

# New England Journal of Public Policy

---

Volume 8  
Issue 1 *Special Issue on Homelessness: New  
England and Beyond*

---

Article 49

3-23-1992

## AIDS and the Homeless of Boston

James J. O'Connell  
*Boston Health Care for the Homeless Program*

Joan Lebow  
*Boston Health Care for the Homeless Program*

Follow this and additional works at: <https://scholarworks.umb.edu/nejpp>



Part of the [Community Health and Preventive Medicine Commons](#), [Infectious Disease Commons](#), [Public Policy Commons](#), and the [Social Policy Commons](#)

---

### Recommended Citation

O'Connell, James J. and Lebow, Joan (1992) "AIDS and the Homeless of Boston," *New England Journal of Public Policy*. Vol. 8: Iss. 1, Article 49.

Available at: <https://scholarworks.umb.edu/nejpp/vol8/iss1/49>

This Article is brought to you for free and open access by ScholarWorks at UMass Boston. It has been accepted for inclusion in New England Journal of Public Policy by an authorized editor of ScholarWorks at UMass Boston. For more information, please contact [scholarworks@umb.edu](mailto:scholarworks@umb.edu).

# AIDS and the Homeless of Boston

James J. O'Connell, M.D.

Joan Lebow, M.D.

---

*Homeless persons with AIDS and HIV infection face significant health hazards during the daily struggle for survival on the streets and in the crowded shelters of our cities. This article offers a historical perspective on the evolution of the AIDS epidemic within the homeless population of Boston and examines the demographics, risk behaviors, and survival statistics of that epidemic. The Boston Health Care for the Homeless Program is presented as a model of service delivery that offers quality health care to homeless persons with AIDS while addressing the special needs of those bound by the immediacy of the next meal and a night's shelter. Health care is inextricably woven into the fabric of social policy and cannot be delivered without an accessible network of housing, entitlement, job training, mental health, and substance-abuse services.*

---

**O**n Labor Day 1991, a *New York Times* cover article offered a sobering assessment of a tragic problem entering the second decade of national prominence and shame: "Shift in Feelings on the Homeless: Empathy Turns into Frustration." The good will of neighborhoods and cities has been eroded by the encroaching visibility of homelessness, the hard times of a national recession, and a public policy bereft of solutions despite an exuberant patchwork of emergency and transitional services. While answers to solving the problem are elusive, the causes of homelessness are more evident: poverty, lack of affordable housing, the disintegration of the nuclear family, poor education, and the disappearance of the low-skilled factory jobs that gave an opportunity for homes and education to generations of American workers and their families, and gave cause for past Labor Day celebrations.

Homelessness is the chasm below the social safety net, an abyss of abject poverty known to a heterogeneous cross section of society's most vulnerable citizens: families with children, runaway and throwaway adolescents, and single men and women suffering from chronic mental illness, substance abuse, physical or sexual violence, illiteracy, complex medical problems, the nightmares of war, or advancing years with

*James J. O'Connell is director of the Boston Health Care for the Homeless Program. Joan Lebow is director of the AIDS Program of the Boston Health Care for the Homeless Program.*

meager financial reserves and atrophied gray matter. Most are without the support of family, neighbors, or community.

This article explores the effects of AIDS and human immunodeficiency virus (HIV) infection on this world below the safety net as witnessed by the physicians, nurses, and caseworkers of the Boston Health Care for the Homeless Program (BHCHP). Where possible, we have included the stories of people who have quietly and courageously borne this virus during the struggle to survive on the streets of the city. Understanding the magnitude of the problem and the special needs of persons with AIDS who have no homes is critical in formulating a humane public health policy.

---

### **The Beginnings of the Epidemic**

Only one person with AIDS was known to be living in the shelters or on the streets of Boston when BHCHP began direct care services in the summer of 1985. This white homosexual male in his early forties, working at a moderate-wage job without medical benefits, lost both his employment and his apartment in the South End as a result of his illness, and humiliated and alone, he came to a 360-bed shelter in Boston. Despite the anonymity of the streets, shelter guests and staff soon knew this frail person's diagnosis, and uncomfortable community meetings at the shelter were required for several weeks to allay understandable fears of an infection largely unknown at the time. He was accepted into the shelter and cared for by a committed staff that allowed him to remain indoors on days when his fatigue or diarrhea were disabling. He died later that autumn, from complications of cryptococcal meningitis, in a nursing home not far from the shelter, where he was visited each day by friends from his new community.

During the next two years, twelve homeless persons were diagnosed with AIDS. At a time when over 80 percent of AIDS cases in the United States were among homosexual men, the demographics of this small sample foreshadowed an ominous shift in the epidemic: the spread of HIV infection to a heterosexual population, especially people with a primary risk behavior of intravenous (IV) drug use and those who have been sexual partners of IV drug users. Three (25%) of our initial twelve AIDS patients were women. Seven (58%) were persons of color: four Hispanics and three African-Americans. Eleven of the twelve (92%) had used IV drugs in the recent past.

All had histories of alcohol abuse, as evidenced by withdrawal seizures, delirium tremens, hepatitis, or admissions to detoxification units. Over half these people had been hospitalized for prolonged periods for serious mental illness. Fifty percent had been incarcerated for a year or longer. Efforts by BHCHP and shelter providers to offer primary care to this group proved Sisyphean, thwarted by the lack of housing, the fragmentation of services, and the dearth of substance-abuse treatment and rehabilitation programs. The first seven persons lived an average of only 5.3 months, and most were found dead in the streets — abandoned, alone, and without dignity. An unpublished BHCHP study found that these individuals had been admitted to an average of three different area hospitals for a total mean of 144 days in the year before death; the hospital costs per patient averaged \$84,000 in 1986 dollars.

