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Caring for Homeless People with HIV Disease

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Many individuals are at risk of becoming homeless due to the adverse effects of HIV disease on physical, economic, and social function. At the same time, people who are homeless may engage in activities that increase the risk of contracting HIV. This article discusses the association between homelessness and HIV infection, explores some of the problems that arise when addressing the needs of homeless people with HIV, and presents a model of community-oriented, multidisciplinary service for homeless people affected by the disease.

Relationship of Homelessness and HIV Infection

A unique combination of experiences and social and personal factors result in an individual's homelessness. Social causes of homelessness include the diminishing availability of affordable housing, the lack of adequate and meaningful employment, and the progressive weakening of the safety net of public assistance programs. Personal factors include physical and mental illness, substance abuse, financial misfortune, and social isolation. In addition, there have always been a small number of people who have *chosen* to be homeless.

People with HIV disease may experience financial hardship, social isolation, and mental incompetence, each of which may lead to homelessness. As a result of discrimination or declining health, people infected with HIV may face loss of job and medical insurance. Medicaid requirements force people to "spend down," that is, to use all of their resources, before becoming eligible for benefits. HIV infection commonly undermines family and social supports, and repeated hospitalization may further disrupt households. Finally, HIV-related dementia may impair a person's ability to keep a job, maintain a household, or apply for public benefits.

Many people who are homeless engage in behaviors that put them at risk of contracting and spreading HIV. An estimated 30 to 60 percent of homeless people use alcohol or illicit drugs, and, despite the availability of needle-exchange programs in some major U.S. urban centers, sharing needles remains common among intravenous (I.V.) drug users. Increasing rates of sexually transmitted diseases appear to be related to trading sex for drugs, especially among those who use crack cocaine. Finally, about 25 to 30 percent of homeless people have some form of mental illness. This group in particular may be unable to avoid or change behaviors that put them at risk.

Homelessness itself may compound the virulence of HIV-related illnesses, since it is characterized by exposure to the elements and violence, poor hygiene and nutrition, increased susceptibility to contagious diseases, and poor conditions for rest or convalescence. A New York study showed that, among people diagnosed with AIDS, those who were homeless had a higher than expected incidence of acute *Pneumocystis carinii* pneumonia and tuberculosis.[1] In the Health Care for the Homeless AIDS Outreach Program, run by the San Francisco Department of Public Health at the Tom Waddell Clinic, it is common for patients to have well-advanced HIV disease and to be suffering from catastrophic psychosocial problems. Often these people have received little or no previous medical attention despite the fact that they may have clear symptoms of AIDS.

Epidemiology

In order to properly address the needs of the homeless, researchers must develop a better demographic characterization of this population. These goals may be difficult to achieve since the homeless population is constantly moving, increasing, and becoming more ill with time. Estimates of the total homeless population in the United States range from less than 500,000 to three million. The 1990 census will attempt to provide the first comprehensive enumeration of homeless people in this country, counting people in previously identified sites, including shelters, parks, abandoned buildings, below freeways, and on the streets.

Since the homeless with HIV infection comprise a disenfranchised group with a history of negative experience with authority, outreach workers must develop trusting relationships with homeless people.

The Centers for Disease Control (CDC) estimates that there are between one million and 1.5 million people with HIV infection in the United States; there is as yet no data regarding the housing status of these people. A 1986 study by the AIDS Shelter Project of New York found that one year after receiving an AIDS diagnosis, more than 30 percent of gay men and 50 percent of I.V. drug users were homeless. The best estimates suggest that 20,000 people with AIDS and symptomatic HIV disease nationwide are homeless, with 5,000 to 8,000 living in New York City alone.

Barriers to Care

Even in San Francisco, a city known as a model of innovative HIV care, many people with HIV infection remain homeless and without basic services. Many who are homeless distrust or lack access to the mainstream media and traditional sources of health information. Some speak little or no English; some may be functionally illiterate in any language; others may have diminished capacity to understand because of impaired mental health.

