

HIV/AIDS & HOMELESSNESS
**Recommendations for Clinical Practice
and Public Policy**

**Developed for
The Bureau of Primary Health Care and
The HIV/AIDS Bureau
Health Resources and Services Administration
by
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PREFACE

HIV/AIDS and homelessness are twin plagues that take a staggering toll. Each condition complicates the other, and lives hang in the balance as health care providers and their patients try to sort through the complications and assure critical services. This paper is dedicated to the improvement of HIV/AIDS care for homeless people, and to the end of both of these plagues.

In considering HIV/AIDS and homelessness together, this paper explores largely uncharted territory. Its principle author, Dr. John Y. Song, brought to the task his insight from treating HIV-infected people as a volunteer with Health Care for the Homeless, Inc., of Maryland, and writing skills honed in part through his experience as a leader of a homeless writers' group in Baltimore. He also brought a kind and generous heart. We are grateful that Dr. Song chose to devote part of his dual fellowship in General Internal Medicine and in Ethics and Public Policy to this project. The Johns Hopkins School of Medicine and Georgetown University deserve appreciation for the support they provided for his endeavor.

In defining the parameters of the paper, Dr. Song consulted with an HIV/AIDS Advisory Committee of the Health Care for the Homeless Clinicians' Network, whose members also reviewed various drafts as the work progressed. Advisory Committee members are listed in **Appendix IV**. Brenda J. Proffitt, MHA, ably staffed and guided the Committee in her role as Project Director for the HCH Clinicians' Network.

A Symposium on HIV/AIDS and Homelessness — convened by two agencies of the Health Resources Services Administration, the Bureau of Primary Health Care and the HIV/AIDS Bureau — brought together researchers, HIV-infected homeless people, health care providers, HIV/AIDS specialists and homeless advocates to contribute further advice to the project. Many of the recommendations in this paper emerged from that very productive Symposium. Participants are listed in **Appendix V**.

Special thanks is due to Jean L. Hochron, MPH, and Lori S. Marks, BA, of the Bureau of Primary Health Care's Division of Programs for Special Populations, for understanding the need for this publication and for guiding its development. Equally valuable were the support and resources provided by HRSA's HIV/AIDS Bureau staff, particularly Magda L. Barini-Garcia, MD, MPH, and Kim Y. Evans, MHS. Patricia A. Post, MPA, Communications Manager for the National Health Care for the Homeless Council, edited this paper into its final form with remarkable skill. Carlos Velez also provided editorial assistance.

Thank you to all who contributed to the work represented here, and to the many others who struggle against HIV/AIDS and homelessness each day.

John N. Lozier, MSSW
Executive Director
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I.

EXECUTIVE SUMMARY

This document is intended for clinicians and other service providers, health care policy makers and advocates. It was developed by the National Health Care for the Homeless Council in collaboration with the Bureau of Primary Health Care and HIV/AIDS, Health Resources and Services Administration, Department of Health and Human Services, in response to the following concerns:

- **The prevalence of HIV/AIDS is dramatically higher among homeless people than in the general population.**
- **Homelessness and HIV/AIDS are widespread and intersecting problems that occur in both urban and rural populations throughout the United States.**
- **Conditions associated with homelessness make HIV prevention and control especially difficult.**
- **Limited access to medical care severely restricts HIV/AIDS prevention, risk reduction and treatment for homeless persons.**
- **Adherence to complex HIV treatment regimens presents special challenges for homeless patients and their caregivers.**

Of the 400,000 to 600,000 individuals currently estimated to be living with AIDS in the United States (CDC), approximately one-third to one-half are either homeless or at imminent risk of homelessness (Goldfinger, as cited in ACLU). Median prevalence rates of the human immunodeficiency virus (HIV) that causes AIDS have been found to be at least three times higher —3.4% versus under 1% — in homeless populations than in the general population (Allen). Even higher prevalence rates (8.5% – 62%) have been reported in various homeless subpopulations, including adults with severe mental illness (Zolopa; Paris; Susser; Fournier; Torres).

Neither HIV nor homelessness is limited to urban populations. Both problems are widespread, intersecting in rural and urban areas across the United States. Although the prevalence of HIV is likely to be highest in large metropolitan areas, there is evidence that the AIDS case rate is increasing more in non-metropolitan areas (CDC). Among persons known to be at highest risk for HIV infection, including intravenous drug users and persons engaging in high-risk sexual behaviors, those without a stable home are even more likely to be HIV-positive, wherever they may live (Wiebel; Smereck).

Although new medications have reduced the number of HIV cases that progress to full-blown AIDS, antiretroviral therapy is not universally available. Despite their disproportionately high risk for HIV infection and transmission, homeless individuals have limited access to preventive and therapeutic HIV/AIDS care. Moreover, their limited access to comprehensive health care delays the identification of HIV, accelerates the onset of AIDS, and impedes the resolution of behavioral disorders that interfere with HIV risk reduction and treatment. Restricted access to health care is also a contributing factor in the increased prevalence of opportunistic infections and other medical conditions, including tuberculosis, that are more common among homeless people than among other groups.

To address these critical public health issues, access to health care for homeless individuals must be increased through expanded health coverage. Better coordination of care must be achieved among providers of clinical and social services, which must include behavioral health care and housing. In addition, continuity of care must be improved, especially following admission to and discharge from inpatient and criminal justice facilities.

HIV/AIDS Prevention

Preventive measures commonly used in other populations at increased risk for HIV infection are often unavailable to homeless men and women. Although homeless shelters, food kitchens and clinics are ideal settings for primary HIV prevention, insufficient resources limit the health education and risk reduction interventions these organizations can provide.

Nor are HIV testing and counseling generally available to homeless individuals, who experience unique barriers even when these services are available. Travel to clinics for testing or to obtain test results is often difficult for people experiencing homelessness, and mobile testing is not provided with sufficient frequency. Homeless persons testing positive for HIV who seek care are often unable to obtain referrals to HIV/AIDS specialty clinics. Compounding these barriers is the lack of routine screening of homeless individuals for sexually transmitted disease, psychoactive substance abuse and mental illness. Early identification and treatment of these conditions would assist in HIV and AIDS prevention.

A number of strategies shown to reduce HIV risks in the homeless population, including substance abuse treatment, needle exchange programs, safe injection education and the provision of condoms, are not routinely available. Linkages among primary care, HIV treatment and behavioral health services, though effective where they exist, are also limited. Similarly, some clinical and social service providers lack sufficient training to engage homeless clients' active participation in HIV risk reduction.

To address these limitations, policy makers, community planning groups and health care providers must assure that HIV prevention programs are made available to all homeless individuals, and that preventive interventions are culturally, developmentally and linguistically appropriate for the individuals they are intended to influence. In addition, harm reduction initiatives should be adequately funded to reduce known risks of HIV infection for homeless individuals. Finally, treatment for HIV, substance abuse and mental illness should be linked to primary care services and coordinated by experienced homeless providers.

Access to Comprehensive Health Care

Although many Americans have limited access to comprehensive and well-coordinated health care, individuals who experience homelessness are particularly vulnerable to increased morbidity and mortality when excluded from integrated medical and behavioral health services. Among the most significant health care access barriers are lack of health insurance and financial resources, difficulty managing entitlement processes, lack of transportation, and a limited number of culturally and linguistically competent caregivers who are willing and able to serve poor and homeless people. Because subsistence needs take most of their time and energy, most homeless people relegate preventive and primary health care to a lower priority in their lives. Lack of provider flexibility (e.g., office hours limited to times when homeless patients are unable to keep appointments) makes needed care even harder to obtain.

Influenza and other respiratory infections, diabetes, anemia and liver disease are among the conditions that tend to be more serious and complex for homeless individuals, primarily because they do not obtain care early. Lack of adequate food and financial resources exacerbates medical problems. All medical conditions are made more complex by HIV, which disrupts the body's natural response to disease. Thus it is essential for health care providers to screen and treat homeless clients for a wide variety of common medical conditions.

Access to HIV Care

While traditional homeless service providers and other community-based clinics can provide necessary primary care services, they often lack the resources and expertise to provide sufficient HIV care. Homeless individuals who receive health care services from safety net providers may have limited access to HIV testing and specialty care. Restricted access to mental health and addictions treatment can further delay and compromise the efficacy of HIV therapy.

Treatment should be made available for all conditions that impact on HIV care, including other sexually transmitted diseases, hepatitis, substance abuse and mental illness. Goods and resources that make care more effective, such as food, shelter and bathroom facilities, should be provided where necessary as an integral part of HIV care.

Prophylactic antibiotic therapy for opportunistic infections (OIs) is relatively inexpensive and can reduce morbidity and mortality in HIV-infected persons. Treatment of these conditions can also prepare homeless clients to adhere to more complex treatment regimens. Nevertheless, not all homeless people who need OI prophylaxis receive it. Whether clinicians are not offering homeless clients treatment, or whether they are refusing it (or both) is unclear. In any case, clinicians should be persistent and creative in their efforts to make OI prophylaxis available to homeless clients, and encourage adherence to antibiotic therapy.

Antiretroviral Therapy

During the last several years, biomedical research has produced a variety of antiretroviral therapeutic agents that have proven effective in suppressing HIV in infected persons. Tests used to measure HIV progression have also improved substantially with the calculation of HIV viral loads in blood plasma. The level of HIV in the blood can be seen as a predictor of disease progression. Combinations of various antiretroviral agents, when taken as prescribed, can reduce viral loads to undetectable levels in relatively short periods of time.

To be successful, antiretroviral therapy requires diligent patient adherence to complicated treatment regimens. Patients may have to take more than twenty pills in several doses daily, following strict dietary instructions. In addition, some individuals experience severe side effects. Antiretroviral therapy does not work for everyone, especially for individuals who do not take their medications as prescribed. They risk treatment failure and the development of drug resistance. When a particular treatment fails, the patient may not be able to resume it, as the medication may no longer be effective in suppressing the virus in that individual. In some instances, failure of a particular medication may mean that other medications are not effective either, due to a phenomenon called cross-resistance.

Prescribing antiretroviral therapy requires a detailed assessment of the individual's health status and lifestyle to assure that medications can be taken as prescribed, with adjustments in therapy where possible to maximize adherence. Especially promising for some individuals are simpler protease-sparing treatment regimens that achieve viral suppression while reducing the risk of drug resistance. An individual's viral load must be monitored closely in case it does not respond to treatment or rebounds after decreasing initially. If a patient fails a particular drug combination, other combinations may be prescribed.

Because antiretroviral therapy is expensive, it is not always available to individuals who are poor and homeless. Although antiretroviral medications are becoming more affordable through government programs and charitable sources, not all homeless individuals have access to them or to clinicians who are familiar with antiretroviral therapy. Additional steps should be taken to make antiretroviral therapy more accessible to homeless persons and to provide them and their clinical providers with the education and resources needed to make treatment successful.

Adherence

It is generally believed that failure of antiretroviral therapy is most often due to lack of patient adherence to the prescribed treatment regimen. Prior to prescribing antiretroviral medications, physicians determine whether a particular individual can or will adhere to the therapy. Many homeless persons are excluded from treatment because they lack stability, housing, regular access to food, water and other resources needed to ensure adherence to antiretroviral therapy. In addition, substance abuse disorders, which affect significant numbers of homeless individuals, are generally considered to be grounds for withholding antiretroviral therapy because they can undermine patients' capacity to adhere reliably to any treatment regimen.

Nevertheless, there are no absolute contraindications to antiretroviral therapy. While it is important to prescribe complex treatment regimens, where appropriate, to individuals who can adhere to them, it is also essential to assist others to obtain the most effective alternative treatment available. Clinicians and service providers should make an in-depth assessment of the impediments their patients may face in adhering to therapy. Rather than using the assessment as a basis for denial of treatment, physicians should respond to identified barriers by working with their patients to overcome them or prescribe regimens that are easier to follow. Where possible, clinicians should prescribe medications that can suppress HIV in simple combinations — a rational strategy for all patients, whether or not they have stable housing.

Patient adherence can also be facilitated through co-management of care by clinicians, non-clinical service providers and other individuals who are in regular contact with homeless individuals. With the exception of some case managers, non-clinical service providers tend to be poorly informed about antiretroviral therapy. It is essential, therefore, that all homeless service providers obtain basic information about antiretroviral therapy, including how it works and how to manage side effects. In this way, a variety of trained service providers and support personnel can assist homeless patients in maintaining appropriate adherence to HIV treatment.

Research

The research literature on HIV/AIDS and homelessness, though sparse, clearly identifies barriers to prevention, health care access and treatment faced by homeless people living with HIV, and points to a number of areas where more investigation is needed. More targeted studies employing standardized methodologies are needed to form a scientific basis for the development of successful HIV/AIDS prevention and treatment strategies for people who lack stable housing.

Such research is warranted by the preliminary evidence, reported here, that HIV/AIDS has a disproportionate effect on particular homeless subpopulations, and that HIV-infected, housed persons are at increased risk of becoming homeless. Failure to measure the scope of HIV/AIDS within the homeless population and to develop effective prevention and treatment strategies is likely to exacerbate the serious public health problem which the human immunodeficiency virus and its devastating sequelae already present.

Epidemiological studies are needed to better characterize the extent of HIV/AIDS among homeless people and the extent of homelessness among persons with HIV/AIDS. These include focused studies on homeless subpopulations for whom HIV prevention and care are known to be especially problematic —e.g., rural populations, homeless women and transgendered individuals. Behavioral research is required to develop successful strategies for decreasing HIV transmission among homeless persons, and to identify individual characteristics that may increase treatment adherence.

Clinical research is needed to measure the impact of co-morbidities and nutritional deficiencies on HIV/AIDS progression, to quantify immunization rates and determine outcomes of antiretroviral therapy in the homeless population. Finally, policy research is needed to document the impact of health coverage on HIV-infected homeless persons' health and access to care, and to develop strategies to increase access to comprehensive health care for all homeless people.