Some of the stories illustrate the chaos. After six weeks in a hospital north of Boston, including several weeks in the intensive care unit in a coma, a young woman with AIDS was discharged at 2:00 A.M. by taxicab to a Boston shelter, a distance of

more than twenty miles. She arrived without information, medications, or follow-up appointments. Subsequent investigation revealed that this weak woman had exhausted the patience and resources of the community hospital and had been sent summarily to the shelter in exasperation. Demented at the age of thirty-four, ataxic and unable to negotiate stairs without assistance, and at great risk for bleeding because of a very low platelet count of less than 30,000, she could hardly have been placed in a more dangerous setting than the shelter. Two days later she fell in the shower, sustained a subdural hematoma (bleeding between the brain and the inside of the skull), and died after three weeks in the Boston City Hospital (BCH) intensive care unit.

A young man with chronic mental illness developed mild dementia and memory loss and was diagnosed with cryptococcal meningitis. The Department of Mental Health refused admission to a psychiatric facility because his HIV infection preceded any known mental illness, and his youth precluded Medicaid coverage for chronic care hospitalization. He was discharged to a shelter, where his erratic behavior became intolerable as he left bloodied razors in the bathrooms and frequently urinated and defecated in the common areas. He was barred from the facility and literally had no other place to go; throughout that winter he slept on the floor between the two glass doors of the shelter foyer. Eventually he was admitted to the AIDS Unit at the Lemuel Shattuck Hospital, a ten-bed facility for the chronic and terminal care of persons with AIDS, where, after several months, he died at the age of thirty-one. He had last seen his father at Children's Hospital, when, at the age of fourteen, he was having cardiac surgery; efforts to locate his family were in vain until a local investigative reporter was able to find the dead man's father: "I can remember him when he was real little, takin' him to the store with me. He was a real gentle little boy, nice little boy. Homeless! Ohmygod, no."<sup>1</sup>

A thirty-year-old Hispanic man, well known to the BHCHP staff, was noted by an observant nurse in the shelter clinic to be acting unusual and having some difficulty walking. The nurse called the BHCHP physician, concerned that this could be related to HIV infection, and the man was sent to the BCH emergency ward for evaluation. During the four-hour wait to be seen, he left the emergency ward, unable to recall the reasons for his referral; the subtle findings of the shelter nurse had not been noted by the busy triage staff. He failed to return to the shelter, and was found in an abandoned car two days later, suffering from shock due to an overwhelming toxoplasmosis infection. He required several weeks in the BCH intensive care unit and died of multiple organ failure four months later in a chronic disease hospital.

Such stories were as commonplace as unfortunate, yet understandable in the context of a health care system ill equipped to understand homelessness and accommodate the special needs of this high-risk population.

---

## Demographics

### *The Elusive Denominator*

Estimating the size of the homeless population in the United States or in any particular city has been contentious and problematic, limited by the definition of "homeless," the transience of the population, and the logistical difficulties with sampling techniques.<sup>2</sup> The numbers have ranged from 250,000 to over 3 million.<sup>3,4</sup> While many individuals and families throughout the country live in shelters and on the streets



and are thereby literally homeless, innumerable others are huddled on the edge of homelessness and living doubled and tripled up in small apartments and rooms. The exact number of such persons is impossible to calculate.

The BHCHP has cared for over 25,000 homeless men, women, and children since 1985; in 1990, 6,800 unduplicated homeless persons received direct health care and social services in almost 28,000 encounters. The yearly Boston census has revealed between 3,000 and 4,000 literally homeless persons on a given night during each of the past two winters;<sup>5</sup> however, the BHCHP numbers in 1990 provide a basis for estimating the number of homeless people living in shelters or on the streets at some time during a full year. Since BHCHP clinics care only for homeless persons willing to accept health care, 6,800 represents well less than half the homeless population in Boston during a year. A more realistic denominator would be at least 14,000 to 15,000, indicating that the problem is far more extensive in Boston than previously thought.

### *Seroprevalence Data*

Very little is known of the seroprevalence of HIV infection in homeless populations; virtually nothing is known of the natural history and outcome of those who suffer with this infection while living in shelters and on the streets. All studies to date have been either retrospective or cross sectional, without control groups, or without the ability to follow homeless persons with HIV infection over significant periods of time.

Torres retrospectively analyzed 169 men living in a congregate shelter in New York City and found a 62 percent HIV seroprevalence rate among those referred for testing. Of the men with HIV infection, 65 percent (62 of 105) identified IV drug use as a major risk behavior. HIV infection was associated with 90 percent of active tuberculosis (TB) cases diagnosed in that shelter. Stratification according to total time spent homeless correlated positively with the development of active TB, as those who developed pulmonary TB had been homeless almost twice as long as those who did not develop the disease (9.7 versus 5.4 months).<sup>6</sup>

A 1990 study by Zolopa found an HIV seroprevalence rate of 11 percent among 500 consecutive homeless persons seeking medical care at four community locations in San Francisco. Of the 56 persons with HIV infection, 58 percent had a history of current or past IV drug use.<sup>7</sup>

An analysis of blinded blood samples from 2,667 runaways aged fifteen to twenty in the Covenant House Clinic in New York City, from October 1987 through December 1989, revealed an HIV seroprevalence rate of 5.3 percent. Of the 95 seropositive adolescents willing to discuss risk behaviors, 10 percent (9 of 95) identified IV drug use. However, the risk assessments were limited to data available in the medical records, and the authors underscore the likelihood of significant underreporting of high-risk behaviors at the time of initial contact with health care providers.<sup>8</sup>

A review of inpatients with HIV infection in a New York hospital found that 13 percent were homeless. The hospital stays averaged 62 days for homeless persons, but only 40 days for those with homes ( $p < 0.02$ ).<sup>9</sup>

