIDS targets several groups on National HIV Testing Day. Older Americans have yet to make the list. NAPWA's policy director, Mike Shriver, was quoted in "POZ", acknowledging "This is a population that we have not done a good job targeting." He is hopeful that efforts will improve in the future.

Primary organizations specific to older adults:
There is a very extensive public and private aging network, which would include, among others, the National Institute on Aging; Administration on Aging/Department of Health and Human Services; Social Security Administration; National Council on the Aging; American Association of Retired Persons. In academia, both UCSF and the Medical College of Wisconsin have conducted relevent research. Also, the University of Illinois at Chicago sponsors the Chicago AIDS and Aging Project of the Midwest AIDS Training and Education Center. An advocacy group is the National Association on HIV Over Fifty, which is co-chaired by Jane Fowler and Nathan Linsk (of the Midwest AIDS Training and Education Center). Kathy Nokes, Associate Professor at Hunter -Bellevue School of Nursing, author of HIV/AIDS and the Older Adult.

Policy Recommendations

It is crucial to avoid overgeneralizations. Adults 50 years old and older comprise a wide variety of subgroups, diverse in terms of socioeconomic background, ethnic and racial status, sexual orientation and even age. Indeed, the medical, psychosocial and service needs of a working person in his or her 50's may be markedly different from those of a retired person in his or her 80's. Further, many of the concerns of retired people with AIDS may parallel those of other older people--such as affordable and accessible health care, senior housing needs, and longterm care services.Age should be viewed as less of a dichotomy than a continuum, with the primary focus on examining what remains the same, and what is different. In comparisons between age groups, as well as between most groups of people with pressing needs, there will usually be some of both.

Given the increasing numbers of older people with HIV/AIDS, and the concurrent aging of American society in general, a starting point for policy recommendations would include the following:

> Increased prevention efforts targeted to older adults and to encourage at-risk older adults to be tested for HIV

> Increased research specific to older adults, such as risk behaviors, disease progression and treatment issues, psychosocial needs, and service needs

> Improved training for physicians, other health personnel and caregivers regarding HIV/AIDS and older adults

Jack Gardner
White House Office of National AIDS Policy
1/6/99

1/13 Wed

Todd,

I've made a few minor changes to this paper. Let me know whatever else I can do to help out.

Thanks,
Jack

HIV/AIDS and Older Adults

Scope of the problem

Census:
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Jack Gardner
White House Office of National AIDS Policy
1/6/99

133RD STORY of Level 1 printed in FULL format.

A6 E

CNN

SHOW: CNN THE WORLD TODAY 20:00 pm ET

February 21, 1998; Saturday 8:19 pm Eastern Time

Transcript # 98022103V41

TYPE: PACKAGE

SECTION: News; Medical

LENGTH: 402 words

HEADLINE: Number of Senior AIDS Patients Increases

BYLINE: Bobbie Battista, Jim Hill

HIGHLIGHT:
There's a surprising trend in the spread of HIV in America. Health experts say they're noticing a marked increase in the number of AIDS patients over age 50.

BODY:
BOBBIE BATTISTA, CNN ANCHOR: There's a surprising trend in the spread of HIV in America. Health experts say they're noticing a marked increase in the number of AIDS patients over age 50.

CNN's Jim Hill reports.

(BEGIN VIDEOTAPE)

JIM HILL, CNN CORRESPONDENT (voice-over): In retirement communities like Sun City, Arizona, the good life spreads before seniors like a lush green fairway. But for a growing number of older Americans, the golden years have been invaded by the virus that causes AIDS.

INOCENCIA ACREY, HIV PATIENT: I didn't think it could happen to me because of my age. It's kind of hard to believe, but it happened.

HILL: Fifty-six-old Inocencia Acrey is not a Sun City resident, but her infection from a former boyfriend underscores a trend. According to the Centers for Disease Control and Prevention, one in every 10 HIV patients nationwide is over age 50. In Arizona, 15 to 20 percent of the new HIV cases are among seniors.

Like almost any groups, seniors have their share of fear and misunderstanding of AIDS. But counselors say unlike many other groups, seniors are all the more likely to think the virus is simply not a part of their generation.

HIV strikes a sharp contrast to the Arizona image of active, healthy seniors.

FATHER JOSEPH O'BRIEN, CATHOLIC AIDS OUTREACH: Many seniors feel that HIV is something that doesn't specifically infect them.

UNIDENTIFIED FEMALE: We're very much talking about us.

HILL: So, in AIDS seminars like this, seniors are getting an earful about HIV.

UNIDENTIFIED FEMALE: Unsafe sex is a problem. Only 20 percent of seniors, people my age and older, who are sexually active, use condoms.

HILL: They learn HIV among older women has climbed 27 percent in the past three years.

RUBIN MOSES, AGE 79: I'm not a guy to do it every day, but once or twice a month, I can get some lady and have fun. And now I'm scared.

HILL: Counselors say many seniors believe that since they can no longer become pregnant, sex can be carefree.