II.

INTRODUCTION

L. T. started antiretroviral medications in 1997, taking them for six months with diligence. During that time, he was housed in a single residence hotel. When he became homeless again, however, he told me that he knew that he would not be able to take his medications as prescribed, and he did not want to take them for fear of resistance. For the last year, L. T. has been homeless and not taking medication. His CD4 count fell to 250 and his viral load climbed to over 300,000. He is aware that he may be in trouble medically.

– Barry Zevin, M.D., San Francisco

Between 1981 and 1999, the United States Public Health Service reported 688,200 cases of acquired immunodeficiency syndrome (AIDS). Currently, 400,000 – 600,000 U.S. residents are estimated to be living with the human immunodeficiency virus (HIV) that causes AIDS, and about 40,000 new cases of HIV are reported each year (CDC). An estimated one-third to one-half of people living with AIDS in the United States are either homeless or at imminent risk of homelessness (Goldfinger, as cited in ACLU).

A large, multi-site housing needs assessment survey found that 41% of respondents with HIV/AIDS had been homeless sometime in their lives (Lieberman), and local needs assessments from Los Angeles and Philadelphia portray similar housing instability among those with HIV/AIDS (Low; Aquaviva). Given that homeless people in general are less likely to be counted (Link) and are less likely to be tested for HIV than housed individuals (Rockwell), these figures probably underestimate the scope of the problem.

The prevalence of HIV infection in homeless populations studied is at least three times higher than in the general population. A multi-site study tracking the spread of HIV in 16 U.S. cities between 1989 and 1992 reported a median HIV seroprevalence of 3.4% among homeless adults, compared to less than 1% in the general population (Allen). Local studies conducted during the 1990s in urban areas with high HIV prevalence rates have reported even higher rates of HIV infection in homeless subgroups, ranging from 8.5% to 62% (Zolopa; Paris; Susser; Fournier; Torres). Although the range is broad because of different study protocols, locales, subpopulations and definitions of homelessness, these figures are significantly higher than the estimated prevalence in the general population.

Among persons known to be at highest risk for HIV infection — intravenous drug users and persons engaging in high-risk sexual behaviors — those who do not have a stable home are even more likely to be HIV-positive (Wiebel; Smereck). A 1995 study found that 69% of homeless adults surveyed were at risk for HIV infection from unprotected sex with multiple partners, injection drug use (IDU), sex with IDU partners, or exchanging unprotected sex for money or drugs (St. Lawrence; ACLU). Homeless persons with severe mental illness and/or chemical dependencies are especially vulnerable to the disease because of their impaired capacity to learn and practice risk reduction behaviors (Susser).

Homeless people have alarmingly high HIV infection rates for a variety of reasons, including engagement in high-risk behaviors and the lack of resources to prevent HIV transmission. For those already infected, HIV antiretroviral therapy (ART) is often delayed or never begun. Even when initiated, treatment regimens are so complex that they pose adherence difficulties that may result in the development of drug-resistant strains of the virus. Lack of health insurance, transportation,

housing and other subsistence needs make health care extremely difficult for homeless individuals to obtain, resulting in poorer health and diminished capacity to resolve problems that led to their homelessness in the first place. When these problems are compounded by HIV/AIDS, they are beyond the capacity of homeless individuals to solve alone.

In response to these issues, the National Health Care for the Homeless Council initiated a project in 1998 to gather more detailed information about HIV and homelessness in the United States. Intermediate goals were to explore problems encountered by clinicians serving homeless people who are engaged in HIV prevention and treatment, and to derive from their experience recommendations for clinical practice and public policy. The ultimate goal of this project is to improve HIV prevention and care for all people who are homeless.

John Song, M.D., M.P.H., M.A.T., volunteered to spearhead this effort while completing dual fellowships in General Internal Medicine at The Johns Hopkins University School of Medicine, Baltimore, Maryland, and in Ethics and Public Policy at Georgetown University, Washington, DC. Dr. Song conducted a comprehensive literature review, interviewed HIV specialists and other clinicians experienced in treating homeless persons with HIV/AIDS, and conducted a survey of homeless service providers through the Health Care for the Homeless Clinicians' Network. On March 19–20, 1999, the Bureaus of Primary Health Care and HIV/AIDS of the Health Resources and Services Administration hosted a symposium to discuss HIV/AIDS and Homelessness, involving HIV-infected homeless people, health care providers, researchers, advocates and policy makers. Dr. Song summarized these discussions and information gathered from other sources to develop this document, in collaboration with the National Health Care for the Homeless Council.

The document is intended for clinicians and other service providers, policy makers and advocates, and contains information that should help all of these parties to better understand and address a variety of issues faced by persons living with HIV. The document explores current practices of clinicians who provide HIV care to homeless patients, including factors they should take into account when prescribing highly active antiretroviral therapy (HAART). It also identifies deterrents to HIV/AIDS prevention and optimal care for homeless individuals, and suggests directions for further discussions among clinicians and policy makers to help overcome these barriers.

III.

HIV PREVENTION

S. A. was 21 years old when I met her in March 1997. She was brought to our urgent care clinic by an outreach worker who told me that S. A. only spoke Spanish and was recently released from jail for prostitution. She was at the time in one of the city shelters, where our medical and social services staff had established a satellite clinic. S.A. is a transgender male to female, who tested HIV-positive a year before. She was rejected by her family in Mexico and came to the U. S. two years ago with a boyfriend. Shortly after arriving in the States, S. A. was alone and depending on sex work for an income. She had multiple sexual encounters without protection, at her clients' requests. She was smoking methamphetamines and using injectable estrogens as frequently as she could to keep her feminine characteristics.

— *Linette Martinez, M.D., San Francisco*

A. Background

Homeless individuals engage in behaviors that place them at high risk for HIV infection, and do so at alarming rates. These behaviors include injection drug use (Rekart; Erickson; Lieberman), high-risk sexual behavior (Johnson; Hudson; Kouzi), needle-sharing (Williams; Rekart; Beardsley; Bluthenthal), shooting gallery use (Celentano; Beardsley), and exchange of sex for money or drugs (Schilling; Corby). High-risk behaviors are motivated by the need to subsist on the streets, by co-occurring mental illness and substance abuse, and by a peer culture that encourages these behaviors.

Data regarding the prevalence of addictive disorders among homeless people are varied. Studies conducted in the 1980s, from which high prevalence rates are often quoted, over-represented long-term shelter users and single males, among whom rates of substance abuse are known to be especially high. Moreover, these studies reported lifetime substance use rather than current addiction (NCH). It is estimated that the prevalence of drug use among homeless people is 30–40% (Koegel), although some studies have demonstrated even higher proportions (Susser; Spinner; Robertson).

Substance Abuse Treatment

Although there are no generally accepted prevalence rates that accurately describe the proportion of all homeless adults engaging in substance abuse, addictions are generally acknowledged to be more prevalent in homeless than in domiciled populations. Nevertheless, treatment for substance abuse and dependence is not usually available to homeless men and women, who are sometimes denied treatment because they are homeless. Active substance abuse is associated with lack of access to HIV care and poor adherence to antiretroviral therapy (Samet; Eldred; Ohmit).

In a study conducted by the HCH Clinicians' Network, 78% of homeless health care providers surveyed found it difficult to obtain substance abuse treatment for their HIV/AIDS patients (HCHCN). Other studies found that less than half of homeless individuals in need of addiction treatment obtained it (NCH), and that patients were excluded from treatment because they were homeless (Oakley). Although estimates of the prevalence of alcohol and other drug use among homeless individuals vary, alcohol use and alcohol use disorder are acknowledged to be more common among homeless than domiciled individuals (Robertson; Susser; Breakey; Wright).

Mental Health Care

High-risk behaviors are practiced regardless of a co-occurring mental illness (Valencia; Susser; Goldfinger; Fischer), but mental illness is both an impetus and a consequence of substance abuse in many homeless people, and can exacerbate high-risk behavior. Mental illness also complicates HIV prevention and care (Ferrando; Singh; Chesney). Like addiction treatment, mental health services for homeless people are often inadequate (Oakley). The HCHCN survey found that 69% of providers had difficulty obtaining mental health services for their homeless patients.

Targeted Prevention

Homeless men and women engage in the exchange of sex for money or drugs, but lack the resources to engage in safer sexual or other practices. Homeless women with children may place themselves at increased risk for HIV transmission in response to the economic pressure of having to provide for their families with few marketable skills. Individuals identified as homeless are more likely to engage in high-risk behavior during periods of homelessness compared to periods of relative stability (Celenzano).

Few prevention programs are designed for people without stable housing, and studies demonstrate that existing risk reduction interventions may not be as effective for homeless individuals as for their domiciled counterparts (Clatts; Abdul-Quader). Nevertheless, successful risk reduction has been demonstrated in homeless populations as a result of targeted prevention programs (Nyamathi; Susser; Goulart).

Harm Reduction

Harm reduction refers to activities that are designed to reduce or minimize the damage caused by high-risk behaviors such as injection drug use and prostitution (McMurray-Avila), with the ultimate goal of eliminating these behaviors. Essential to the process of harm reduction is engagement, with the realization that elimination of high-risk behavior may take time and small steps. Harm reduction techniques include needle exchange programs, safe injection education (such as sterilizing needles with bleach), safer sex negotiation, and relapse policies which recognize that treatment success is often preceded by multiple episodes of failure.

B. Recommendations

Clinical Recommendations

HIV prevention and risk reduction should be an integral part of any program serving homeless people. To be successful, prevention initiatives should include the following elements:

- **Provider training.** All service providers who work with homeless people on a regular basis, both clinical and non-clinical, should be trained in HIV prevention.
- **Engagement.** Primary care providers should inquire tactfully but persistently about high-risk behaviors as a routine part of clinical assessments. Clinicians should provide HIV prevention and risk reduction information and resources to their homeless clients, and should actively engage them in preventing risky behaviors.
- **Cultural sensitivity.** Information about HIV prevention and risk reduction should be culturally

and linguistically appropriate for the people expected to benefit from it. More educational materials targeted to particular homeless populations should be developed and made available.

- **Outreach.** Street-based outreach is needed to convey HIV prevention information and resources to unsheltered homeless persons. Targeted outreach to special populations — women, transgendered individuals, persons with chemical dependencies and rural populations — is particularly needed. Prevention strategies should include providing access to condoms and clean needles. Outreach services must be linked to HIV counseling and testing and to primary care services.
- **Multidisciplinary linkages.** Because many homeless people have multiple and complex health conditions that heighten their risk for HIV infection, risk reduction interventions should involve clinicians from multiple disciplines. All programs serving homeless individuals should establish linkages with and provide referrals for primary care, substance abuse treatment and mental health services.
- **HIV screening and testing.** Access to HIV screening and provision of HIV prevention information in shelters and mobile units are essential parts of risk reduction. Incentives should be provided to encourage patients to return for test results. Testing and treatment for sexually transmitted diseases should also be provided, when necessary.
- **Substance abuse treatment.** Substance abuse treatment providers should assess their clients' living conditions prior to beginning and concluding treatment. Homeless individuals should be given priority for in-patient addiction treatment and for referrals to support services including transitional housing following discharge.
- **Harm reduction.** Harm reduction should be an integral component of HIV prevention. Health care and other service providers should be trained in introducing and advocating harm reduction techniques. Substance abuse treatment programs should adopt relapse policies that incorporate the concept of harm reduction.

Public Policy Recommendations

Support is needed for the following targeted HIV prevention activities:

- **Housing.** Better linkages should be established among housing programs, health departments, HIV prevention programs and health care providers. Housing for homeless people should be funded as a preventive health measure.
- **Community planning groups.** State and local HIV Prevention Community Planning Groups should place a high priority on the needs of homeless persons.
- **Harm reduction.** Interventions designed to reduce HIV transmission risks for injection drug users, especially needle exchange programs, should be adequately funded to provide clean needles, syringes and substance abuse treatment.
- **Mental and behavioral health care.** Funding should be increased to provide more on-demand substance abuse and mental health treatment.

IV.

ACCESS TO CARE

Larry is a 52-year-old black man who was first seen in the Homeless Health Care Center on May 17, 1988. At the time, he was sleeping on the street and in shelters. During 1988, he had eight clinic visits, mainly to treat multiple episodes of tracheobronchitis and to monitor his blood pressure. On April 5, 1990, he left the clinic without being seen. During the next two years, Larry visited intermittently. His use of alcohol and crack was heavy during this time. On August 2, 1994, he returned to the clinic with a laceration under his right eye; he also informed the staff that he had been HIV-positive since May. Labs were ordered, but Larry left without having his blood drawn. He was referred to a caseworker, but he also left without seeing the caseworker. In September, he finally came back to have his blood drawn; his CD4 count at the time was 480. He was not seen until August 1997. He had been receiving care at the VA, and brought in his medications — AZT, Epivir, Phenergan, and Desipramine. The prescriptions were filled.

— Ardyce Ridolfo, MSN, FNP, RNC, Chattanooga, TN

A. Background

Barriers to Health Care

Homeless men and women face a host of barriers to health care, including lack of awareness of services and resources, suspicion of health care institutions, lack of insurance, competing subsistence needs, transportation difficulties, lack of comprehensive services and poor provider attitudes (McMurray-Avila; Gallagher; Gelberg; Woods; Brickner). As a result, many homeless people have no regular source of health care, and fail to seek or obtain medical attention even for known medical conditions. Moreover, despite having more serious and complex health conditions than poor people who are housed, homeless individuals have demonstrably less access to health care.

- A study of homeless individuals in Los Angeles found that 66% had no medical insurance, 56% had no regular source of care, and study participants had, on average, 2.9 physician contacts in a year. These figures are contrasted to a national poverty sample of housed people which reports 36% without insurance, 24% without a regular source of care, and 6.3 physician contacts a year (Gallagher).
- Another study from Los Angeles reported that 14% of homeless respondents had never sought medical attention for a known medical condition and only 51% with a known medical condition had sought medical attention in the previous year (Roper). Only 47% of homeless men and 30% of homeless women in Baltimore could name a usual source of care (Breakey).