### *Homeless Women and AIDS*

Women comprise an increasing proportion of new AIDS cases in the United States. While women accounted for only 2 percent of the reported cases in 1985, this figure had increased to 11 percent in May 1991. Black and Latin-American women share

a disproportionate burden of AIDS in the United States. Although only 19 percent of all U.S. women are either black or Hispanic, 72 percent of reported female AIDS cases occur among these two minority groups.<sup>10</sup> IV drug use is the main risk behavior for AIDS in women, associated with 71 percent of AIDS cases: 52 percent are IV drug users (IVDUs) themselves, and 19 percent are sexual partners of IVDUs.<sup>11</sup>

Little detailed information exists concerning the natural history of AIDS among women, and even less is known about the course of the disease in homeless women. The impact of gender on disease outcomes or response to treatment is unclear, and specific barriers to care for women have not been elucidated. Data from the AIDS Clinical Trials Group suggest that only 6.7 percent of patients in federally funded national AIDS trials have been women.<sup>12</sup>

Many gynecologic conditions may be more common and more aggressive in the presence of HIV infection. Women infected with HIV have an increased prevalence of lower genital tract dysplasia and human papilloma virus (HPV) infection, even when compared to HIV seronegative controls who used IV drugs or were sexual partners of IVDUs.<sup>13,14</sup> Candida vaginitis, which occurred in 50 percent of women with AIDS, was refractory to treatment in 9 percent of cases.<sup>15</sup> Investigators from Walter Reed Army Medical Center found that 24 percent of HIV-infected women (7 of 29) had a history of chronic refractory vaginal candidiasis.<sup>16</sup> Buehler and colleagues at the Centers for Disease Control presented data from a national cohort of 631 HIV-infected women which showed that 11 percent (70 of 631) developed candida vaginitis during the first year of observation.<sup>17</sup> Homeless women may have an increased risk for sexually transmitted diseases (STDs) as well. In one study, women who live in shelters reported significantly higher number of sexual partners than those who had never lived in them.<sup>18</sup>

The increased incidence of cervical dysplasia and infections with HPV, candida, and STDs has concerned providers because many homeless women have long histories of physical and sexual abuse and often shun routine pelvic and breast examinations. The complex relationships among homelessness, domestic violence, and HIV infection have not been examined critically. Studies have shown that over 15 percent of women seen in primary care clinics have a history of physical or sexual abuse.<sup>19,20</sup> The BHCHP clinical experience suggests that physical and sexual violence is substantially more common among homeless women.

HIV infection in women necessarily involves their children, both those directly infected with HIV and those affected by maternal infection. Cord-blood data collected in Boston and nationally have shown that the majority of births by HIV-infected women occur among ethnic minority groups, and predominantly in impoverished inner-city neighborhoods riddled by IV drug use and homelessness.<sup>21</sup>

### *AIDS and the Homeless of Boston*

To assess the extent and effect of HIV on the homeless population of Boston, we retrospectively reviewed the BHCHP clinical records from July 1985 through March 1990. AIDS had been diagnosed in 40 persons, AIDS-related complex (ARC) in 86, and 44 individuals had documented HIV infection without symptoms. An estimated 200 other persons were identified with high-risk behaviors. A pilot study was then conducted of the 40 people who met the definition for AIDS of the Centers for Disease Control. Eighteen percent were women, while persons of color comprised 75

percent of the cohort (22 black, 7 Latino, and 1 Native American). Thirty-one persons (78%) gave a history of recent IV drug use. Twenty-two (55%) had died, and the mean survival of 10.4 months was similar to housed Boston residents with AIDS.<sup>22</sup>

This latter finding seemed difficult to reconcile with our hypothesis that persons with AIDS living in shelters and on the streets are at significant risk for excess morbidity and mortality when compared to those having the stability and safety of homes. The equal survival rates are especially surprising in light of the original, albeit small, group of seven homeless persons in 1986 and 1987 who lived only an average of 5.3 months after diagnosis with AIDS. Most of the forty persons in the pilot study were diagnosed after 1987, a time when antiretroviral therapy and improved diagnosis and treatment of many opportunistic infections had combined to improve the quality of life and survival time of persons with HIV infection.

We have studied mortality among homeless persons in Boston during the past five years, and over 350 deaths have now been documented. Death certificates, BHCHP clinic records, shelter records, and BCH hospital charts were reviewed to determine the causes of death. Access to a broad network of services has facilitated case finding, and the study has continued into the sixth year. The deaths associated with HIV infection have increased during four years of data analysis, as shown in Table 1.

Table 1

**Mortality and HIV Infection among Boston's Homeless**

Year	Deaths	AIDS	ARC/HIV+	Total HIV-Related Deaths	
1986	56	5	2	7/56	(13%)
1987	53	1	2	3/53	(6%)
1988	68	4	5	9/68	(14%)
1989	73	14	7	21/73	(29%)
Total	250	24	16	40/250	(16%)

These data demonstrate the disturbing fact that many homeless persons with HIV infection die before progression to AIDS, and explain to some degree why the survival curves appear similar in the pilot study. Of the forty deaths among homeless persons with HIV infection in Boston, sixteen (40%) occurred before the infection had progressed to frank AIDS. Since only AIDS cases are reported to the commonwealth of Massachusetts, the true impact of HIV and related opportunistic infections on this population has certainly been underestimated, and the calculation of survival rates becomes far more complex.

### Barriers to Care

#### *The Experience of Homelessness for the Chronically Ill*

The immediacy of survival on the streets is the primary concern and full time occupation of homeless people. Life must be lived in the present, with little time afforded the future. Several logistical problems face homeless persons who are ill. Shelters require guests to leave early each morning, with the doors opening again in the late afternoon. Waits in long queues are required to enter the shelter, obtain a bed ticket, and secure a meal. While they wander in search of refuge during the days, exposure



to the extremes of weather and temperature are commonplace. Public bathrooms are scarce and often locked to indigents. The shame and indignation voiced by our patients over recurrent and often explosive diarrhea is unimaginable. Fatigue and weakness are common constitutional symptoms that are magnified during the struggle to survive on the streets, especially for those who must carry all their worldly possessions during the daily journey. Inanition and malnutrition render homeless persons with AIDS prey to all manner of violence, especially on the first and third days of the month, when entitlement and Social Security checks arrive. Medications like zidovudine, formerly called azidothymidine (AZT), must be taken every four hours, a formidable challenge even to people with the stability of a home and a predictable routine. In addition, AZT and other medications have a high value on the black market and are frequently stolen or sold. Tuberculosis and other communicable diseases are common in the crowded, poorly ventilated, dormitory-style shelters that are characteristic of those found in larger cities.