Once motivated to change high-risk behavior or to seek treatment for an established illness, individuals must overcome many barriers to gain access to health care services. Since homeless people constitute a heterogeneous group with diverse social, cultural, linguistic, and educational backgrounds, a lack of sensitivity to such differences may make care inaccessible. Services suitable for a previously middle class gay white man may not be appropriate for, and therefore not utilized by, a poor black woman or a non-English speaking youth with HIV disease. Any financial barriers to care will limit access for the poor. Logistical barriers, such as geographic distance from care, lack of transportation, and long waits at public clinics, may make it difficult for a homeless person to receive treatment.

Substance abusers have commonly had negative experiences with established health care and social service systems. Active outreach is necessary in order to serve this high-risk and increasingly infected population. Some shelter and hospice programs categorically exclude substance abusers, further limiting access to

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these services. Once secured, hospice care may be threatened by difficulties with socialization to a structured environment, issues of medication use, and drug dependence.

Finally, once a homeless person with HIV disease gains access to appropriate services, there are barriers to their following through with a care plan. These include inadequate nutrition and transportation, theft or loss of medications, and poor rest facilities.

Outreach: A Model Program

Among the most significant barriers to care for homeless people is a lack of knowledge about the availability of and need for treatment services. One approach to conveying this knowledge and care is a multidisciplinary system that includes medical, nursing, mental health, social, and most importantly, effective outreach and educational services.

The AIDS Outreach Program in San Francisco provides a centrally located clinic supported by a variety of outreach services. These services play an essential role in needs assessment, education, enrollment and referral, as well as the provision of ongoing care. The program begins by identifying the homeless. Clinic staff—who are lay people with special training, public health nurses, social workers, and physicians— in their roles as outreach workers, make contact with homeless people in single room occupancy hotels, shelters, and on the streets.

Since the homeless with HIV infection comprise a disenfranchised group with a history of negative experience with authority, outreach workers must develop trusting relationships with homeless people.[2] The provision of bleach, condoms, and perhaps clean needles in exchange for dirty ones, enables workers to educate clients, and provides them with an opportunity to establish meaningful connections. Workers also help clients to see a direct connection between changes in behavior and improvement in overall quality of life.

Ongoing interaction with homeless people allows outreach workers to nurture these connections. For example, workers regularly visit two sites in San Francisco. One is a single room occupancy hotel, with sympathetic management, that provides temporary housing for an average of 50 homeless people with symptomatic HIV disease, and for many others who engage in high-risk behaviors. The second is a semi-permanent encampment of people with HIV infection in a nearby public park.

Care

Once outreach workers identify individuals at risk for HIV infection, they encourage them to undergo antibody testing. Those with obvious symptoms of HIV disease are referred to the clinic for comprehensive evaluation. In cases where patients are physically unable to come to the clinic, the initial evaluation may be carried out entirely by outreach workers who visit homeless people wherever they are. For example, a homeless man with HIV infection recently received care from clinic staff on the street, in shelters, in the local public hospital, and finally, until his death, in a hospice.

Medical evaluation includes a history and physical examination and standard laboratory testing. Clinic staff offer patients antiviral therapy as indicated, and arrange for prophylaxis against *Pneumocystis carinii* pneumonia. Periodic visits allow physicians to monitor patients for disease progression and to identify opportunistic infections as soon as possible. Mental health workers provide psychological evaluation and ongoing counseling on site. A weekly clinic, staffed by a psychiatrist and others, monitors patients who require psychotropic medications, and coordinates services with other community mental health resources.

Clinic social workers address immediate needs for food and shelter, as well as assist in application for Medicaid, federal disability benefits, and other public assistance programs. Outreach team members make referrals for other health and social services, for example, substance abuse treatment programs, housing agencies, hospitals, long-term care, and hospice services.

The program provides services in a flexible manner to maximize accessibility. Patients may drop in without appointments. Clinic staff will arrange for transportation. A weekly clinic addresses the unique needs of homeless women with HIV infection. Active substance abuse, although discouraged, does not preclude care at the clinic.