Access barriers are exacerbated for homeless individuals living with HIV/AIDS, which is associated with poorer health care access than other chronic conditions (Cunningham). The HIV Costs and Services Utilization Survey (HCSUS) found that large proportions of people living with HIV who needed medical care did not receive it because of competing subsistence needs such as food, housing, or transportation (Cunningham).

- In one study, HIV-positive individuals who were homeless had fewer ambulatory visits than those who had homes (Arno). In a New York City shelter with a 62% HIV seroprevalence rate, only 10% of homeless clients requested medical help (Torres). Similarly, the Boston Health Study found that homeless people with AIDS had three times more difficulty accessing care than did housed people with AIDS because of unmet needs (Weissman).
- The Health Care for the Homeless Clinicians' Network (HCHCN) found that primary care clinicians experience difficulty obtaining various kinds of health care for large percentages of their homeless HIV/AIDS patients: general non-HIV/AIDS care (58%), subspecialty care (73%), respite care (57%) and case management (48%).

Several factors affect HIV-infected homeless persons' health and access to health care:

- **Housing.** An essential element of successful HIV/AIDS care is housing, which provides a place to store medication and food, a stable water supply, bathroom facilities, a secure place to rest, a dependable contact location, protection from harm, emotional security and hope. The lack of safe and stable housing has a significant negative impact on the health of homeless people with HIV/AIDS (Lieberman; Low; Song). A study from Los Angeles found that 50% of housed individuals with HIV/AIDS felt they were at high risk of becoming homeless (Low). An evaluation in Philadelphia found 44% of persons with HIV/AIDS living in residences they were unable to afford, a significant risk factor for subsequent homelessness (Acquaviva).
- **Health insurance.** Lack of health coverage is associated with lower access to HIV/AIDS care (Cunningham; Hecht). The HIV Costs and Services Utilization Survey revealed that only 15.6% of homeless individuals with HIV/AIDS had any kind of medical insurance (Arno). This problem is becoming more acute; homeless clinics nationally reported a 35% increase in the number of clients who were uninsured between 1996 and 1997 (O'Connell).
- **Entitlements.** Although homeless individuals with an AIDS diagnosis may obtain Medicaid disability coverage, an HIV diagnosis alone does not trigger either Medicaid eligibility or coverage of HIV care in many states. This distinction between HIV and AIDS impedes early aggressive care, which is essential for treatment success.
- **Transportation.** Fragmentation of services is a significant access barrier. Clients must often travel to several different locations to obtain necessary care and services. Many clients do not have financial resources to pay even minimal transportation costs.
- **Racial and ethnic background.** Most studies on homeless populations with HIV/AIDS have been conducted predominantly among African-Americans (Zolopa; Fournier; Lebow; Allen) who have been shown to have less access to HIV care than white Americans (Pfeffer; Solomon; Stone; Easterbrook).
- **Confidentiality.** HIV/AIDS remains a stigma. Because HIV-infected homeless people are often shunned even by shelter staff and other homeless people, they do not want others to know they are receiving HIV/AIDS care (ACLU). Respecting confidentiality and advocating for patient rights under the Americans with Disabilities Act, if necessary, are essential to an ongoing clinical relationship with these clients.
- **Compassion.** Clients often feel isolated and distrustful of institutions. Providers and clinicians are not always compassionate in their care and may not pay attention to the special needs of homeless individuals. Empathy and compassion are necessary for successful engagement and treatment, particularly when caring for a population that has been traditionally marginalized.
- **Incarceration.** Many criminal justice facilities provide substandard or inadequate HIV care or

none at all. Because inmates cannot use outside care facilities, they may be excluded from HIV care altogether.

- **Special populations.** Women, homeless people in non-metropolitan statistical areas (MSAs), undocumented immigrants and transgendered individuals experience even greater barriers in obtaining health care than do other homeless people with HIV/AIDS. Family responsibilities often prevent women without stable housing from seeking care for themselves. Homeless people in small towns and rural areas have fewer available health facilities, and must travel greater distances to obtain care. Undocumented immigrants experience legal, health coverage and language barriers to health care, and transgendered individuals are less likely to seek services because of fear of discrimination and violence.

HIV Counseling and Testing

Homeless people do not have sufficient access to HIV testing. A large study of injection drug users in New York City found that only 45% of homeless participants had ever been tested for HIV, compared to 58% of housed participants (Rockwell). A shelter-based study in New York City reporting an HIV seroprevalence of 62% found that only 18% of participants had ever received an HIV test (Torres); and in San Francisco, investigators found that only 25% of homeless individuals living with HIV had ever been tested before the study began (Zolopa). Rates of return to obtain HIV test results are also poor, with a 66% return rate reported in Atlanta (Paris) and 70% in New York City (Torres). A study in New Haven, Connecticut, found that only 23% of homeless people ever tested knew their HIV status (Barry).

Eligibility for public assistance, such as Medicaid, is one incentive for homeless individuals to ascertain their HIV status. Another is learning that chances for successful treatment increase with early diagnosis. There are, however, legitimate reasons why some patients refuse an HIV test or fail to return for test results, despite the availability of new treatments — including the debilitating psychological burden of a positive diagnosis (O’Connell) and fear of discrimination (Gostin; Harvey; Torres).

Continuity of Care

Even if available, health care services may not be fully accessible to homeless individuals, many of whom lack the transportation necessary to travel to various sites where care and services are available. Care facilities may also lack some of the basic necessities that many individuals take for granted, such as public bathrooms, accessible food and water, and linkages to housing. Finally, clinic personnel may not be familiar with the needs of homeless persons. Overworked doctors and nurses in many public health facilities may not have sufficient time to question homeless patients about problems they may be having that affect their health care, or to offer these patients the emotional and logistical support they need. Moreover, some clinicians may not be able to hire adequate numbers of full-time support staff, depending instead on rotating part-time or voluntary providers.

Not all persons who receive care are able to continue to obtain needed services. Health care may be discontinued when individuals lose or change health coverage, when they are incarcerated or when eligibility requirements for public assistance programs change. Disruptions in HIV care can also be caused by inadequate transportation, competing subsistence needs, lack of institutional capacity, admittance to and discharge from inpatient facilities and jails, migration, loss of housing and changes in employment.

Many homeless people receive primary care at facilities with inadequate links to inpatient care. Providers may be unaware of changes in patient health, housing or insurance status. Unaware of HIV/AIDS patients' housing instability or unresponsive to their need for transitional housing, hospitals may discharge individuals directly onto the street without follow-up care. Unless health care providers are able to address the many barriers that homeless individuals face in obtaining and maintaining health care, homeless men and women will not receive the long-term care that is required for HIV treatment.

People without stable housing have less success in keeping referral appointments (Schlossstein), have poor follow-up for HIV tests (Torres; Barry; Paris) and lack usual sources of care (Gallagher; Breakey). There is evidence, however, that health care can be successfully provided to HIV-infected homeless persons. The Boston Health Care for the Homeless Program found that homeless people with HIV were not presenting to a clinic at significantly later stages of the disease than others, and that those with a primary care provider made an average of 14.1 visits over a 17 month period (Lebow). Other encouraging results from an observational study of care in San Francisco revealed that 72% of homeless persons with HIV/AIDS could name their primary care provider and 92% were still enrolled after two years (Bangsberg).

Appropriate and proficient care

Patients experience better health outcomes when their health care providers have extensive HIV/AIDS expertise (Kitahata). Unfortunately, expert HIV care is not generally available to patients who are homeless. Homeless individuals may have access only to clinicians and other service providers who are not trained in HIV/AIDS care. Few non-clinical service providers have accurate knowledge about HIV/AIDS or the special needs of clients who are undergoing treatment for the disease (ACLU).

The effectiveness of care for homeless individuals with HIV is also influenced by their health care providers' level of proficiency in both HIV/AIDS care and homeless care. Because a significant and growing number of people are infected with HIV and are either homeless or at risk of homelessness, providers require dual proficiencies. Cross-training of providers in both HIV/AIDS care and the care of homeless people is necessary to meet the needs of the expanding homeless and HIV-positive population.

The appropriate training and specialization of providers who practice primary HIV/AIDS care has been a national concern. Even when homeless people have access to specialty HIV clinics, they continue to seek care at homeless primary care clinics because of their familiarity and convenience. Therefore, homeless providers will always need to be proficient in the primary care of HIV-infected individuals.

Homeless people with HIV/AIDS often work with service providers other than clinicians. With the exception of HIV/AIDS case managers, very few of these personnel have sufficient knowledge of HIV/AIDS care. Individuals who manage shelters and control access to medications, food and water often lack basic understanding of antiretroviral therapy, including the timing of medications, food and water requirements, and the need for strict adherence to treatment regimen.

B. Recommendations

Clinical Recommendations

1. **Initial assessment.** Intake interviews for homeless men and women should include a housing assessment. During the initial visit, providers should assess the health care access barriers each patient may face, including:
 - Knowledge, attitudes and past experiences with health care and health care providers;
 - Financial, employment, housing, and insurance status;
 - Subsistence needs (food, water, shelter, etc.);
 - Transportation requirements;
 - Need for treatment of mental illness and/or active substance abuse; and
 - Caregiver status and family responsibilities.Providers should be alert to additional access barriers faced by homeless women, racial and ethnic minorities, undocumented immigrants, migrant farm workers, rural populations, parolees, homosexuals and transgendered individuals, including fear of violence and discrimination.
2. **Individualized care plan.** Clinicians and case managers should develop individualized care plans for their patients, addressing the special needs of homeless persons identified during and after the initial assessment. An example might be making arrangements with local public transportation authorities to accommodate patients unable to walk to clinic appointments and seeking funding for travel support, where needed.
3. **On-site services.** All services required by HIV/AIDS patients should optimally be available at the same location.
4. **Provider education.** To serve the growing population of HIV-infected homeless people, clinicians must develop dual proficiencies in HIV/AIDS care and homeless care. All service providers who work with homeless individuals should be educated about basic HIV/AIDS care principles and practice. These workers include:
 - Physicians, nurses and other medical providers;
 - Mental health and substance abuse counselors;
 - Case workers and managers;
 - Peer counselors and outreach workers; and
 - Shelter and soup kitchen personnel.Similarly, HIV specialists should be educated about the special access barriers, co-occurring disorders and non-medical needs of homeless clients.
5. **Continuity of care.** Better discharge planning from hospitals and criminal justice facilities is badly needed to promote continuity of care for homeless HIV/AIDS patients. Properly designed, centralized data systems may help to make this possible. Providers should anticipate and attempt to minimize potential disruptions in patient care caused by:
 - Changes in insurance benefit or eligibility status, including loss of Medicaid;
 - Instability and loss of housing;
 - Fluctuations in subsistence needs and access to transportation;
 - Admittance to and discharge from inpatient facilities;
 - Incarceration and release from criminal justice facilities;
 - Seasonal changes;

- Migration and transience; and
 - Change in caregiver or head of household status.
6. **Interdisciplinary and interagency linkages.** Health care providers should establish linkages to non-clinical service providers to prevent disruptions in care. Primary care providers and HIV/AIDS specialists should develop collaborative relationships to ensure quality of care, including basic HIV/AIDS care and practice.
 7. **Provider flexibility.** HIV/AIDS caregivers should establish flexible hours to accommodate homeless persons and to facilitate care for shelter dwellers who may have curfews.
 8. **Patient confidentiality.** In all health care and service delivery settings, patient confidentiality should be a priority; patients should be reassured that their privacy is being protected by individuals and institutions.
 9. **Compassionate care.** Providers should empathize with their patients through becoming better informed about the difficulties they face, and should take steps to remove health care access barriers and to prevent and address homelessness.
 10. **Homelessness prevention.** Linkages to housing assistance programs such as Housing Opportunities for People with AIDS and eviction prevention education should be an integral part of HIV/AIDS programs. In addition, better discharge planning from hospitals and criminal justice facilities is necessary to prevent homelessness from occurring.

Public Policy Recommendations

1. **Outreach and HIV testing.** More public and private funding is needed for HIV outreach and testing programs for homeless people.
2. **Health coverage.** Medicaid coverage should be expanded to include anyone infected with HIV disease, regardless of the existence of clinical manifestations. Ryan White CARE Act (RWCA) funding and third-party payers should provide reimbursement for necessary goods and services, including some not routinely covered (e.g., substance abuse treatment). The AIDS Drug Assistance Program (ADAP, part of RWCA) coverage should continue during incarceration, migration or transience.
3. **SAMHSA block grants.** States that receive substance abuse and mental health block grant resources should demonstrate that they allocate money to the care of homeless people living with HIV/AIDS.
4. **Coordination of public housing services.** Greater coordination is needed among government agencies providing housing and HIV/AIDS services, including the Department of Housing and Urban Development and the Department of Health and Human Services' Health Resources and Services Administration.
5. **Local health departments.** Because shelters, drop-in facilities and food lines are ideal sites for health interventions, local health departments should help to fund, maintain and increase their involvement in these services. Local health departments should employ individuals with expertise in homeless health care and increase their support of homeless service providers.

6. **Interagency Council on the Homeless.** The Interagency Council on the Homeless should direct more attention to problems associated with HIV/AIDS and enhance necessary linkages among other agencies.
7. **Criminal justice.** Jails and prisons should ensure that HIV/AIDS care continues uninterrupted during incarceration, and that appropriate discharge planning is completed for former prisoners with unstable housing arrangements.
8. **Support for provider training.** The educational activities of the Bureau of Primary Health Care and the HIV/AIDS Bureau should be expanded to include more HIV/AIDS and homelessness training for health center providers and staff as well as other service providers.

V.