### ***AIDS Education and Prevention***

Studies assessing AIDS awareness and knowledge among homeless persons have found that 80 to 95 percent of those responding to a questionnaire knew the high-risk behaviors associated with HIV transmission.<sup>23</sup> Findings from a New Orleans survey demonstrated an exceptionally high knowledge rate of HIV infection among homeless adults, yet 57 percent of those responding continued to share needles and 31.7 percent engaged in unprotected sex.<sup>24</sup> Such information underscores the difficulties of changing behavior in this population despite creative efforts at education and prevention. Drug sickness drives the behavior of the addict and renders future health concerns irrelevant as the heroin or cocaine and the "works" are cooked, passed, and shared. Education and prevention programs must recognize this reality of life for those addicted to drugs; programs that target people who continue to engage in high-risk behaviors will inevitably challenge the tolerance of a society that does not condone such behavior. Yet the reality is frightening, and millions of needles and bodies are shared each day in an HIV Russian roulette played by people suffering from the illness of drug addiction.

Condoms and bleach should therefore be readily available in a prominent but unsupervised place in every shelter. Many street workers and drug counselors have advocated needle-exchange programs as a small but important means of minimizing the spread of the virus while awaiting adequate numbers of treatment beds and potential vaccines against it.

### ***HIV Testing***

Evidence suggests that antiretroviral treatment is effective for persons with HIV infection whose CD4 lymphocyte counts are below 500, whether or not symptoms have occurred.<sup>25,26</sup> Prophylaxis against *Pneumocystis carinii* pneumonia (PCP) has been shown to prolong survival and increase the quality of life for persons who have had previous episodes of PCP, and has become a mainstay of preventive therapy for asymptomatic individuals whose CD4 lymphocyte counts are below 500.<sup>27,28</sup> Many other medications are likely to become essential in the early treatment of HIV infection, hence public health officials and primary health care providers should urge persons engaged in high-risk behaviors to seek HIV education, counseling, and antibody testing. The public health goals are straightforward: (1) through education and



behavioral modification, minimize further transmission of the virus by those infected; and (2) assure optimal quality of life and survival through primary and preventive health care early in the course of the infection.

Unfortunately, most providers of care to homeless persons with high-risk behaviors have wrestled with the paradoxical effects of HIV testing in this impoverished population with minimal supports. Two early BHCHP patients with HIV seropositivity, tested in correctional institutions with a minimum of counseling, committed suicide before the development of symptoms. One, arrested for petty shoplifting, was later resuscitated in his cubicle after an attempt to hang himself. A ten-day admission to an intensive care unit was followed by a two-week evaluation in a mental health facility. He returned to the streets, awaited his monthly veteran's check, and wrote a final letter of apology for "a wasted life" to his girlfriend and family before overdosing on heroin during Labor Day weekend of 1986. During many clinic visits, this former high school athlete spoke openly about his "descent into drugs" and confessed that he shared a death wish with other addicts who saw the virus as the only release from the drugs.

The other person, a heralded saxophone player in the big band jazz era, was in his mid-fifties. A heroin habit, dating to 1955, had eroded family and career while ushering him to the margins of single-room-occupancy (SRO) establishments and shelters. Brief clean and sober periods invariably brought full cognizance of life's losses and a simple acknowledgment that heroin was better than an awareness of his loneliness in a bare room with a shared toilet. He came to our clinic in early 1986 with questions about his positive HIV antibody test, obtained by a corrections facility while he was serving a short sentence for possession. His vision of AIDS, despite his own blessing of robust health with no constitutional symptoms, was limited to several emaciated and demented friends who had died utterly alone on the streets of New York. Our caseworker helped him obtain SSI benefits within a month and found him a two-room apartment in a downtown neighborhood. A trusting and convivial relationship had developed with the BHCHP staff, and he had managed to remain drug free for over three months. He was found dead in his apartment several weeks later from an overdose of heroin, a note on his sofa thanking us for the help.

If public health policy suggests HIV testing in order to change behavior and minimize the spread of infection, it must be acknowledged that the opposite generally results when homeless persons suffering from chronic opiate or cocaine dependence are tested. The most common response has been to embark on a drug run, to get high, and to escape. As one young woman with a seven-year cocaine habit told us, "My HIV test is negative, and I'm disappointed. The truth is, I'm not ready to deal with life without drugs, and a positive test would have given me all the reason in the world to use my drugs without worry. And the funny thing is, now that I'm negative, maybe I can just keep doing things the same way and be safe!" Her pattern had been to prostitute for her drugs, and she had never used condoms or bleach despite an advanced knowledge of HIV transmission.

HIV testing in a homeless population therefore poses ethical dilemmas that are often overlooked by an otherwise rational public health policy. High-risk behavior often escalates, and primary care becomes difficult and disjointed at best. Chemical dependency is a chronic and relapsing illness, a complex medical and behavioral puzzle that has not yet been successfully solved. When accompanied by the extreme

poverty and lack of community and family supports that are the hallmarks of homelessness, the illness is virtually untreatable. And the burden of a fatal illness like AIDS completes a triad that destroys all vestige of hope. To expect drug behavior to change in the midst of an agony and despair hardly imaginable to educated Americans with homes and families is simply unrealistic. Every housing, rehabilitation, or transitional program available to homeless persons with HIV infection in the Boston area requires sobriety, an understandable need to assure the acceptance, feasibility, stability, and maintenance of these innovative programs. Unfortunately, such supports become attainable only when most homeless individuals become too ill to hustle and support a habit, a time often far advanced in the course of the infection.