It is a common stereotype, but not one borne out by the program's experience of over 1,000 encounters with 400 individuals in the past year, that homeless people, and particularly I.V. drug users, do not comply with medical treatment. Program administrators find that when services are provided in a culturally sensitive way that respects people's dignity, follow-up is adequate. This conclusion is supported by other studies.[3]

Conclusion

The barriers to full implementation of the model presented here are both financial and attitudinal, and can only be overcome through increased public awareness and social commitment. By ignoring the haunting specter of the homeless with HIV infection, society is making a largely unconscious decision. Implicit in such inattention is the presumption that the situation will take care of itself, and that natural selection will operate to limit the problem. In other words, some may subconsciously believe that homeless people with HIV infection should not receive help because they have demonstrated that they are not fit for survival.

The homeless with HIV constitute a swelling reservoir of infection with the potential to overflow into the non-drug-using heterosexual population. To avoid a third wave of infection, it is imperative that education about HIV transmission be linked to programs that address the basic needs of homeless people. In order to change behavior, services must be provided in ways that develop and maintain trust, and respect people's dignity.

But beyond the public health imperative, there is the moral obligation of a civilized society to care for its weakest members. Society must commit to limiting the spread of HIV among disadvantaged people and to addressing the needs of all people affected by this epidemic.

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References.

1. Torres RA, Lefkowitz P, Kales C, Brickner PW. "Homelessness among hospitalized patients with the acquired immunodeficiency syndrome in New York City" (letter). *Journal of the American Medical Association.* 1987; 258(6): 779-780.
2. Froner G, Rowniak S. "The health outreach team: Taking AIDS education and health care to the streets." *AIDS Education and Prevention.* 1989; 1(2): 105-118
3. Williams IY, Noel-Conner J, El-Sadr W. "Compliance with zidovudine (AZT) therapy in an inner-city HIV-infected population" (abstract). V International Conference on Acquired Immunodeficiency Syndrome, 1989, page 414.

Request for Submissions and Comments

We invite readers to send letters responding to articles published in **FOCUS** or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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Older People: An Overlooked Population

Bruce A. Folsom, LCSW

Discussions of HIV disease rarely focus on the elderly. This exclusion appears to be based on a number of false assumptions: that older people are not sexually active, that they are not homosexual or bisexual, and that they do not use intravenous (I.V.) drugs. While, in the United States, the incidence of HIV infection among the elderly is low, approximately 10 percent of all new cases of AIDS are among those older than 50 years. This figure has remained constant since 1982, and it includes 1 percent who have reached or passed age 65. In 1988 alone, this 1 percent represented 1,000 older people newly diagnosed with AIDS.[1]

Older people with HIV infection cope with circumstances that may be different in dramatic ways from the majority of other people with HIV infection: young, white men, many of whom are gay, and young people of color, including women and children, many of whom have become infected as a result of I.V. drug use or sex with I.V. drug-using partners. At the same time, despite the public perception to the contrary, some older people do engage in high-risk sexual activities and do use I.V. drugs.[2] Health professionals must learn how the situations of older people compare to those of people now receiving HIV-related services.

Defining the term "elderly" is difficult. Lumping together an active 68-year-old who plays tennis twice a week and a retired 58-year-old who has suffered a severe stroke ignores significant individual differences in terms of health care, demographics, and character. Surveys regarding HIV infection are inconsistent and arbitrary about the age categories they use to define data. Some include everyone older than 50 in one category; others separate data into ranges from 50 to 64, and 65 and older. The very fact that there is no standard definition demonstrates how little attention is paid to aging. For the purposes of this article, the group labeled "elderly" includes those who are 50 and older, since this seems to be the most common statistical description.

Transmission

Given the difficulties of defining who is elderly and the lack of sufficient information about older people, there are limits to any discussion of HIV transmission in this population. Some data does exist, however, and it is clear that the risk of HIV transmission differs between older and younger people not in terms of routes but in terms of rates of transmission.

For example, as of mid-1988, in the 50 to 64 age group, 70 percent of new cases of AIDS in the U.S. were among gay and bisexual men; blood transfusions accounted for only 9 percent. For people 65 years old and older, gay and bisexual transmission dropped to 27 percent, and blood transfusions accounted for 55 percent. Due to the long incubation period of HIV infection, and the fact that blood screening programs were not instituted until 1985, it is reasonable to assume that the number of new cases of transfusion-related AIDS has not yet peaked. A more important statistic is that, while in the U.S., all other age groups have shown a decline in the rate of heterosexual HIV transmission, among adults age 50 and over, heterosexual transmission has risen from 1.3 percent in 1982 to 4.6 percent in 1987. For those age 50 and over, HIV transmission through I.V. drug use has remained stable at around 8 percent.