GENERAL HIV CARE

I met Mr. R. in the homeless shelter around 1994. He had been a resident of multiple homeless shelters in the city as well as up and down the state of California for the past four years. A non-smoker and non-drinker, Mr. R was generally in good health until August 1990. At that time, he was residing in the Episcopal Sanctuary Shelter, where he was treated for a fever and cough for six weeks before being admitted to San Francisco General Hospital. I was doing outreach at the shelter, and found him in his bed with a fever of 103°F. I took him to the emergency room and stayed with him until he was admitted. Mr. R. was hospitalized for two days. He had an unremarkable work-up. However, his HIV test returned positive. Previously, he had mentioned that he had had a negative HIV test, but it turned out that he had end-stage AIDS. Perhaps he was in denial. His initial CD4 count was 8, and his viral load was 300,000. His fever turned out to be secondary to cryptococcal meningitis and pneumonia.

— Chuck Marion, M.D., San Francisco

D. W. is a 30-year-old female I first met in our urgent care clinic in August 1997. She insisted that she wanted to start antiretroviral treatment. At that time, she was housed via the AIDS Foundation and accompanied to the clinic by her HIV-negative boyfriend T. R., who seemed very supportive. She admitted to crack use, but said that both she and T. R. had been clean and sober for two weeks. On July 22, her viral load had been greater than 800,000 and her CD4 count was 187. On this first visit, I did something I probably would not do now: I wrote a prescription for Zerit, Epivir and Virecept. We discussed the necessity of adherence and possible side effects. For some reason, I sensed that D. W. was committed to sticking with therapy. ...As of October 29, her viral load was undetectable and her CD4 count 446. During much of 1998, D.W. received care at BAPAC, the Bay Area clinic for HIV-positive prenatal care. In June 1998, D. W. delivered a healthy HIV-negative baby girl; D. W. and the baby received peripartum AZT...I did not see D. W. again until September 14, when she came to urgent care with pharyngitis. She was using crack cocaine again. As of September 30, she was off ART with a CD4 count of 350 and an HIV viral load of 40,000.

— Alisa Oberschelp, M.D., San Francisco

A. Background

The treatment of homeless individuals with HIV/AIDS must include vigilant control of associated medical conditions that may complicate HIV care and cause health to deteriorate. Homeless people with HIV/AIDS are particularly susceptible to a number of other medical conditions which, untreated, may exacerbate their illness and even threaten their survival. Crowded, unsanitary living conditions increase their risk of exposure to communicable diseases and parasites. Limited resources result in unmet subsistence needs, reducing their natural resistance to disease. Their vulnerability is compounded by the gradual destruction of their immune system by HIV. Limited access to routine health care, described in the previous section, may increase the severity of medical conditions through delayed treatment.

Respiratory infections (Weinreb; Brickner) and infestations are especially common (Brickner; Wright; Gillis). One study found that 14% of homeless adults had suffered from influenza the previous year (Marwick). The prevalence of tuberculosis is higher among homeless people than in the

general population (Brickner), and higher still in homeless people whose immune systems are compromised by HIV/AIDS (Zolopa; Torres; Saez; Gollub; Gordin). Infestations such as scabies and fleabites tend to be much more florid in people with HIV/AIDS, and some conventional treatments are ineffective in those with advanced disease (Berger).

Other prevalent conditions in the homeless population include diabetes (White), hypercholesterolemia (Gelberg), anemia (Breakey) and chronic gastrointestinal tract illnesses (Weinreb; Wright). Homeless persons also have high rates of liver disease, most often secondary to viral infection or alcoholism (Wright). Neurologic disorders are also more frequent; one study revealed that homeless people were six times more likely than housed persons to suffer from neurologic conditions (Wright). Less well documented medical conditions include soft tissue infections and peripheral neuropathies.

Poor caloric intake, malnutrition (Gelberg; Weinreb; Wright; Wiecha) and consequent loss of muscle mass, common among homeless people, are associated with increased AIDS morbidity and mortality (Schambelen). As little as 5% loss of muscle mass over four months is associated with an increased risk of opportunistic infections and death (Wheeler).

The following studies document conditions that are more common among homeless persons living with HIV/AIDS:

- A study from San Francisco reported 8.5 times greater likelihood of infection with *Bartonella quintana*, the bacterium that causes bacillary angiomatosis-peliosis (Koehler).
- Researchers in Boston found differences in AIDS-defining diagnoses, including esophageal candidiasis (17% vs. 9%) and disseminated TB (9% vs. 2%) (Lebow).
- A study from New York found higher rates of bacterial pneumonia in HIV-infected persons (Torres).
- A study in New York City reported 21% of HIV/AIDS patients with syphilis and 43% having antibodies to hepatitis B (Torres).
- A study from Baltimore not limited to HIV/AIDS found hepatitis B seroprevalence to be 45% among homeless people (Osher); another revealed that 37% of homeless injection drug users were hepatitis C (HCV)-seropositive (Garfein).

In addition to other concerns about substance abuse, medication interactions and painful HIV-related neuropathies may require the prescription of narcotics to HIV-infected individuals with a history of substance abuse. Homeless persons may sell these prescribed medications on the street, where there is an active market for over-the-counter and prescription drugs.

Immunizations and Testing

Immunizations are critical for persons living with HIV/AIDS, whose immune systems lose the capacity to fight disease. Vaccinations for influenza, pneumococcal infection and hepatitis A are absolutely essential because of frequent outbreaks of these conditions among shelter dwellers and high rates of hepatitis C in the homeless population. Homeless people have not demonstrated poorer rates of completing hepatitis B vaccination regimens and should receive this precautionary measure. Co-infection with hepatitis C — which occurs in approximately 40% of all HIV-positive individuals — can hasten full-blown AIDS and death. Although no vaccine is currently available to prevent hepatitis C, HCV testing and antiviral therapy are recommended by some clinicians, in addition to hepatitis A and B immunizations, to reduce morbidity and mortality in persons co-infected with

HIV (Dietrich).

In a Boston study, only 56% of homeless patients with HIV/AIDS had received a pneumococcal or influenza vaccination and only 36% had received testing for syphilis; 46% had received PPD testing for tuberculosis; 28% had received PAP smears; and 37% had been tested for hepatitis B or C (Lebow). A study from San Francisco revealed that 25% of homeless persons with HIV/AIDS found to be PPD positive had never been tested before (Zolopa). Less than 20% of a high-risk subset of homeless people in New Haven had received a pneumococcal vaccination, and only 27% had received an influenza vaccination (Barry).

Tuberculosis

As mentioned, the prevalence of TB is higher among homeless people than in the general population. Crowding and poor ventilation, common in many homeless facilities, make transmission easier; poor access to health care prevents treatment of primary TB; and suppression of the immune function by HIV infection and other conditions common to homeless people makes activation of TB more likely (NHCHC). Latent TB prevalence is extremely high among homeless persons with HIV/AIDS, ranging from 32% to 67% in populations studied (Zolopa; Torres). A study in New York City found 22% of HIV-infected participants with active TB and 4% with extrapulmonary TB (Torres). Another study of homeless men with HIV/AIDS found a 50% prevalence of active TB (Saez). These figures are much higher than the 4.7% – 10% prevalence of active TB generally found among persons with HIV/AIDS (Gollub; Gordin).

Homeless people have poor rates of return to have tuberculin skin tests read (Torres; Barry) and poor rates of adherence (11% – 55%) to TB prophylaxis (Brudney; Pablos-Mendez; CDC). Directly observed therapy programs have also demonstrated poor adherence to TB treatment regimens (Nazar-Stewart; Burman), which is associated with high rates (19% – 60%) of drug-resistant tuberculosis (Pablos-Mendez; Morris; Barry). Nevertheless, successful experiences with TB prophylaxis and treatment are also reported, by programs that vary dramatically in their approaches to adherence promotion. Some interventions emphasize cultural sensitivity, using peer advisors and financial incentives (Pilote); others employ more coercive techniques such as detention (Oscherwitz).

Homeless Women

As noted in the previous section, homeless women face special barriers to health care. Like housed mothers, homeless mothers tend to subordinate their own health needs to those of their children; but the extraordinary demands of raising a family without stable housing are especially disruptive to regular health care for these women. Stretched thin by multiple roles as childbearer, caregiver and provider, homeless mothers are often dealing simultaneously with the psychological effects of trauma and abuse (Bassuk). Competing subsistence needs and caregiver roles have been found to adversely influence health care access for women living with HIV/AIDS (Shelton, Cunningham).

Moreover, the needs of women with children may be overshadowed by those of single men, who comprise the vast majority of clients served in many homeless health care projects. Nevertheless, women with families now constitute more than a third of the homeless population (Weinreb). Although having a family may increase or decrease accessibility to a shelter, depending on the program, having children usually hinders access to health care for homeless mothers.

Single homeless women are more likely to have addiction disorders, suffer from mental illness, and

trade sex for commodities or housing. They are consequently at increased risk for contracting HIV/AIDS, but may have difficulty obtaining addictions treatment, mental health services and screening for STDs, which could lower their risk.

Certain conditions that are more prevalent among homeless than domiciled women have been shown to be directly related to homelessness. Researchers in Worcester, Massachusetts, found that 41% of homeless women had a history of substance abuse or dependence compared to 34.7% of housed women. Homeless women were less likely to have a regular provider or source of care, and were more likely to list lack of childcare as a barrier to care (Weinreb). These findings were reproduced in Los Angeles (Wood) and Philadelphia (Parker). A study in St. Louis showed that 48.6% of homeless women had a psychiatric disorder, compared with 31.7% of low-income domiciled women (Smith). Major depression was over twice as prevalent among homeless women surveyed, and the prevalence rate of posttraumatic stress disorder was more than ten times higher for homeless than housed women (Smith).

Homeless women are more likely to be victims of domestic violence or sexual abuse than are housed women (Weinreb; Wood). “Homeless women frequently associate with men for protection and end up being sexually abused; they are four times more likely than domiciled women to be raped” (Fisher, as cited in ACLU). Women with HIV/AIDS may suffer from greater psychological stressors, including violence. The National Institutes of Health Women’s HIV Interagency Study found that nearly 50% of women with HIV had suffered sexual abuse in the past, and 60% had experienced domestic violence (Anderson).

Women with HIV are particularly susceptible to a number of conditions including the human papilloma virus, the most common genital tract infection, which is associated with increased rates of neoplasia (cervical cancer) and decreased immune function. Because women have often been excluded from clinical trials due to concerns about pregnancy (Mangino), the effect of HIV medications on pregnant women is not well understood. Preventing vertical transmission of HIV from infected mothers to their babies through pregnancy or breast-feeding is an additional concern for these women and their caregivers.

Access to care is related to the quality of care that women receive. Less than half of homeless women surveyed in a multi-site study from Massachusetts could name “a family doctor or hospital from which they had received ‘helpful’ treatment within the previous year” (Bassuk). Investigators in Philadelphia reported that 19% of homeless mothers could not even identify a place where they could go for care (Parker). HIV counseling, testing and treatment are among the services which women have particular difficulty obtaining. A multi-site study found that significantly fewer women than men received pre- and post-test HIV counseling (Weissman), and women have been found to have lower CD4 counts and higher HIV viral loads when they enter care (Bartlett). Women are less likely to be seen by an experienced clinician (Kitahata), and less likely to receive OI prophylaxis or antiretroviral therapy than men (Bartlett; Odem).

Rural Areas¹

Measuring homelessness is difficult in rural areas, where there are few shelters or places homeless people congregate (NRHA), and where “doubling up” with friends or family members is more common than on-the-street homelessness. Nevertheless, rural homelessness is a significant and growing

¹ Adapted from comments by Martha McKinney, Ph.D., President, Community Health Solutions, Inc.

problem. Extrapolations from statewide studies in Iowa and Pennsylvania indicate that approximately 11% – 14% of homeless people in America live in rural settings (Foster); two other statewide studies estimate a proportion of 18% (NRHA).

The U.S. Public Health Service measures AIDS case rates according to prevalence in metropolitan statistical areas (MSAs) or non-MSAs.² As of December 1997, non-MSA residents accounted for 5.7% of cumulative AIDS cases and 7.2% of new AIDS cases reported in that year (CDC). The AIDS case rate increased by 60% in non-MSAs between 1991 and 1997 as compared to 43% in large metropolitan areas (CDC).

Homelessness may not be as prevalent among individuals with HIV/AIDS who live in rural areas as among urban dwellers (McKinney), but studying HIV in rural communities presents additional challenges. Two studies of HIV patient migration patterns found individuals leaving large cities to live with their families in rural areas (Cohn; Davis). A third study found rural HIV-infected women living with family members, husbands, partners or friends (McKinney).

Although homelessness manifests itself differently in rural and urban areas, homeless individuals in both settings have one thing in common — unstable and often inadequate living arrangements.³ Evidence that many individuals in rural areas live in inadequate housing (McKinney) is substantiated by the fact that more than half of substandard housing in the United States is located there (Sowell). Even though literal homelessness may be less frequent in rural areas, individuals living there with HIV/AIDS, like their urban counterparts, often lack running water or refrigeration — conditions that complicate HIV care (Berry; Sowell).

Persons who live in rural areas without stable and adequate housing face some of the same health care access barriers encountered by homeless persons in urban areas. These barriers are exacerbated by scarcity of concentrated resources, greater distances to travel, rugged terrain or severe weather to overcome in seeking health services, and fewer public modes of transportation (McKinney; Berry). In rural areas of the Southeast, people with HIV/AIDS often travel as long as two hours to see an infectious disease specialist in a tertiary care center (McKinney).

Provider attitudes can negatively affect care for rural HIV/AIDS patients, who tend to be diagnosed

² The Office of Management and Budget defines a non-metropolitan area (non-MSA) as either a county with a city of less than 50,000 residents or an area that is not part of a county or group of counties with at least 100,000 people.