Homeless persons with HIV infection need a stable residence and routine in order to begin the process of recovery. The immediacy of the struggle for survival on the streets usurps all hope for addressing one's addiction, especially with the dearth of treatment beds in most large cities. Public health policy must recognize the reality of this condition; treatment beds must be available on demand, and new programs are essential to offer admission to homeless persons in order to help them address the issues of addiction *after* securing the stability of a regular residence.

---

#### **The BHCHP Model of Care for Homeless Persons with AIDS**

The Boston Health Care for the Homeless Program was one of nineteen four-year projects nationwide funded in 1985 by the Robert Wood Johnson Foundation and the Pew Memorial Trust. The mission of assuring available and accessible quality health care for all homeless families and individuals in Boston mandates that the BHCHP services become an essential part of the existing health care system rather than a separate or alternative system. Multidisciplinary teams of full time physicians, nurses, and caseworkers have become the focus of a service delivery system that integrates direct health care and social services in over forty shelter and outreach clinics throughout the metropolitan area with the primary care and specialty clinics of two major teaching facilities, Boston City Hospital (BCH) and Massachusetts General Hospital (MGH).

Primary care clinics for homeless persons are held four days each week at BCH, and twice a week at MGH. All homeless persons admitted to those hospitals are visited by BHCHP teams, who collaborate with the medical, nursing, and social service staffs to facilitate practical discharge planning and adequate follow-up.

A twenty-five-bed Medical Respite Unit operated by the BHCHP in the Lemuel Shattuck Shelter accepts direct referrals from area hospitals for homeless patients ready for discharge to a home with visiting nurse and home health aide support, but too ill to withstand the hazards of life on the streets. This unique model of cost-effective recuperation provides medical and nursing care in addition to assistance with entitlements and housing. Alcohol and other substance-abuse counseling is available in addition to Alcoholics and Narcotics Anonymous meetings. Physical and occupational therapy are provided; literacy classes have also been initiated in response to the high percentage of persons admitted who are unable to read and consequently have had great difficulty in the competitive job market. The average stay has been about three weeks, although for the 15 to 20 percent of admissions for HIV-related illnesses, this

approaches one month. The window of opportunity afforded by such a time of recuperation and concentration of services has resulted in the placement of almost one-quarter of these patients to permanent housing or long-term rehabilitation or transitional programs.

The BHCHP Family Team cares for women and children living in family shelters and safe shelters for women throughout the city; a family physician journeys with the nurse practitioners and family advocates to motels in an area from Peabody on the North Shore to Hull on the South Shore, where Boston families are often sent when the shelters are full. The Perinatal Team has followed women who have become pregnant while living in shelters in an attempt to engage them in early prenatal care and adequate nutrition programs.

Portable dental equipment allows the BHCHP dentist and dental assistant to provide comprehensive services several days each week at St. Francis House, a soup kitchen located in the heart of Boston's Combat Zone. Services are also brought directly to families and adults in several other shelters on a rotating basis.

In response to the intensity and burden of the escalating HIV epidemic in the homeless populations, BHCHP has evolved significantly while trying to address the needs of those served. The care of these patients requires lengthy and frequent clinic visits for education, prevention, management of medications, and the early diagnosis and treatment of opportunistic infections. Existing funding streams do not allow for such intensity of care, and community health centers and hospital clinics have been understandably reluctant to manage "difficult" and uninsured homeless HIV-infected patients.

Two BHCHP physicians, two nurse practitioners, and a Hispanic caseworker conduct weekly sessions in the BCH AIDS Clinic, a multidisciplinary specialty clinic for persons with symptomatic HIV disease. This collaboration has allowed for full access to state-of-the-art care for homeless people with AIDS, including participation in all appropriate clinical trials and experimental protocols. The BHCHP staff has been able to keep abreast of the changing medical management and approaches to HIV infection, and primary HIV care is thereby brought to homeless persons throughout the network of shelter clinics. All those eligible are offered antiretroviral therapy with AZT, pneumonia and influenza vaccinations, and prophylaxis against tuberculosis (isoniazid, rifampin) and *Pneumocystis carinii* pneumonia (trimethoprim-sulfamethoxazole, dapsone, or aerosolized pentamidine).

---

### **The Continuum of Care and the Network of Services**

The experience of the BHCHP has emphasized that health care is inextricably woven into the socioeconomic fabric of society, and the effectiveness of this model of care depends entirely on access to an array of services provided by private and public agencies, especially housing, entitlements, welfare, substance-abuse treatment, and mental health services.

### ***The Futility of the Traditional Medical Model***

The health care of homeless persons can be fragmented and futile for patient and provider. An illustrative scenario may be helpful.

A caring social worker notices a fatigued and cachectic-appearing young IV drug user in a soup line. A taxi voucher or subway token is given to provide transportation to the nearest emergency room, where he waits several hours to be seen. Indeed,



this problem is more chronic than acute, and far less emergent than the trauma or heart attacks or drug overdoses that overburden the staff of such facilities. When finally seen by an exhausted intern, the man is scolded for coming to an emergency room and reprimanded for failure to seek primary care for his chronic problems. An open sore is noted on one foot, and the treatment plan calls for a prescription antibiotic to be taken four times a day for ten days, elevation of the foot during the next several days, and dressing changes three times a day. A follow-up appointment is given for two weeks hence in primary care clinic.