VELMA BAILEY, AGE 90: People are too old for those things.

HILL: But as seniors are learning, even a new disease can claim older victims.

O'BRIEN: I think the important thing is to let them know that HIV is not discriminatory, and it's ageless.

ACREY: Be aware, because it can happen to anybody, any age.

HILL: Jim Hill, CNN, Phoenix, Arizona.

(END VIDEOTAPE)

LANGUAGE: ENGLISH

LOAD-DATE: February 21, 1998

Hard sell: Seniors often won't believe AIDS can be a threat to them

Tuesday, June 01, 1999

By Cristina Rouvalis Post-Gazette Staff Writer

Monica Wilson-Klein tries to promote AIDS awarenessat senior centers, but she faces a tough audience. Many seniors there just assume that AIDS is that awful disease for those who are young or gay. They don't want to hear it.

So Wilson-Klein, who leads a Pittsburgh AIDS service organization, tries pitching it as a disease that their children or grandchildren might contract some day.

Only then will the seniors listen to her -- but just barely.

What that lukewarm audience might not realize is that the threat of AIDS may not be as preposterous as it sounds.

Nationwide, older people are the fastest growing group with AIDS, presenting a new health concern for graying men and women. "We are all at risk," said Wilson-Klein, who is executive/development director for Shepherd Wellness Community. "How many seniors, how many widows, can be sure their husbands didn't have some indiscretion? He might have taken the secret to the grave."

In 1996, an estimated 6,400 cases of AIDS were diagnosed among people 50 and older, up 22 percent from the 5,260 cases in 1991, according to the Centers for Disease Control and Prevention in Atlanta. That compares to the 9 percent increase in new AIDS cases for the 13-to-49 age group, a jump from 46,000 to 50,300 cases.

Even so, people 50 years and older still represent only about 11 percent of the total AIDS population. But the graying of AIDS patients is expected to continue as people live longer with the disease.

ISSUES - Groups - Older Persons

In Allegheny County, there is no reported increase in AIDS cases among people 50 and over. The percentage has held steady at about 10 percent of the AIDS population since 1991, according to the health department.

Given our graying population, Wilson-Klein and others believe it is only a matter of time before the number of seniors with AIDS grows.

AIDS can be traumatic at any age, but an older person who contracts the disease often deals with a unique set of problems.

Often they don't even realize that they have the disease because they confuse symptoms of AIDS -- such as fatigue or anemia -- with normal signs of aging, said Dr. Amy Justice, staff physician for the VA Pittsburgh Health Care System. She believes many cases go unreported. Many others are diagnosed late.

Justice is studying older people with AIDS under a National Institute on Aging grant. She recently moved here from Cleveland, where she was treating an openly gay, 65-year-old Shakespearean actor who was being treated for terrible anemia, one of the side effects of AIDS.

"He had no idea. When I asked him what the story is, he said, 'I didn't think it could happen to me. It happens to young gay men.' "

Initially doctors didn't even think of giving him an HIV test because they assumed he was too old for AIDS. It was only when an intern insisted, she said, that the medical team eventually tested him. Too often, Justice said, doctors don't ask.

"There is a conspiracy of silence. People are still under the misguided perception that people in their 60s are no longer sexually active. Young physicians are uncomfortable talking to patients about their sexual history."

Likewise, people in their 60s are often too embarrassed to talk about their sexual encounters.

AIDS can be particularly traumatic for a bisexual man who has been in the closet his whole life and has kept his secret from his wife and children. "There are issues like, 'When my kids find out, will they not let me see my grandchildren?' " Justice said.

A 60-year-old gay man in Bloomfield agrees. The man, who asked not to be identified, has AIDS after being diagnosed as HIV-positive in the early 1980s. He came out as a gay man in the 1970s. He is active in the gay community and does outreach work for AIDS. But he says, "I am not your typical older AIDS patient."

So he doesn't have to worry about hiding or denying AIDS the way some of his contemporaries have to.

"Growing up in the 1940s and '50s, you weren't able to be gay. It's impossible to come out when you are in your 60s. It's a double stigma of being gay and having AIDS."

Many seniors with AIDS are also straight. They might have had one sexual indiscretion that they kept hidden from their spouse, Wilson-Klein said, and it comes back to haunt them.

Teaching AIDS prevention to older people is not easy. They have no use for condoms because there is no risk of getting pregnant at their age.

"A 63-year-old woman says, 'What do I need protection for? What is the worst thing that can happen?' " Wilson-Klein said. "They don't know that the worst thing that can happen is AIDS."

Once they are diagnosed with AIDS, the older person has to weigh the terrible side effects of the drugs on a body that is past its prime. Gastrointestinal problems, diarrhea, and stress on the pancreas and kidneys can be especially taxing on a frail body, Wilson-Klein said.

The Bloomfield man, who has beat his doctor's prediction that he would die a few years ago, keeps plodding on with a positive attitude. But sometimes he doesn't know what is happening to his body.

"You say to yourself, 'Does this have to do with your medication, the disease or getting old?' "