³ A homeless individual is defined in section 330(h)(4)(A) of the McKinney Act as “an individual who lacks housing (without regard to whether the individual is a member of a family), including an individual whose primary residence during the night is a supervised public or private facility (e.g., shelter) that provides temporary living accommodations, and an individual who is a resident in transitional housing.” The Bureau of Primary Health Care has expanded this definition in its description of Health Care for the Homeless program expectations for federal HCH grantees to capture the many faces of homelessness: “A homeless person is an individual without permanent housing who many live on the streets; stay in a shelter, mission, single room occupancy facility, abandoned building or vehicle; or in any other unstable or non-permanent situation. An individual may be considered to be homeless if that person is ‘doubled up,’ a term that refers to a situation where individuals are unable to maintain their housing situation and are forced to stay with a series of friends and/or extended family members. In addition, previously homeless individuals who are to be released from a prison or a hospital may be considered homeless if they do not have a stable housing situation to which they can return. A recognition of the instability of an individual's living arrangement is critical to the definition of homelessness.” (Principles of Practice for Health Care for the Homeless grantees, Bureau of Primary Health Care/HRSA/DHHS, March 1, 1999)

later because HIV/AIDS is perceived to be an urban disease and their physicians do not consider them to be at risk (NRHA; McKinney). The HIV Costs and Services Utilization Survey found that only 1.4% of rural people living with HIV/AIDS were receiving medical care in the area where they lived (Cohn, 1994). Even if physicians are available, many rural providers do not have adequate HIV experience (McKinney).

Confidentiality may be more difficult to preserve in rural areas (McKinney). Rural residents with HIV/AIDS are less likely to have medical insurance (Weslowski). A comparison of urban and rural responses to AIDS-related questions on the 1991 National Health Interview Study revealed that urban residents were 1.5 times more likely to have been tested for HIV and 1.4 times more likely to expect to have an HIV test than people in rural areas (Mainous). Undocumented resident status and transience, in addition to cultural and linguistic barriers, make general HIV care more difficult to obtain for migrant farm workers, who have extremely high rates of tuberculosis and infestations.

Even when they are able to obtain care, persons living with HIV in rural communities may not have access to all of the diagnostic tools and routine treatments that are presupposed by current standards of care. A study of individuals receiving care in rural areas during the first half of 1996 showed that only 21% had ever had their HIV viral loads checked (Cohn). The same study found that 63% of homeless individuals with AIDS were receiving *Pneumocystis carinii* pneumonia (PCP) prophylaxis, and only 46% were receiving *Mycobacterium avium* complex (MAC) prophylaxis (Cohn). Fewer pharmacies carry front-line medications in rural communities, especially where the demand is extremely low (McKinney).

B. Recommendations

Clinical Recommendations

1. **Standards of care.** Service providers should abide by evidence-based standards of care for HIV/AIDS patients; a lower standard should not be used for people who are homeless.
2. **Medical history.** HIV/AIDS providers should be particularly thorough in documenting their patients' medical histories, including results of the following examinations and reports:
 - Oropharynx, focusing on poor dentition, candidal infections, and nutritional deficiencies;
 - Skin and nails, looking for infestations, soft tissue infections, bacillary angiomatosis-peliosis, trauma, liver disease, and syphilis;
 - Neurologic, to assess for neuropathies, nutritional deficiencies, syphilis, dementia, and mental illness;
 - Substance abuse, mental illness and medication histories; and
 - Frequent TB testing, up to once every six months.
3. **Shorter prophylaxis.** Providers should take advantage of shorter prophylactic regimens and use interventions that increase adherence to prophylactic TB therapy.
4. **Immunizations.** Health care providers should administer recommended vaccinations, including hepatitis B, as soon as possible.

5. **Pharmacist education.** Providers should educate local pharmacists about the needs of homeless persons living with HIV/AIDS.
6. **Homeless women.** Service providers should address the barriers that homeless mothers face, including lack of childcare, support services for their families and help in obtaining public assistance. Additional training is necessary to alert homeless service providers to the importance of providing linkages and referrals to HIV care for homeless women and their families. The special profile and risk factors of homeless women that should be addressed include:
 - Caregiver status and motherhood,
 - Mental illness,
 - Domestic or other violence,
 - Substance abuse, and
 - High-risk sexual behavior.
7. **Rural concerns.** Service providers in rural areas should address patient concerns about confidentiality, transportation, and lack of providers and pharmacies. Health care providers should assess the dwellings of rural patients to determine adequacy of shelter, medication storage capacity and water supply.

Public Policy Recommendations

To improve general HIV care for homeless persons, more resources should be devoted to the following:

- **Primary care.** Increased access to primary care providers, particularly in rural areas;
- **Nutrition and water.** Improved availability of proper nutrition and clean water;
- **Dental care.** More accessible oral health care;
- **Immunizations.** Vaccinations for hepatitis A and B, influenza and pneumococcal infections; and
- **Women's health care.** Mental health services, addiction treatment, HIV testing and counseling.

VI.

ANTIRETROVIRAL TREATMENT

Samuel is a 32-year-old man who entered our therapeutic community for alcohol abuse treatment. He had tested positive for HIV two years previously. His blood work was remarkable for a CD4 count of 410 and a viral load of 130,000. An antiretroviral regimen of AZT, Epivir, and Viracept was prescribed. It was stressed that Viracept had to be taken on a full stomach. We saw Samuel two weeks later and—among other things—reminded him to take Viracept after a full meal. He told us he was doing so, with the exception of Saturday and Sunday mornings. The shelter in which the therapeutic community was located served three meals on weekdays, but on weekends served only two meals a day – brunch (at noon) and dinner (in the evening). So on Saturdays and Sundays, Samuel took his morning Viracept on an empty stomach.

— Elizabeth Lutas, M.D., New York City

Being housed and in a more stable situation — and seeing social and nursing staff on a regular basis — S. A. successfully recovered from rectal surgery and kept her regular follow-up appointments with me. In October 1997, almost six months after her initial visit and frequent subsequent visits, I felt comfortable and eager to begin ART. She started AZT, 3TC, and Nelfinavir. The regimen caused her only minimal diarrhea, and after a month her viral load had decreased considerably to 16,000 and her CD4 had doubled. These results were encouraging, but after three months, her viral load was again over 300,000. S. A. disclosed to me that she had stopped the Nelfinavir after the first month because there were too many pills, and that very rarely would she take the 3TC or AZT. A few months later, her CD4 count was 10, but we felt ready to attempt therapy again. With the assistance of the Bridge Project physician and other staff, we amplified and reinforced the message of adherence. Since May 1998, her viral load has been undetectable, and her last CD4 count was 240. I keep frequent visits with her. ...There are still many obstacles, however. Bridge Project housing, for example, is limited to 18 months.

— Linette Martinez, M.D., San Francisco

A. Background

In recent years, biomedical research has made significant strides in the development of antiretroviral agents that can delay the onset of AIDS. Antiretroviral therapy (ART) is directed toward suppressing the replication of HIV-1 (the most common HIV viral strain) in order to improve HIV-related symptomology, preserve and restore immune function, and decrease viral burden. There are currently 14 approved antiretroviral drugs divided into three classes that are prescribed in recommended three-to-five drug combination cocktails called highly active antiretroviral therapy (HAART).

HAART has been demonstrated to profoundly suppress viral replication, increase immune function, and improve quality of life. It can also decrease the incidence of opportunistic infections and other AIDS-related conditions by as much as 75% – 80% (Pallela; Moore; Hammer). Some anecdotal reports indicate that HAART has led to long-term remission of CMV retinitis and disseminated MAC infections (Whitcup; McArthur). It may also lead to the resolution of cryptosporidiosis, microsporidiosis and progressive multifocal leukoencephalopathy — conditions previously thought to be incurable (Carr; Hoffman). HAART is also associated with a significant decrease in hospitalizations

for AIDS-related conditions (Torres; Goetz), a significant decrease in mortality (Palella; Hogg; Chaisson), and an incremental decrease in morbidity and mortality (Palella).

HAART requires great diligence, attention and tolerance on the part of the patient, as some regimens may exceed 20 pills per day and may require two to three doses daily. Timing and dietary requirements, which must be observed to the letter, are critical to ensure absorption and steady blood levels.

Other concerns about the impact of ART include severe side effects, need for hydration, refrigeration and storage. The side effects can range from mild to life threatening, and may cause many interactions, requiring monitoring and evaluation of HIV viral load and CD4 count every three to four months. These factors may decrease quality of life for patients (Carpenter) and may prompt them to discontinue therapy.

Treatment Failure

Drug treatment failure is defined as the confirmed detection of plasma HIV virus after initial suppression to undetectable levels, a persistent decrease in CD4 count, or clinical deterioration and the emergence of symptoms. Failure can be caused by primary or cross-viral resistance, development of secondary viral resistance, poor absorption of medications, altered metabolism, multi-drug pharmacokinetics, and nonadherence (Carpenter). The latter is considered the main reason for drug failure and subsequent viral resistance (Sande).

Resistance

Resistance to individual antiretroviral agents is a major concern, as already limited treatment options may be reduced even more if the patient fails treatment. Resistance can be caused by the selection and transmission of resistant variants; by poor absorption, altered metabolism, poor potency and protein binding of antiretroviral medications; or by altered host immune function (Mellors). Once the virus has become resistant to a particular antiretroviral drug, it may not sustain viral suppression (Katzenstein).

Cross-resistance — the resistance to more than one antiretroviral medications — means that once a patient fails on a particular agent, the efficacy of others may also be limited in the future (Gallant). This is the case among the three approved drugs of the non-nucleoside reverse transcriptase inhibitors (NNRTI) class and, to a certain degree, protease inhibitors (Gallant). Cross-resistance can also impact the effectiveness of drugs in different classes. One study demonstrated that nonadherence to Didanosine, used in a triple-combination with Zidovudine (AZT) and Nevirapine, resulted in resistance to both Zidovudine and Nevirapine (Montaner).

Combinations without Protease Inhibitors

Due to concerns about resistance, practitioners and patients may occasionally opt to emphasize delay in the use of protease inhibitors while still seeking viral suppression. Forty-eight week data from a trial comparing the combination of AZT, 3TC, and Efavirenz to another combination using a protease inhibitor, demonstrated a pronounced and sustained benefit; Efavirenz appeared to suppress the viral load better (Manion). Other such regimens include a ddI, d4T, and hydroxyurea combination and Abacavir with two other nucleoside reverse transcriptase inhibitors (NRTIs). Both combinations have been found to be much more effective and sustainable than dual NRTI regimens (Gal-

lant; Montaner). The second combination is especially attractive because it involves only one 300 mg tablet of Abacavir twice a day plus one Combivir (AZT/3TC) tablet twice a day. A study of this combination has shown that 71% of those on this regimen had undetectable viral loads at 48 weeks (Fischl).

Other protease-sparing regimens are also attractive because of their simplicity, such as Nevirapine, ddI and d4T; all of these drugs are taken once a day. This combination was recently tested on eight treatment-naive individuals with some success at 22 weeks (Pell).

Access

Because resistance to antiretroviral therapy is such a critical issue, it is essential that individuals begin therapy and continue treatment once begun. Access to ART is hampered by lack of insurance (Shapiro; Graham), which limits access to protease inhibitors (Hecht; Celentano; Sorville) and AZT (Solomon). The attitudes, beliefs and prejudice of some providers toward homeless individuals may prevent them from prescribing HAART. Research demonstrates that African-Americans are less likely to receive protease inhibitors (Hecht; Stone; Sorville) or any ART (Moore; Graham; Solomon). Active illicit drug use (Celentano), lack of enrollment in treatment programs (Strathdee; Solomon) and lack of continuity of care (Celentano) also influence whether an individual will receive ART.

It is unclear whether homeless persons are refusing ART, whether it is not being offered to them (Sontag), or whether they are not taking prescribed medications when evaluated.

- A national survey found that only 17% of homeless individuals were taking ART, compared to 51% of housed individuals (Lieberman).
- In San Francisco, only 7% of homeless patients were on combination therapy at baseline (Bangsberg).
- In Baltimore, only 8.8% of homeless injection drug users were taking combination therapy (Celentano).
- In New York City, only 19% of HIV-infected homeless persons were taking AZT when it was the only drug available (Torres).
- In Worcester, Massachusetts, only 63% of HIV-positive individuals experiencing homelessness were prescribed AZT (Rapaport).

OI prophylaxis is an inexpensive method of preventing illness and death that can also provide a means of evaluating and reinforcing patient adherence patterns before prescribing ART. Although it is not uniformly difficult for homeless patients to obtain OI prophylaxis, access barriers remain for some patients because not all providers are prescribing these medications as frequently as they should. For example, a Boston study showed that only 82% of homeless individuals were receiving PCP prophylaxis (Lebow). Access to PCP prophylaxis is particularly limited for African-Americans (Solomon; Moore; Easterbrook) and current injection drug users (Solomon).

Poor self-esteem and lack of desire for wellness may also impede access to HAART and influence treatment effectiveness. Some homeless people appear to have lost the capacity to care because of the systematic stigmatization and rejection they experience. Confidentiality may be hard to maintain because homeless individuals must spend so much time in public and crowded spaces where it is difficult to conceal medications and medical appointments.

B. Recommendations

Clinical Recommendations

1. **Standards of care.** Homeless people should be treated with ART according to current guidelines, which provide for broad discretion but do not warrant denial of medications to individuals who desire them.
2. **Patient education.** Before initiating therapy, providers must educate patients on the following aspects of ART:
 - Objectives and principles of antiretroviral therapy;
 - Difficulties, challenges, side effects, and intrusiveness;
 - Resistance, need for adherence, and the potential to lose treatment options;
 - Harm reduction with nonadherence (e.g., not supplementing therapy with antiretrovirals borrowed or purchased from others, and stopping all medications if the patient wants or needs to stop ART).
3. **Access barriers.** Providers should explore and address possible barriers to obtaining ART their patients may face, including:
 - Lack of insurance or ADAP coverage,
 - Lack of financial resources,
 - Subsistence and transportation needs,
 - Caregiver needs,
 - Incarceration,
 - Mistrust of medical institutions or treatment, and
 - Confidentiality concerns.
4. **Engagement.** Successful HIV/AIDS care requires taking the time to develop a trusting relationship with patients; fostering a relationship prior to offering ART is necessary for patient acceptance of treatment.