Many hours have passed. Transportation to a shelter has not been provided, the evening meal is finished, and no more beds are available for the night. He has no money to buy his prescription, and he would be unlikely to remember to take it four times a day. Elevation of the leg and dressing changes are impossible while wandering the streets during the days while the shelters are closed. Despite the proper diagnosis and the textbook treatment plan, this painful encounter with the health care system too often results in a prolonged and costly hospitalization for a life-threatening cellulitis of the lower extremity.

### *The Changing Topography*

AIDS has blurred the traditional boundaries within internal medicine. This retrovirus, once thought to be the rarefied domain of microbiologists and infectious disease specialists, became of vital interest to oncologists when identified as a probable factor in cancers such as Kaposi's sarcoma and non-Hodgkin's lymphoma. With advancing clinical and laboratory knowledge, the virus has involved virtually all of the medical specialties: cardiology, hematology, nephrology, psychiatry, neurology, dermatology, pulmonary medicine, and many others. Primary care physicians and specialists have found that full collaboration is the only effective treatment and management strategy for the care of persons with this unusual infection.

The AIDS Clinic at BCH is staffed by oncologists and infectious disease specialists as well as internists and nurses. Nutrition services, psychiatric care, support groups, addictions counseling and placement, on-site staff from the AIDS Action Committee and the Massachusetts Rehabilitation Commission (responsible for SSI/SSDI in the commonwealth), a dedicated chaplain, and energetic social service advocacy for housing and entitlements represent some of the services offered in the clinic. A philosophy of highly involved and personalized care has evolved in this clinic.

This metaphor extends to the larger network of health and social services, in which traditional boundaries and "turf" issues have been challenged by the epidemic. HIV infection is a chronic illness that waxes and wanes in unpredictable cycles; persons who are severely ill and near death with PCP can recover and return to a productive life. The health care system must recognize the continuum of this disease process and provide a variety of treatment facilities that address the changing needs of those to be served. An example of one of the Medical Respite Unit patients illustrates the need for a range of accessible and flexible services.

A forty-year-old black male was admitted to BCH for elective knee surgery. The anesthesiologist noted oral thrush during preoperative evaluation. The surgery was postponed, an HIV antibody test drawn, and the patient was discharged to a local shelter. The following morning the patient was seen at Project TRUST, an anonymous HIV counseling and testing center on the grounds of BCH, and an alert staff member brought him to the Homeless Clinic at BCH. Despite attempts to establish

a primary care relationship, he was lost to follow-up until two months later, when he was intubated and admitted to the intensive care unit with fulminant PCP. He recovered uneventfully and was discharged to the Medical Rescue Unit (MRU), where oral Bactrim therapy was continued and the patient was begun on AZT with careful monitoring. He enrolled in an on-site drug and alcohol treatment program. The BHCHP caseworker assisted him with SSI and housing applications. After returning to his original shelter, he continued to see his BHCHP team in the clinic on site as well as in the AIDS Clinic. He attends an AIDS support group each week, and receives aerosolized pentamidine every other week at the Fenway Community Health Center. After an adverse reaction to AZT, he was enrolled in the phase I trial of dideoxyinosine (DDI). Weeks after receiving housing, he became ill with tuberculosis and required a chronic hospital stay for several months.

---

## Essential Services and Practical Pitfalls

### *Substance-abuse Treatment*

Nearly 80 percent of homeless persons with AIDS in Boston have identified IV drug abuse as a major risk behavior. The lack of treatment beds on demand delays the primary health care needed by many homeless persons with HIV infection and reverberates on other emergency services. For example, the time between receiving a positive HIV test result and the institution of primary care treatment has averaged fourteen months for all patients entering the Diagnostic Evaluation Unit at BCH. The major factor appears to be continuous substance abuse, lending further credence to concerns over HIV testing in this population. The BHCHP experience suggests that acute care hospitalization or admission to a drug treatment program are the most common precipitants of entry to primary health care. Substance-abuse services must recognize the chronic and relapsing nature of this illness, and the availability of various modes of treatment is essential. Many patients continue to come regularly to scheduled appointments despite daily drug use. Detoxification is urged and offered at each visit.

Methadone maintenance continues to be an important treatment for opiate dependence, despite a frequent acceleration in the use of cocaine, methadone-enhancing substances (such as Xanax and perhaps Prozac), and alcohol. Unfortunately, these polysubstance-abuse problems are further complicated because most detoxification units refuse to maintain patients on methadone while they are withdrawing from alcohol, cocaine, and other substances.

Andrew House Dual Diagnosis Detoxification Unit on Long Island in Boston Harbor has provided care for polysubstance abusers, many of whom have chronic mental illness. Methadone can be maintained during detoxification from other substances, and many patients are admitted for withdrawal from methadone after varying periods of maintenance therapy. More than half the admissions are referred from area shelters, and many have HIV infection. A strong nursing component has assured that complex medical issues can be monitored, while mental health and behavioral issues are overseen by the staff psychiatrist. A variety of treatment modalities is offered, including Alcoholic and Narcotics Anonymous as well as individual and group counseling. Many patients return for several admissions before achieving significant periods of sobriety, and the staff is aware of providing a secure and welcome place for those who repeatedly fail.

### ***Housing and Entitlements***

Affordable housing is obviously essential if the problem of homelessness is to be solved. The issue has been eloquently addressed elsewhere in this journal. Equally obvious, homeless persons with AIDS need the same continuum of housing options as other persons with AIDS, including independent living, group and shared homes, infirmaries or respite care centers, acute and chronic care facilities, and hospices.

Efforts to deliver quality health care are hampered by the delay in obtaining entitlements and housing. SSI regulations recognize only the Centers for Disease Control AIDS-defining diagnoses as sufficient evidence of permanent disability, despite the fact that many persons with chronic fatigue and other constitutional symptoms are too incapacitated to engage in gainful employment. Unfortunately, housing often comes too late in the course of the infection, or as one BHCHP patient complained during the public hearings for the Ryan White Act, "Why do you wait until I get sick before you give me the housing and stability I need to keep myself healthy?"