Health factors may contribute to the risk of transmission among the elderly, especially the increased risk of heterosexual transmission. In particular, factors like the declining potency of the immune system and thinning of the vaginal walls may increase the likelihood of infection following exposure to HIV.

Education

People age 50 and older know less than younger people about the risks of HIV infection, are less likely to have been tested for HIV antibody, and are less willing to be tested.[1] One study found that people 50 and older are more likely than younger people to fear contagion from casual contact, such as using public toilets or eating in a restaurant whose cook has AIDS. Two studies found that among sexually active transfusion recipients, none of the older transfusers had used condoms since the transfusion, and in one of those studies, over half of the older transfusers did not know that latex condoms can prevent HIV transmission.

There has been little research into the attitudes of the elderly towards sexuality, drug use, or HIV. The few studies that do exist suggest that older people learn more slowly, are more likely to state that they "know nothing" about AIDS, and respond less often to surveys about sex and AIDS. It appears that older gay men are less likely to be in primary relationships than younger men, and are less likely to report using "safe sex" measures. Older gay men also report fewer sexual partners and fewer sexual episodes, and, in San Francisco, are far better informed about using condoms than older heterosexual men.[1] These findings are tentative due to the small number of studies and their small sample sizes.

These findings probably result, at least in part, from the fact that the elderly are rarely targeted for HIV education. The majority of educational materials are written to address the concerns of younger people, and it would be unlikely to find an older person depicted on a brochure about HIV. The elderly need education aimed specifically at them, and, since older people do not comprise a homogeneous group, educators need to develop specific strategies aimed at educating particular subgroups, including gay men, heterosexual men and women, and people of color.[3]

While, for all other groups, there has been a decline in the rate of heterosexual transmission, for adults age 50 and over, heterosexual transmission has risen.

Part of the failure of education among older people lies with family members and care providers, who sometimes know little about HIV disease themselves and who are often reluctant to discuss or sometimes even to consider issues of sexuality or drug use among elders. There are already reports of lack of recognition of symptoms of HIV infection in the elderly by their caregivers, thus delaying diagnosis and treatment.

Conclusion

HIV education targeting older persons should be available through senior organizations such as the American Association for Retired People, retirement communities and senior centers. Family members and service providers for the elderly—including physicians, religious counselors, nurses, social workers, home health aides and others—need HIV education in order to encourage realistic risk reduction as well as to be able to detect early symptoms of HIV infection. Finally, educators must develop methods to respond to the particular needs of subgroups of the elderly, and to healthy as well as frail older people.

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References

1. Riley MW, Ory MG and Zablotsky D, eds. *AIDS in an Aging Society.* New York: Springer Publishing Co., 1989.
2. Catania JA, Stall R, Coates TJ, et al. "Issues in AIDS primary prevention." *GENERATIONS: Journal of the American Society on Aging.* Fall 1989.
3. Nickel CS. "Elderly are important audience for education on AIDS prevention." *O.T. Week.* 1988; 2(14): 3.

Recent Reports

AIDS Street Education. San Francisco Department of Public Health. (*AIDS Education and Prevention*, Summer 1989).

Providing health assessment, case management, and risk-reduction education requires street outreach workers to spend substantial amounts of time developing trust with clients. In San Francisco during 1987 and 1988, a team that included a public health nurse and a health educator, made about 120 monthly contacts, many with homeless individuals.

To gain the respect and trust needed to provide significant assistance, team members began by distributing condoms and bleach. They approached clients slowly, allowing them to protect their anonymity. With repeated encounters, some clients began to accept the workers, and acceptance grew as clients saw that others were willing to accept the workers. Workers improved their chances of being accepted by learning the language, culture, and subtle behaviors of the people in each neighborhood.

For example, the team had a 45-minute contact with a 20-year-old sex-industry worker who related her fears about HIV infection and drug use. The team provided education about HIV transmission and made referrals to women's clinics and a prostitutes' support group. The authors conclude that the woman was candid because the team met her in her own environment, avoided judging her, and allowed her to direct the relationship.