Public Policy Recommendations

1. **Formulary guidelines.** National or state formulary guidelines should be developed to allow for increased use of antiretroviral therapy by uninsured individuals.
2. **Medicaid coverage for persons with asymptomatic HIV infection.** In many states, unless a person with HIV is eligible for welfare or supplemental security income (SSI), or is a pregnant woman or a child, he or she is not eligible for Medicaid, no matter how low the individual's income may be. Currently, a person with asymptomatic HIV infection does not meet the SSI standard of disability, according to which a person must have a manifest symptom of HIV-infection to qualify for Medicaid coverage (Westmoreland). Low-income homeless persons with HIV infection who do not fit into another Medicaid eligibility category often have no access to medical care that could prevent the onset of opportunistic illness or further deterioration of their immune system. Ironically, such persons become eligible for preventative care only *after* they have developed OIs or full-blown AIDS. Such a policy is unwarranted from several points of view — ethical, financial and epidemiological. Federal Medicaid eligibility criteria should be broadened to include all persons with HIV infection.

- 3. Increased coverage for HIV specialty care.** Sufficient public funding should be provided to make antiretroviral therapy accessible to all persons living with HIV/AIDS, regardless of their housing or insurance status. There should be state-by-state increases in ADAP coverage for antiretroviral medications. Additional funding is also needed for specialized programs, such as Health Care for the Homeless, the Ryan White CARE Act, and Special Projects of National Significance, which promote outreach and multidisciplinary work with HIV-infected homeless persons.

VII.

ADHERENCE

Pierre is a 32-year-old man living on the streets, ...referred to our clinic from our mobile van after requesting an HIV test. He spoke little English, having come from Haiti three years previously. ... He had had no medical care since his arrival in this country. ...[Because] he often seemed distracted, ... I thought he had psychiatric difficulties. This belief and his lack of a stable situation — no housing, no support from any friends or family — made me reluctant to test. ... On examination, he had a growth — 3 – 4 cm. in diameter, irregular, rough, erythematous, with purulence — on the glans of his penis. I urged him to go to our emergency room, but all he wanted was the HIV test. I referred him for an evaluation of the growth, which I felt was a cancer that had become infected. As we awaited the escort, the patient disappeared. I thought we would not see again.

Pierre returned to the shelter one week later. I asked if he had gone to the hospital. He said he had not. He was afraid because he was undocumented in this country and did not speak English. He asked again to be tested for HIV. ... I did pre-test counseling, drew blood and ... asked him to go to the emergency room to take care of the lesion.... I received the HIV test results a week and a half later. He did have antibodies to HIV. I had second thoughts about what I had done. Two weeks after the blood test, Pierre came to the clinic and I gave him the results. He said he thought he would be positive. We spoke at length. ... To my surprise, he showed me a bottle of antibiotics he had obtained in the emergency room. He had kept his part of our bargain.... Pierre is now with us in the clinic receiving care.

—Elizabeth Lutas, M.D., New York, NY

A. Background

One of the most controversial issues to be addressed when providing care for homeless individuals is patient adherence to prescribed treatment. To avoid building resistance to antiretroviral drugs, it is essential for persons living with HIV to take their medication exactly as prescribed. Individuals who take their medications according to instructions are much more likely to control their disease than those who do not. Because failure to take all medications as prescribed may cause the virus to become resistant to one or more antiretroviral drugs, it is essential for patients to adhere strictly to their treatment regimens.

An 80% adherence level, considered effective for other conditions, is not sufficient for antiretroviral therapy (Sackett). Even brief drug holidays can lead to the loss of viral suppression and the development of resistance (Gallant; Katzenstein). In a recent study, 81% of patients demonstrating greater than 95% adherence had complete viral suppression, compared to only 64% of those demonstrating 90% – 95% adherence (Paterson). Nonadherence rates of 40% – 50%, reported in studies of hypertension, asthma, psychiatric and antibiotic therapy, may not bode well for adherence to antiretroviral HIV/AIDS therapy (Sherer; Lerner; Sackett; Eraker; Stephenson). Studies of non-adherence have consistently shown that the problem is widespread, regardless of condition or population examined, and cannot reliably be predicted on the basis of patient characteristics (Lerner).

The controversy about whether or not to prescribe antiretroviral therapy to homeless persons reflects physicians' concerns that homeless individuals may begin treatment and, if unable to carry it out, will develop resistance to the drugs. This would limit their present and future treatment op-

tions. Nevertheless, there are no absolute contraindications for ART or justifications to withhold therapy from those individuals who desire it. The decision about which treatment options to use is subject to physician and patient discretion. Physicians must assess each individual's likelihood to adhere to treatment, and based on that assessment, decide what, if any, medications to prescribe.

Adherence Assessment

Data collection from various sources may be helpful to physicians in assessing patient adherence to treatment. Measurement may include provider assessment, collateral observation, subject self-assessment through interviews and monitoring, pill counts, electronic bottle monitors (MEMS caps), and biological markers (Katzenstein; Blackwell; Levine). Recent reports have demonstrated that provider assessment alone may be no better than chance (Gilbert), that self-reporting results in over-estimation of ART adherence compared to more "objective" measures (Bangsberg; Golin), and that providers may overestimate HAART adherence in their patients (Miller). Use of multiple measurement techniques to assess adherence may therefore achieve more realistic results.

An observational study from San Francisco showed that 56% of homeless people were adherent to ART 75% – 85% of the time (Bangsberg). In Boston, 52% of 30 patients on triple therapy were able to achieve undetectable HIV viral loads (Lebow), and researchers in New York found that 71% of homeless participants on AZT claimed adherence (Torres). Nevertheless, studies in other populations report high rates of non-adherence: 64% (Chesney), 64% (Hecht), 67% (Samet), 42.3% (Muma), 63% (Singh), 62% (Mostashari), and 49% (Eldred).

Reasons for Nonadherence

Some of the most common reasons given by patients for missing doses of medication are:

- Forgetting (Chesney; Ohmit);
- Side effects (Samet; Broers; Ohmit);
- Sleeping through dose (Chesney);
- Change in routine (Chesney);
- Feeling better (Ohmit; Richter); and
- Fear of medications (Ohmit; Richter).

Other factors that may affect adherence include mental health and depression (Chesney; Singh), stress (Chesney), the need for psychiatric evaluation (Ferrando), age (Chesney), problems taking medications (Muma) and skepticism about them (Muma). Race is predictive of non-adherence (Singh; Muma; Ohmit), but it may be a surrogate for literacy with respect to ART adherence (Sippler). The most important considerations cited by clinicians in deciding whether to prescribe ART are active substance abuse (78%), access to regular food and water (70%), side effects (69%), active mental illness (64%), and housing status (54%) (HCH Clinicians' Network).

Maximizing Adherence

The following factors have been shown to increase adherence:

- Close relationship with a provider (Mostashari; Stone),
- Close peer relationships (Mostashari),
- Reduced pill frequency (Eldred),
- Fitting the pill regimen into daily routine (Wenger),

- Knowledge of ART action (Eldred),
- Perceived ability to take medications (Eldred; Stone),
- Patient belief that medications are helpful or prolong life (Eldred; Samet),
- Use of a medication timer (Samet).

The development of a constructive provider-patient relationship is essential to successful antiretroviral therapy. Cultural competence of service providers is key in improving patient adherence to treatment. Education of non-medical service providers in the basic principles of ART can also help to promote adherence. Finally, service linkages and better communication between health care providers and other community venues where homeless people congregate facilitate patient follow-up and assessment of ART adherence.

Public Health Considerations

The quality of life for homeless people may improve while they are taking ART, regardless of viral or immunologic response (Castello-Branco). Other health benefits of treating homeless individuals include the possibility of reducing the risk of HIV-1 transmission by decreasing the amount of virus transmitted during exposure (Wainberg). Even partially successful therapy can reduce blood and genital secretion of the virus, at least theoretically resulting in diminished risk of HIV transmission (Wainberg). Studies have also shown that even drug resistant viral strains may have impaired replication competency (Goudsmit; Louder) and decreased transmissibility (Wahlberg).

The main public health concern is the possible increase of resistant strains of HIV-1 through sexual intercourse (Imrie; Conlon), injection drug use (de Ronde) and perinatal transmission — to the fetus *in utero* or to the infant during breastfeeding (Colgrove). Transmission of HIV-1 variants resistant to Lamivudine (Conway), Nevirapine (Imrie) and protease inhibitors (Wainberg) has also been demonstrated. A recent study detected transmission of a viral strain that is resistant to multiple medications, including protease inhibitors and NRTIs, from one host to another (Hecht).

B. Recommendations

Clinical Recommendations

1. **Provider education.** All medical and non-medical homeless service providers should be educated about the basic principles of antiretroviral therapy and adherence promotion, including cultural sensitivity.
2. **Commencement of ART.** While it is preferable to maximize stability before initiating ART, instability is not sufficient cause to deny treatment.
3. **Co-management of ART.** Medical providers should consider co-management of antiretroviral therapy with other service providers, including case managers, substance abuse and mental health counselors, infectious disease specialists, shelter providers and parole officers.
4. **Identification of adherence barriers.** Providers should aggressively identify barriers to adherence, listed below, and seek to ameliorate them.
 - Mistrust of health care, including institutions and medications
 - Lack of patient understanding of HIV/AIDS care and ART
 - Unmet subsistence needs including food, water, housing and bathroom facilities
 - Transportation needs
 - Caregiver responsibilities and needs
 - Lack of storage facilities for medications

- Loss or theft of medications
 - Inability to carry medications or limited access to them
 - Confidentiality concerns
 - Lack of peer or family support
 - Lack of fixed, dependable daily routine
 - Dependence on the schedule of others
 - Medication side effects
 - Active substance abuse
 - Mental illness and/or depression
5. **Adherence promotion.** Providers should facilitate patient adherence to ART through the following:
- Tailor the treatment regimen to the patient's lifestyle;
 - Plan ahead for changes in routine;
 - Simplify medication regimens and preserve low frequency of dosing (BID);
 - Use organizational aids such as timer watches and pillboxes;
 - Enlist peers to reinforce and support adherence;
 - Recruit family members to lend support;
 - Institute or refer patients to day or night programs, depending on their scheduling needs;
 - Provide on-call service or triage by personnel with a working knowledge of ART;
 - Be available during evening and weekend hours;
 - Develop on-site food pantry, emergency meal or meal voucher programs;
 - Provide water fountain or bottled water on-site;
 - Provide medications on-site and institute on-site medication storage program;
 - Provide childcare at clinics; and
 - Identify housing options.
5. **Incentives for treatment.** Providers should consider the use of monetary or other incentives to improve attendance to follow-up visits and ART success.
6. **Aggressive outreach.** Outreach teams and personnel should be employed to:
- Increase follow-up visits by providing reminders and transportation;
 - Identify and address barriers to adherence at various locations and facilities;
 - Conduct pill counts and adherence evaluations;
 - Reinforce treatment goals and the need for adherence;
 - Provide medications to individuals who may run out; and
 - Provide food or water.
7. **Adherence assessment.** Providers should evaluate their patients' history of adherence with other medications. Once ART is begun, providers should do adherence assessments at every clinical visit and provide the means to increase adherence.

Public Policy Recommendations

1. **Provider education.** Mainstream providers should be educated about identifying homeless patients and addressing their unique treatment needs.
2. **Service linkages.** All jurisdictions should encourage linkages among health care facilities, service providers and correctional institutions.

VIII.

RESEARCH

M. A. is a 45-year-old woman with a history of HIV disease, ... depression, hepatitis C, a long-standing narcotic addiction, amenorrhea, [and] chronic low-back pain ... status post-laminectomy. ...She had applied for SSI, but was declined; she is now appealing. She is a sex worker and receives general assistance. She has two children, six and seven years old, who are in foster care. Shortly after she found out that she was HIV positive, M. A. came to the clinic to establish primary care for her HIV disease. At that time she had no specific complaints, but was interested in methadone maintenance treatment for her narcotic addiction. Her viral load was about 46,000, and her initial CD4 count was 576. ... It quickly became obvious that she was unable to commit to therapy. She seemed distracted by a number of needs; for example, she needed a letter for her SSI application, and she needed another letter in order to receive methadone maintenance. She did not have stable housing, and she had so many other priorities that taking medication on a regular basis was not one of them. ... When I saw her most recently, however, M. A. expressed interest in HIV treatment, feeling that if she does not get treatment she will die, and she is not ready to die. I prescribed Combivir and Nevirapine, hoping to get her started without using protease inhibitors. I am uncertain that M. A. is able to adhere, so I am retaining the possibility of using protease inhibitors in the future.

—Karen Bayle, M.D., San Francisco, California

A. Background

The research literature on HIV/AIDS and homelessness, though sparse, clearly identifies barriers to prevention, health care access and treatment faced by homeless people living with HIV, and points to a number of areas where more investigation is needed. More targeted studies employing standardized methodologies are needed to form a scientific basis for the development of successful HIV/AIDS prevention and treatment strategies for people who lack stable housing. Such research is warranted by the preliminary evidence, reported here, that HIV/AIDS has a disproportionate effect on particular homeless subpopulations, and that HIV-infected, housed persons are at increased risk of becoming homeless. Failure to measure the scope of HIV/AIDS within the homeless population and to develop well-tested prevention and treatment strategies is likely to exacerbate the serious public health problem which the human immunodeficiency virus and its devastating sequelae already present.