Another chronically homeless man waited a full year for housing after his diagnosis of AIDS. During that time he was hospitalized several times for PCP, esophageal candidiasis, pneumococcal pneumonia, herpes simplex virus, anemia, a nonhealing leg ulcer, and several episodes of high fevers without a known source. At the MRU, the caseworker finally located an apartment for him, although he died only a few months afterward.

Finally, housing is necessary but not always sufficient for homeless persons with AIDS. Many have been chronically homeless, and some have never owned or rented a room or apartment. Some individuals have asked to die in the familiarity of the shelter or the Respite Unit, fearing to face an unknown alone. Others are anxious for places of their own, but are without the skills necessary for independent living. One young man, who obtained a studio apartment, sullenly brought his \$4000 phone bill to his physician in the AIDS Clinic. He suffered insomnia, and responded to late-night television commercials by calling 900 numbers to talk to someone and assuage his loneliness and fear, unaware of the exorbitant costs of these alluring businesses.

---

### **Future Policy Considerations**

The human faces of homeless persons with AIDS have been blurred by the epidemic's overwhelming statistics, strained by the "compassion fatigue" of a society increasingly exasperated by what it regards as the "undeserving poor," and hidden within the shadows of urban gentrification. The stories recounted here illustrate an eclectic and complex problem with few stereotypes. No single solution to homelessness will be the panacea, just as no single vaccine is likely to prevent the constantly mutating human immunodeficiency virus. Solutions to homelessness will be forthcoming only when society resolves to care for its least fortunate citizens, those with hope shattered and choices limited by poverty, unemployment, fractured families, violent neighborhoods, decimated school systems, and a dearth of affordable housing.

The Hydra of homelessness, substance abuse, and HIV infection presents a daunting challenge to the public health and social welfare. Science and society have yet to implement the cure for any of these; homeless persons with HIV infection and chemical dependency suffer an unimaginable burden. Public policy must recognize the plight of those on the fringes of a suspicious and frightened society.



We believe that the Boston Health Care for the Homeless Program offers a unique model for the effective delivery of state-of-the-art health care to homeless persons, especially those with HIV infection. The collaboration of public and private agencies, shelter providers and teaching hospitals, and the various professional disciplines has allowed the care of a person in a street clinic to be fully integrated into Boston's established health care network. The funding streams of the BHCHP are consonant with the mission of the agency and mandate the program to evolve continually to meet the changing needs of those to be served.

The evolution of the AIDS Program of the BHCHP, for example, has been in response to a need that was essentially nonexistent in 1985. Homeless persons with AIDS require a continuum of care, a series of fully accessible and readily available health care "stations" during the course of the infection: forty shelter clinics, primary care clinics at BCH, MGH, and Lemuel Shattuck Hospital, BCH AIDS Clinic, inpatient care at several hospitals, Mattapan Chronic Disease Hospital AIDS Program, the Medical Respite Unit, Project TRUST, Andrew House and other detoxification units, BCH and Bay Cove methadone clinics, the AIDS Action Committee, Paul Sullivan Housing Trust, Seton Manor AIDS housing program, the Mission Hill Hospice, and countless others. AIDS is a chronic illness with a variable clinical course, and each of these "stations" is an essential component in the array of services needed to meet the particular needs of individuals during varying degrees of health and illness.

Yet the very success of this program begs the uncomfortable question: Is this just another Band-Aid approach, a salve for a complacency of a society unwilling to implement the fundamental changes necessary to eradicate persistent poverty? We applaud those volunteering as "points of light" in the darkness, but they hardly substitute for the political will and leadership required for change and enlightenment in the health and human services in this country. BHCHP has not used volunteer physicians and nurses, because homeless persons voiced a desire to be treated as other Americans are, with an identified and easily accessible primary care doctor; hence, seven physicians are employed full or parttime by the program, and all remain active on the staffs of the teaching hospitals and associated medical schools.

Fundamental change at the policy level will require both the blurring of institutional boundaries and the abolition of categorical funding streams. The myriad of agencies designed to address the basic needs of a single individual is as bewildering as the bureaucracies are Byzantine. The health of a homeless person with HIV infection requires adequate housing (Boston Housing Authority, U.S. Department of Housing and Urban Development), access to entitlements (Massachusetts Rehabilitation Commission), welfare and medical insurance (Department of Public Welfare), primary and specialty medical care for the uninsured (Department of Medical Security), and access to substance-abuse (Department of Public Health) and mental health (Department of Mental Health) treatment facilities.

The many programs working to meet the needs of homeless persons with AIDS and HIV infection have demonstrated effective strategies for delivering quality health care and social services. Without the fundamental commitment of society to care for those most in need, however, these are only Band-Aids on a festering and gangrenous wound. ■