Many clients, even after persistent outreach efforts, refused to accept help or failed to comply with the plan for care. Individuals who failed to comply often believed they had been mistreated by health care institutions or individual outreach workers, and therefore, that such interventions were not in their best interests.

AIDS in an Older Person. Mount Sinai Medical Center, New York (*Geriatrics*, July 1989).

Age itself may affect the care of older people with HIV infection. In the case of a 90-year-old man with AIDS, the lack of testing for HIV antibody, and a late diagnosis of his infection complicated care. The patient, who received a transfusion in 1983, was tested for HIV antibody in July 1987 when, while traveling in Austria, he developed diarrhea. HIV antibody tests were required of all foreigners seeking hospital care.

In November 1988, the patient showed acute cognitive impairment and was diagnosed with HIV-related dementia. The patient, who had been physically active, developed *Pneumocystis carinii* pneumonia (PCP) and oral lesions, and was treated with pentamidine and AZT. He was released from the hospital, but was readmitted within a month, and died in January 1989.

In this case, the patient was not diagnosed with HIV infection early in the course of the disease. Older people may be affected by a number of diseases that have symptoms similar to HIV disease, or that mask HIV infection. For instance, it is often difficult to differentiate HIV-related dementia from other illnesses, such as Alzheimer's disease. In general, AIDS Dementia Complex is more often subcortical than cortical, and may include complications, such as myelopathy and peripheral neuropathy, that are not seen in Alzheimer's disease.

To reduce the uncertainty about diagnosing HIV infection, physicians treating older people should consider the following factors as reasons to suspect HIV infection: a history of transfusion, respiratory distress with signs typical of PCP, a decline in the number of blood platelets, and symptoms of subcortical dementia. The authors also use the case to discuss palliative care, nursing and discharge issues, and dealing with spouses of older patients.

AIDS & An Aging Society. (Special AIDS issue of *GENERATIONS: Journal of the American Society on Aging*, Fall 1989).

"AIDS & An Aging Society," features 23 articles on topics such as grief and bereavement, nursing home care for older people with AIDS, and moral aspects of the commitment by partners to care for one another. Two articles deserve special attention.

One article includes a survey conducted by the University of California San Francisco's Center for AIDS Prevention Studies. Subjects, 65 to 78 years old, were participants in a university's extended education program. Of 71 respondents, 41 were sexually active, and, of this group, five had received blood transfusions between 1977 and 1985. None of these five subjects had tested for HIV antibody, nor had any used condoms during intercourse. Forty percent of all respondents disagreed with the statement that condoms can prevent HIV transmission, 58 percent said that condoms are physically uncomfortable, and 45 percent said that buying them is too embarrassing.

In another article, a researcher at the University of Texas Medical Branch in Galveston presents the results of a random survey of older people's attitudes toward people with AIDS. The survey included 43 Georgia subjects between 60 and 65 years old. While 71 percent said that people with AIDS were worth getting to know, 48 percent said an employer should be able to fire a person with AIDS, 58 percent said that people with AIDS should be sent to sanitariums, and 58 percent agreed with the statement that homosexuals were responsible for AIDS.

Correction

In "Evaluating AIDS Prevention Programs," by Deborah Rugg, PhD (February 1990), the second reference was inaccurate. It should read: Coyle S, Boruch R, Turner C, eds. *Evaluating AIDS Prevention Programs*. Washington, D.C.: National Academy Press, 1989.

Next Month

While the gay community has devised prevention programs that have dramatically reduced unsafe sexual behavior among gay men, educators are concerned about evidence that significant numbers of gay men are reverting to unsafe behaviors. In the May issue of **FOCUS, Jeffrey A. Kelly, PhD,** Professor of Psychology at the University of Mississippi Medical Center, reviews the models for HIV-risk reduction that have worked, and discusses ways that these might be adapted to fit this changing situation.

Psychoneuroimmunology, the study of the reciprocal effects of the mind, the nervous system, and the immune system, may be important for HIV disease treatment. Also in the May issue, **Robert M. Kertzner, MD,** Assistant Clinical Professor of Psychiatry at Columbia University, defines psychoneuroimmunology and its relevance to HIV infection.

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