Relatively few clinical or epidemiological data exist on HIV prevention and treatment for homeless individuals, in part because of limited resources to study medical conditions in this population. At the same time, there is a great need for behavioral and clinical research on particular homeless subgroups, to form a scientific basis for the development of successful prevention strategies and treatment protocols. Finally, there is a need for policy research to further document and address system barriers to HIV prevention and care for homeless people.

Needs Assessment

The current standard of care for HIV prevention and risk reduction requires a needs assessment of targeted populations and the tailoring of interventions to the populations' demonstrated needs. Needs assessments of particular homeless populations should specify barriers to HIV prevention and services experienced by different cultural and linguistic groups in different geographical areas.

Priorities

Additional research is needed to develop and test strategies to decrease HIV transmission among homeless persons, and to identify those who are infected for treatment. Research to identify individual characteristics that may increase adherence to antiretroviral therapy is also essential. Absent objective data, clinicians must rely on their own subjective perceptions in deciding whether to prescribe ART. Given their poor track record in predicting patient adherence (Gilbert), there may be better ways to select patients for and encourage their adherence to treatment.

B. Recommendations

Epidemiology

- **General.** Better characterization of the extent of HIV/AIDS among homeless people, and of the extent of homelessness among persons with HIV/AIDS.
- **Specific.** Better characterization of the extent of HIV/AIDS in various subpopulations — e.g., rural populations, homeless women, transgendered individuals, etc. Determine the incidence, prevalence and natural history of HIV/AIDS within these subpopulations.

Behavioral Research

- **Behavioral change.** Develop better methodologies to evaluate behavioral change in people without stable homes.
- **HIV prevention.** Investigate high-risk behaviors. Develop and implement HIV prevention strategies for homeless men and women in targeted subpopulations.
- **Testing, notification and adherence.** Identify barriers for homeless persons to HIV testing and counseling, notification of test results and treatment. Develop and test interventions that improve rates of HIV testing, notification and adherence to treatment.
- **ART.** Identify effective ways to reduce barriers to antiretroviral therapy for homeless people and to increase ART utilization.

Clinical Research

- **Co-morbidities and nutritional deficiencies.** Measure the impact of co-morbidities and nutritional deficiencies on HIV/AIDS progression.
- **Immunization rates.** Quantify immunization rates for homeless people with HIV/AIDS, including completion rates for hepatitis B immunizations. Design and evaluate interventions to increase immunization rates.
- **Outcomes.** Determine the outcomes of antiretroviral therapy among homeless people.

Policy Research

- **Impact of health coverage.** Determine the effect of Medicaid enrollment on homeless peoples' access to care and health status.
- **Health care access.** Describe system barriers to health care access for particular homeless subpopulations. Based on these data, develop strategies to increase access to comprehensive health care for all homeless people.

Appendices

Appendix I - REFERENCES

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Appendix II - CASE HISTORIES

1.

Pierre is a 32-year-old man living on the streets. He was referred to our clinic from our mobile van after requesting an HIV test. He spoke little English, having come from Haiti three years previously. Our HIV counselor spoke only English, so he was referred to me because of my fluency in French. He had had no medical care since his arrival in this country. When speaking with him, he often seemed distracted, with wandering thoughts. I thought he had psychiatric difficulties. This belief and his lack of a stable situation - no housing, no support from any friends or family - made me reluctant to test.

When I asked if there were any reasons why he thought he might have HIV, he said he had something on his penis. On examination, he had a growth — 3 – 4 cm. in diameter, irregular, rough, erythematous, with purulence — on the glans of his penis. I urged him to go to our emergency room, but all he wanted was the HIV test. I referred him for an evaluation of the growth, which I felt was a cancer that had become infected. As we awaited the escort, the patient disappeared. I thought we would not see again.

Pierre returned to the shelter one week later. I asked if he had gone to the hospital. He said he had not. He was afraid because he was undocumented in this country and did not speak English. He asked again to be tested for HIV. I felt reassured that he had returned exactly one week after his first visit, knowing it was the day I was there. We had made a connection. He was coherent, not at all distracted, and he responded appropriately to questions of what his reaction would be, were he to have a positive test result. I did pre-test counseling, drew blood and requested that he do something for me in return. I asked him to go to the emergency room to take care of the lesion on his penis. I prepared the referral papers and gave them to him.

I received the HIV test results a week-and-a-half later. He did have antibodies to HIV. I had second thoughts about what I had done. Two weeks after the blood test, Pierre came to the clinic and I gave him the results. He said he thought he would be positive. We spoke at length. He wanted to do the complete initial work-up, which we did. To my surprise, he showed me a bottle of antibiotics he had obtained in the emergency room. He had kept his part of our bargain and had gone to the hospital, received antibiotics and been given an appointment to the urology clinic for a biopsy. Pierre is now with us in the clinic receiving care.

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2.

Samuel is a 32-year-old man who entered our therapeutic community for alcohol abuse treatment. He had tested positive for HIV two years previously. He had had no illnesses related to HIV, and he had received no care for his infection. His initial physical examination was normal except for periph-

eral generalized lymphadenopathy. Blood work was remarkable for a CD4 count of 410 and a viral load of 130,000. An antiretroviral regimen of AZT, Epivir and Viracept was prescribed. It was stressed that Viracept had to be taken on a full stomach.

We saw the patient two weeks later and—among other things—reminded him to take Viracept after a full meal. He told us he was doing so, with the exception of Saturday and Sunday mornings. The shelter in which the therapeutic community was located served three meals on weekdays, but on weekends served only two meals a day – brunch (at noon) and dinner (in the evening). So on Saturdays and Sundays, Samuel took his morning Viracept on an empty stomach.

The problem was solved when I spoke to the shelter staff and explained the need for the morning meal. A list of HIV-positive patients was provided for the kitchen staff and these individuals now are served breakfast early Saturday and Sunday mornings in addition to the brunch and dinner meals.

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3.

John is a 36-year-old man who has known about his HIV infection for five years. He had had one episode of pneumocystis carinii pneumonia two years previously. His CD4 count had fallen below 100 one year prior to our meeting him. He had a negative PPD and was anergic several months before. His physician at that time had begun isoniazid and pyroxidine to prevent active tuberculosis. He was thus on a complicated medical regimen, receiving Crixivan every eight hours, Zerit twice daily, Epivir twice daily, as well as Bactrim, Zithromax, Isoniazid, Pyridoxine, folic acid and vitamins.

The policy of the shelter in which John lived was for the shelter to keep the patients' medications. The patients would come to the shelter to get their medications twice a day, once in the morning and once in the evening. The times of the medication call varied from day to day. John was thus having difficulty adhering with his medical regimen, especially the Crixivan. On occasion, John informed us, the evening medication call was forgotten.

When we learned about this situation, I asked to meet with the shelter director. I explained to him our patients' needs, such as the need to take medications at specific times, the need to take medications more than twice a day, and so on. The shelter director agreed to allow our patients to keep their medications so that they could follow their medical regimen as closely as possible.

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4.

Michael is a 49-year-old man who had worked as a nurse. He had cared for his partner who had died from AIDS. Michael was tested and found to be positive for the HIV antibody. As the infection progressed, Michael suffered from venereal warts, recurrent herpes infections, pneumonia and CMV infection of his gastrointestinal tract. He became so fatigued and weakened that he was forced to leave work. He soon became homeless and came to New York City, where he sought shelter at our drop-in center.

Physical examination revealed a thin man, with herpes simplex lesions around his mouth and anus and venereal warts on his penis. He also had peripheral generalized lymphadenopathy. His CD4 count at this initial encounter was 148, essentially unchanged from his previous reported CD4 count of 150.

He was taking medications which included Norvir, Invirase, Rescriptor, Zovirax, Bactrin and vitamins. The Invirase was being given in the form of soft gel-caps, which needed to be refrigerated. This shelter staff dispensed medications to the patients. We created a space in the refrigerator for the Invirase gel-caps and instructed the staff that this medicine would be kept there. This action led to general education of the shelter staff about antiretroviral medications - when they should be taken; how they should be stored; etc.

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5.

S. A. was 21 years old when I met her in March 1997. She was brought to our urgent care clinic by an outreach worker who told me that S. A. only spoke Spanish and was recently released from jail for prostitution. She was at the time in one of the city shelters, where our medical and social services staff had established a satellite clinic. S. A. is a transgender male to female, who tested HIV-positive a year before. She was rejected by her family in Mexico and came to the U. S. two years ago with a boyfriend.

Shortly after arriving in the States, S. A. was alone and depending on sex work for income. She had multiple sexual encounters without protection, at her clients' request. She was smoking methamphetamines and using injectable estrogens as frequently as she could to keep her feminine characteristics. At the time of her first visit, she was complaining of rectal pain and bleeding. On physical exam, there was a large condyloma in her rectum needing surgical removal. Our social work team was able to place her with the Bridge Project, a special grant program that provides housing and ancillary services to HIV-positive patients with dual diagnosis.

Being housed and in a more stable situation -- and seeing social and nursing staff on a regular basis -- S. A. successfully recovered from rectal surgery. She kept her regular follow-up appointments with

me. Initially, her viral load was 350,000 and her CD4 count 73. I was concerned about when to start antiretroviral treatment. It took time for me and the clinic staff to educate S. A. about AIDS and the possible consequences. Fortunately, besides her rectal problem, she had not experienced any opportunistic infections. I prescribed oral estrogens, so that she did not have to buy unpredictable doses of IM estrogens. Along with the estrogens, S. A. developed the habit of taking prophylactic medication and vitamin supplements. She also continued smoking speed, however, assuring me that her use was limited and that she always remembered to take her medication, even under the influence. She started to receive general assistance money, but was still doing sex work. I review safe sex practices during each visit.

In October 1997, almost six months after her initial visit and frequent subsequent visits, I felt comfortable and eager to start ART. S. A. was very young, and, during that six months, her CD4 had dropped to 23. She started on AZT/3TC and Nelfinavir. The regimen caused her only minimal diarrhea, and after a month her viral load was 16,000 and her CD4 doubled. These results were encouraging, but after three months, her viral load was again over 300,000. S. A. disclosed to me that she had stopped the Nelfinavir after the first month because there were too many pills, and that very rarely would she take the 3TC or AZT.

I told her to not take any of the medications; she was very relieved. She continued taking Septra and other medications, however. I felt responsible for this failed attempt, thinking my message did not get through. I had interpreted the patient's agreement to treatment as something that she wanted, not as something she agreed to do to please me.

Her CD4 count continued to decrease. When it reached 10, I wanted to begin therapy again. With the assistance of the Bridge Project physician and other staff, we amplified the message of the importance of being on therapy. Since May 1998, her viral load has been undetectable and her last CD4 was 240. I keep frequent visits with her. In the past few months, S. A. has enrolled in an English class, and she has gained 24 pounds.

There are still many obstacles, however. The Bridge Project housing is limited to 18 months, and her legal status in the country is questionable. S. A. may be able to apply for asylum due to her transgenderism and possible life-threatening situations in Mexico if she returns, but she may be deported if the application is not accepted. She cannot apply for SSI, and her educational and vocational alternatives are almost nonexistent at this moment. Many of S.A.'s circumstances are beyond the abilities of our clinical team, but she is receiving life-saving treatment and her quality of life has improved significantly under our care. She is well engaged with our clinic and medically, she is fine.

The other day, S. A. told me that she wants to think about herself and work for herself. I asked her if she could say this a year ago. She answered no - a year ago she did not care about herself. I look at this young person, who is smiling, growing, and developing self-esteem in spite of the many, very difficult obstacles in her life. I can only feel the deepest respect for her, and I realize how much this patient is teaching me. I tell her how great it is to be her physician.

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6.

D. W. is a 30-year-old female I first met in our urgent care clinic in August 1997. She had been seen three times in urgent care in 1997 for various issues, but it was not until June 1997 that she was diagnosed as HIV-positive as part of the REACH project, a University of California-San Francisco study of HIV among homeless people in San Francisco.

On July 31, 1997, D. W. came to our urgent care clinic with a dry cough, fever and oxygen desaturation to 91% with exertion. She was hospitalized for PCP, and I met her just after she was discharged from the hospital on August 18. At that time she felt fine, stating that she had completed her full course of Septra. She insisted that she wanted to start antiretroviral treatment. At that time, she was housed via the AIDS Foundation and accompanied to the clinic by her HIV-negative boyfriend T. R., who seemed very supportive. She admitted to crack use, but said that both she and T. R. had been clean and sober for two weeks. On July 22, her viral load had been greater than 800,000 and her CD4 count was 187. We talked about her boyfriend's seronegative status, and stressed the importance of using condoms.

On this first visit, I did something I probably would not do now: I wrote a prescription for Zerit, Epivir and Viracept. We discussed the necessity of adherence and possible side effects. For some reason, I sensed that D. W. was committed to sticking with therapy. I arranged a follow-up visit with me at the HIV clinic.

The next time I heard from D. W., however, she was in the hospital. She had gone to the emergency room due to a rectal tear and was complaining of sweats. It turned out that she had only received an eight-day course of Septra for her PCP. She was thus started on a 21-day course and given Acyclovir for probable rectal HSV. I saw her after her discharge on August 29, and she was again doing fairly well. By September 17, D. W.'s viral load was 3,286 and her CD4 count 221, which was very good news for both of us and proof that she was adhering to the antiretroviral regimen. My notes from October 15, however, state "back on meds" so I know that there was at least one interruption. She was found to be PPD positive in October, and she started taking INH. By October 29, her viral load was undetectable and her CD4 count had risen to 446.