---

## Notes

1. Mike Barnicle, *Boston Globe*, January 21, 1987.
2. P. H. Rossi, J. D. Wright, G. A. Fisher, and G. Willis, "The Urban Homeless: Estimating the Composition and Size, *Science* 235 (1987): 1336-41.
3. U.S. Department of Housing and Urban Development, *A Report to the Secretary on the Homeless and Emergency Shelters*, (Washington, D.C.: Office of Policy Development and Research, 1984).
4. M. E. Hombs and M. Snyder, *Homeless in America, a Forced March to Nowhere*, 2d ed. (Washington, D.C.: Community of Creative Nonviolence, 1983).
5. *Commitment and Compassion: Boston's Comprehensive Policy for the Homeless, Winter 1990-91* (Emergency Shelter Commission, City of Boston, Raymond L. Flynn, mayor, November 1990).
6. R. A. Torres, S. Mani, J. Altholz, and P. W. Brickner, "Human Immunodeficiency Virus Infection among Homeless Men in a New York City Shelter," *Archives of Internal Medicine* 150 (1990): 2030-36.
7. A. Zolopa, R. Gorter, R. Meakin, A. Keffelow, H. Wolfe, and A. Moss, "Homelessness and HIV Infection: A Population-based Study. Abstract presented at the Proceedings of the Seventh International Conference on AIDS, Florence, Italy, June 1991.
8. R. L. Stricof, J. T. Kennedy, T. C. Nattell, I. B. Weisfuse, and L. F. Novick, HIV Seroprevalence in a Facility for Runaway and Homeless Adolescents, *American Journal of Public Health* 815 (1991): 50-53.
9. R. A. Torres, P. Lefkowitz, C. Kales, and P. W. Brickner, "Homelessness among Hospitalized Patients with AIDS in New York City," letter to the editor, *Journal of the American Medical Association* 258, no. 6 (1987): 779-80.
10. Centers for Disease Control, "AIDS in Women — United States," *Morbidity and Mortality Weekly Reports* 39 (1990): 845-46.
11. H. Minkoff and J. A. Dehovitz, "HIV Infection in Women," *AIDS Clinical Care* 3 (1991): 33-35.
12. D. Cotton, J. Feinberg, and D. Finkelstein, "Participation of Women in a Multicenter HIV Clinical Trials Program in the United States." Abstract presented at the Proceedings of the Seventh International Conference on AIDS, Florence, Italy, June 1991.
13. A. R. Feingold, S. H. Vermund, R. D. Burk, et al., "Cervical Cytologic Abnormalities and Papillomavirus in Women Infected with Human Immunodeficiency Virus," *Journal of the Acquired Immune Deficiency Syndrome* 3 (1990): 896-903.
14. L. K. Schrager, G. H. Friedland, D. Maude, et al., "Cervical and Vaginal Squamous Cell Abnormalities in Women Infected with Human Immunodeficiency Virus," *Journal of the Acquired Immune Deficiency Syndrome* 2 (1988): 570-75.
15. N. Imam, C. C. Carpenter, K. H. Mayer, A. Fisher, M. Stein, and S. B. Danforth, "Hierarchical Pattern of Mucosal Candida Infections in HIV-Seropositive Women," *American Journal of Medicine* 89 (1990): 142-46.
16. J. L. Rhoads, D. C. Wright, R. R. Redfield, et al., "Chronic Vaginal Candidiasis in Women with Human Immunodeficiency Virus Infection," *Journal of the American Medical Association* 257 (1987): 3105-7.
17. J. W. Buehler, K. M. Farizo, and R. L. Berkelman, "The Spectrum of HIV Disease in Women." Abstract presented at the Proceedings of the Seventh International Conference on AIDS, Florence, Italy, June 1991.

18. T. Nemoto, L. S. Brown, M. M. Chu, A. Chu, and D. C. Ajuluchukwu, "Drug and Sexual Behaviors among Intravenous Drug Users (IVDUs) in Relation to Homeless Shelter Experience." Abstract presented at the Proceedings of the Seventh International Conference on AIDS, Florence, Italy, June 1991.
19. N. E. Gin, L. Rucker, S. Frayne, R. Cygan, and F. A. Hubbell, "Prevalence of Domestic Violence among Patients in Three Ambulatory Care Internal Medicine Clinics," *Journal of General Internal Medicine* 6 (1991): 317-22.
20. L. S. Friedman, J. H. Samet, M. S. Roberts, M. Hudlin, J. Chen, and P. Hans, "Do Patients Want to be Asked about Victimization Experiences and Do Doctors Want to Ask?" *Clinical Reports* 39 (1991): 625A (abstract).
21. R. Hoff, V. Berardi, B. Weiblen, L. Mahoney-Trout, M. Mitchell, and G. Grady, "Seroprevalence of Human Immunodeficiency Virus among Childbearing Women: Estimation by Testing Samples of Blood from Newborns," *New England Journal of Medicine* 318 (1988): 525-30.
22. J. Lebow, J. J. O'Connell, R. K. Avery, and K. A. Freedberg, "AIDS among the Homeless of Boston: A Cohort Study." Poster presented at the Sixth International Conference on AIDS, San Francisco, June 1990.
23. S. Gunston, "Life Lines AIDS Awareness Study," *Life Savers* 1, no. 2 (1991): 1-3 (the newsletter of the Life Lines AIDS Prevention Project for the Homeless, Massachusetts Department of Public Health).
24. D. Hoadley, M. Wahaj, K. McGuire, A. Forster, H. Dean, K. McCaffery, and B. Lutz, "HIV-related Knowledge, Attitudes, and Practices among Homeless Adults in New Orleans, Louisiana." Abstract presented at the Proceedings of the Seventh International Conference on AIDS, Florence, Italy, June 1991.
25. M. A. Fischl, D. D. Richman, M. H. Grieco, M. S. Gottlieb, P. A. Volberding, O. L. Laskin, et al., "The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-related Complex: A Double-blind, Placebo-controlled Trial," *New England Journal of Medicine* 317, no. 4 (1987): 185-92.
26. P. A. Volberding, S. W. Lagakos, M. A. Koch, C. Pettinelli, M. W. Meyers, D. K. Booth, et al., "Zidovudine in Asymptomatic Human Immunodeficiency Virus Infection: A Controlled Trial in Persons with Fewer than 500 CD4-positive Cells per Cubic Millimeter," *New England Journal of Medicine* 322, no. 14 (1990): 941-49.
27. J. A. Kovacs and H. Masur, "*Pneumocystis Carinii* Pneumonia: Therapy and Prophylaxis," *Journal of Infectious Diseases* 158, no. 1 (1988): 254-59.
28. M. A. Fischl, G. M. Dickinson, and L. LaVoie, "Safety and Efficacy of Sulfamethoxazole and Trimethoprim Chemoprophylaxis for *Pneumocystis Carinii* Pneumonia in AIDS," *Journal of the American Medical Association* 259, no. 8 (1988): 1185-89.