On December 10, D.W. informed me that she was pregnant. This had been discovered as part of the Partner's Project, a study of HIV-positive patients and their seronegative partners. D. W. and T. R. had discussed the issue of having children previously, and they wanted to have a child. I had told them the risks involved, and I am certain that I conveyed my opinion that it might not be a good idea. D. W. had had ten prior pregnancies and three prior children. She and T. R. were fairly sure that they wanted to keep this child. After several appointment reschedulings, D. W. went to BAPAC, the Bay Area clinic for HIV-positive prenatal care. She had her first appointment January 13, 1998. BAPAC followed her throughout the pregnancy, keeping her on the same antiretroviral regimen, Septra, and INH. On February 10, she had an undetectable viral load and a CD4 count of

457. In June 1998, D. W. delivered a healthy HIV-negative baby girl, who is now living with T. R.'s sister in Oakland. D. W. and the baby received peripartum AZT. D. W. also had a tubal ligation.

I did not see D. W. again until September 14, when she came to urgent care with pharyngitis. She was using crack again. As of September 30, she was off antiretroviral therapy with a CD4 count of 350 and viral load of 40,000. On November 14, she came to my HIV clinic and wanted to restart triple therapy, which I agreed to. D. W. and T. R. are still together. T. R. is living in a clean and sober post-detox residential facility and D. W. is on a waiting list for permanent supportive housing. D. W. and T. R. visit their daughter several times a week.

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7.

L. T. is an HIV-positive person without a home. He is 43-years-old with a history of long-term homelessness, and he has been HIV-positive since 1984. He is a Vietnam veteran and carries a diagnosis of PTSD and schizophrenia. He came to the Tom Waddell Clinic after being banned from other clinics for exhibiting threatening and violent behavior. L. T. complained of chronic back pain and had been on opioid analgesis intermittently. He had been seen by a psychiatrist and treated with antipsychotics and benzodiazepines. His drug of choice is methamphetamine, which he is trying to stop using.

We first started seeing L. T. in 1995. At that time he was coming to our urgent care site; later he engaged with a primary care physician who began to treat his HIV disease and pain. He saw the psychiatrist at the clinic, who restarted his antipsychotic medications. For most of that time, L. T. was homeless and on the street. He received SSI and VA benefits, but the money always seemed to escape him.

L. T. spent his most of his time pushing a cart, recycling. He would search dumpsters, seeking plumbing supplies or other things to sell. Often, we have the perception that individuals who are homeless do not work hard. L. T. works harder than most people do. Many of his crises have occurred after an injury which prevents him from working – prevents him from collecting things, from walking many miles a day, from pushing around 50 – 100 pounds in his cart.

In 1997, L. T. started antiretroviral medications, taking them for about six months. During that time he was housed in a single residence hotel. When he became homeless again, however, he told me that he knew that he would not be able to take his medications as prescribed, and he did not want to take them for fear of resistance. For the last year, L. T. has been homeless and not on therapy. His CD4 count fell to 250 and his viral load was over 300,000. He is aware that he may be in trouble medically.

Recently, however, he has been engaged in a new project called TLC. TLC has more community services, and nurses and other health care workers are able to check with patients almost on a daily basis. L. T. has been more adherent with his psychiatric medications and his behavior has been more

stable. In the last month, L. T. secured housing with the help of TLC, and it looks that he will be able to stay in a residential hotel with support services.

We will begin talking about highly active antiretroviral treatment (HAART) soon. L. T. knows that he is medically ready. Taking a long view, L. T. is doing better now than he was two or three years ago. He is very well engaged in practice. HAART could save L.T.'s life, but I am able to accept the fact that HAART may or may not be possible.

In the two years that I have been caring for L. T. regularly, the one thing I find most characteristic is his chaotic ups and downs. He would come to the clinic for a month or two, work with a case manager and get a housing plan; then he would slip into a pattern of being on the verge of physical violence; and then transition back into a model patient. To most clinicians in medical practice, this scenario can be incredibly frustrating. A lot of the chaos has to do with substance abuse. I always ask L. T. about drug use, and his answer is always "two or three months ago." He can only be honest with us to a point and then he feels that he must hide the fact that he is using drugs.

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8.

Larry is a 52-year-old black man who was first seen in the Homeless Health Care Center on May 17, 1988. At the time, he was sleeping on the street and in shelters. During 1988, he had eight clinic visits, mainly to treat multiple episodes of tracheobronchitis and to monitor his blood pressure. His last visit was on April 5, 1990; at that time he left the clinic without being seen. During the next two years, Larry visited the clinic intermittently. His use of alcohol and crack was heavy during this time.

On August 2, 1994, he returned to the clinic with a laceration under his right eye; he also informed the staff that he had been HIV-positive since May. Labs were ordered, but Larry left without having his blood drawn. He was referred to a caseworker, but he also left without seeing the caseworker. In September, he finally came back to have his blood drawn; his CD4 count at the time was 480. It wasn't until February 1995 that he returned to the clinic, and he allowed the provider to complete a complete physical examination and to send appropriate tests. He also received a flu and pneumococcal vaccination as well. But it wasn't until September 1995 that Larry was seen again. During that time, clinic staff had applied for benefits for Larry and had devoted a considerable amount of energy attempting to locate him. He was treated for otitis externa and then left the clinic. He wasn't seen again until the end of the year, when Larry appeared, demanding treatment with AZT. He was started – after a long discussion about treatment - on AZT as well as MVI and given a return appointment for the following month.

He next returned to clinic at the end of May 1996. Again, the provider spent a long time with him discussing the need for adherence and the importance of the medication. He left without his full examination, and was not seen until August 1997. He had been receiving care at the VA, and brought

in his medications - AZT, Epivir, Phenergan, and Desipramine. The prescriptions were filled. He next returned in February 1998; he was not taking antiretroviral medications. After a long hospitalization for multiple problems including esophageal candidiasis, Larry returned next in July 1998. He now weighed 97 pounds and had been given the diagnosis of advanced AIDS and wasting syndrome. He again became lost to follow-up until the staff saw his obituary in the newspaper on October 10, 1998 - he had died at the local county nursing home.

This was a very difficult case due to the inability to follow this patient on a regular basis and because of his nonadherence to any care plan. Although he had received repeated education on HIV, medications, safe sex, and so on, he continued to follow his own plan - which was based on alcohol and drug use. He had received several detoxification treatments. It is notable that when he was the sickest, he was sexually active with multiple partners (names unavailable - he couldn't remember - he didn't even mention he was married.) He did not tell his wife about his HIV status, and we had to test her and tell her that she was infected with HIV.

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9.

Miguel, a 28-year-old undocumented Mexican national, first became known to the staff at the Albuquerque Health Care for the Homeless in 1997. He presented as a well-developed, well-nourished male whose only complaint was that of pain in his left shoulder, which had been on going for three months following a blow he had taken during a fight. Within a week, Miguel had a positive PPD of 23mm induration and a positive HIV test. Initial recommendations for TB treatment included INH therapy for one year, but realistic goals were for ten months.

Attempts by HCH staff to provide incentives or motivate Miguel with short-term housing in exchange for his adherence to the medication proved to be successful only for brief periods of time. At one point, Miguel was given the opportunity to receive free room and board at a local retreat center in exchange for yard work. All went well for approximately three weeks until Miguel decided to take his friends out for a short ride using the center's vehicle without permission. When asked what he had thought he was doing, he responded by saying he thought he had the trust of the center manager. Miguel was told he had to leave, and we did not see him until one month later.

The local men's shelter was sympathetic to Miguel's physical and social circumstances and also tried to motivate him with room and board for an indeterminate amount of time in exchange for light yard work. In time, Miguel complained that he felt confined and eventually left.

Miguel learned only a few words in English, but nevertheless proved to be extremely resourceful in finding work. His desire to send money to his family in Mexico seemed to be his strongest reason for continuing to live in this country. Over one-and-a-half years, he was deported to Mexico four times; four times he made his way back. Upon each return, he would appear at HCH physically wasted, in need of nourishment and rest. Each time, the challenge of finding short-term respite for Miguel was renewed.

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January 1999

10.

M. A. is a 45-year-old woman with a history of HIV disease since May 1997. She also has a history of depression, hepatitis C, a long-standing narcotic addiction, amenorrhea, chronic low-back pain, is status post-laminectomy. Originally from Phoenix, Arizona, M.A. is divorced. She had applied for SSI, but was declined; she is now appealing. She is a sex worker and receives general assistance. She has two children, six and seven years old, who are in foster care.

Shortly after she found out that she was HIV positive, M.A. came to the clinic to establish primary care for her HIV disease. At that time she had no specific complaints, but was interested in methadone maintenance treatment for her narcotic addiction. Her viral load was about 46,000, and her initial CD4 count was 576. I explained the significance of these lab values and asked her how she felt about taking medications regularly on a long-term basis. It quickly became obvious that she was unable to commit to therapy. She seemed distracted by a number of needs; for example, she needed a letter for her SSI application, and she needed another letter in order to receive methadone maintenance. She did not have stable housing, and she had so many other priorities that taking medication on a regular basis was not one of them.

When I first see patients such as M.A. who has numerous psychosocial problems, I prefer that they demonstrate that they are able to visit the clinic on a regular basis before I handle a complicated prescription. The initial visit is used to explain treatment benefits. The patient must show up for a follow-up appointment, demonstrating that they are really interested and able to comply with therapy.

After I first saw M. A., she did not return to the clinic for about six months. At this subsequent visit, we discussed methadone detoxification, rechecked some laboratory tests, and scheduled a follow-up in two weeks. Her lab work showed her viral load had increased to almost 100,000 and her T-cell count had decreased to 186. I referred M.A. to our case manager to help her keep her appointment.

She did not keep the scheduled appointment, but dropped in on another occasion. She had gonorrhea and was willing to take Septra for PCP prophylaxis, but she was not ready to take antiretroviral medications. M.A. reported that she has regular clients who are aware of her serostatus, but they prefer not to use condoms. According to her, the unprotected sex is consensual.

Here is a patient who would clearly benefit from therapy, but cannot make it a priority. When I saw her most recently, however, M.A. expressed interest in HIV treatment, feeling that if she does not get treatment she will die, and she is not ready to die. I prescribed Combivir and Nevirapine, hoping to get her started without using protease inhibitors. I am uncertain that M.A. is able to adhere, so I am retaining the possibility of using protease inhibitors in the future.

I think M.A. trusts me and in spite of her chaotic lifestyle, she manages to come in fairly regularly.

M.A. remains overwhelmed with other problems and still uses heroin. She wants to get into substance abuse treatment, but she is unable to take the first step to do so. She is marginally housed, living in a SRO. Depression also seems to interfere with her ability to act, so I have added Prozac to her regimen, hoping it will make a difference. She always has a list of things for me to do for her, and she relies on me for things I feel she could do for herself. I spend time and energy trying to give her these things, but she often abuses them to get the services she wants.

Karen Bayle, M.D.

Tom Waddell Clinic, Community Health Network of San Francisco

San Francisco, CA

February 1999

11.

I met Mr. R. in the homeless shelter around 1994. He had been a resident of multiple homeless shelters in the city as well as up and down the state of California for the past four years. A non-smoker and non-drinker, Mr. R was generally in good health until August 1990. At that time, he was residing in the Episcopal Sanctuary Shelter, where he was treated for a fever and cough for six weeks before being admitted to San Francisco General Hospital. I was doing outreach at the shelter, and found him in his bed with a fever of 103°F. I took him to the emergency room and stayed with him until he was admitted.

Mr. R. was hospitalized for two days. He had an unremarkable work-up. However, his HIV test returned positive. Previously, he had mentioned that he had had a negative HIV test, but it turned out that he had end-stage AIDS. Perhaps, he was in denial.

His initial CD4 count was 8, and his viral load was 300,000. His fever turned out to be secondary to cryptococcal meningitis and pneumonia. He was treated as an inpatient, then transferred to a long-term care facility, Laguna Honda Hospital to complete his IV antifungal treatment and for psychosocial evaluation. After being discharged from Laguna Honda to a SRO hotel, he visited the clinic three days later. He had another fever, so he was again admitted to the hospital.

Following his transferal back to Laguna Honda, he stayed there for six weeks. His social worker found housing for him at Lelan's House, a long-term living facility for advanced HIV-positive patients. Finally, he has stable housing. After the cryptococcal infection was stabilized, I started him on antiretroviral therapy and prophylactic medications. He is on 3TC, D4T, Crixivan and Sustiva. His viral load is less than 50 and he is doing very well.

Chuck Marion, M.D.

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February 1999

Appendix III - GLOSSARY

ADAP	AIDS Drug Assistance Program, part of RWCA
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BPHC	Bureau of Primary Health Care, HRSA
CD4	Blood cells destroyed by HIV during replication; a CD4 count has been used as a surrogate marker for HIV progression but has been replaced by viral load measurement in recent years.
CDC	Centers for Disease Control and Prevention, HHS
CMV	Cytomegalovirus, an opportunistic infection
CPG	HIV Prevention Community Planning Group; determines priorities at the state level for the implementation of HIV prevention activities
HIV	Human Immunodeficiency Virus
HAB	HIV/AIDS Bureau, HRSA
HAART	Highly Active Antiretroviral Therapy
HCHCN	Health Care for the Homeless Clinicians' Network
HHS	US Department of Health and Human Services
HRSA	Health Resources and Services Administration, HHS
IDU	Injection or Intravenous drug user
MAC	<i>Mycobacterium avium</i> complex, an opportunistic infection
MSA	Metropolitan Statistical Area
NHCHC	National Health Care for the Homeless Council
NRTI	Nucleoside Reverse Transcriptase Inhibitor, a class of antiretroviral drug
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor, a class of antiretroviral drug
OI	Opportunistic Infection
PCP	<i>Pneumocystis carinii</i> pneumonia, an opportunistic infection
PI	Protease Inhibitor, a class of antiretroviral drug
RWCA	Ryan White CARE Act, which provides Federal funding for HIV-related services
STD	Sexually Transmitted Disease
TB	Tuberculosis

Appendix IV

HCH CLINICIANS' NETWORK HIV/AIDS ADVISORY COMMITTEE

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Appendix V
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