

ADAPTING YOUR PRACTICE

Treatment and Recommendations for Homeless Patients with HIV/AIDS

Health Care for the Homeless
Clinicians' Network

2003

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The information and opinions expressed in this document are those of the Advisory Committee for the Adaptation of Clinical Guidelines for Homeless Patients with Asthma, not necessarily the views of the U.S. Department of Health and Human Services, the Health Resources and Services Administration, or the National Health Care for the Homeless Council, Inc.

PREFACE

Clinicians with extensive experience caring for individuals who are homeless routinely adapt their medical practice to foster better outcomes for these patients.

Standard clinical practice guidelines often fail to take into consideration the unique challenges faced by homeless patients that may limit their ability to adhere to a plan of care. Recognizing the gap between standard clinical guidelines and clinical practices used by health care providers experienced in the care of individuals who are homeless, the Health Care for the Homeless (HCH) Clinicians' Network has made the adaptation of clinical practice guidelines for homeless patients one of its top priorities.

An Advisory Committee comprised of 11 health and social service providers experienced in the care of homeless individuals with HIV/AIDS devoted several months during 2002–2003 to developing these adapted clinical guidelines, drawing from their own experience and from that of 28 HCH practitioners¹ and other service providers across the United States. The adaptations reflect their collective experience in serving HIV-infected homeless people.

We hope these recommendations provide helpful guidance to primary care providers serving individuals who are homeless, and that they will contribute to improvements in both quality of care and quality of life for these patients.

Patricia A. Post, MPA
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INTRODUCTION

The prevalence of HIV/AIDS is dramatically higher among homeless people than in the general population. Approximately one-third to one-half of persons living with acquired immuno-deficiency syndrome (AIDS) in the United States are estimated to be either homeless or at imminent risk of homelessness (Goldfinger et al., 1998). Median prevalence rates of the human immunodeficiency virus (HIV) that causes AIDS have been found to be at least three times higher in surveyed homeless populations (3.4%) than in the general population (less than 1%) (Allen, 1994, Lopez-Zetina, 2001). Even higher prevalence rates (8.5% – 62%) have been reported in various homeless subpopulations, including adults with severe mental illness (D'Amore J, 2001; Paris, 1996; Fournier, 1996; Susser, 1993; Zolopa, 1991; Torres, 1990).

Homelessness and HIV/AIDS are widespread and intersecting problems that occur in both urban and rural populations throughout 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. Even among persons known to be at highest risk for HIV infection — including individuals who engage in intravenous drug use without sterile syringes and/or unprotected sex with infected partners — those without stable housing are more likely to be HIV-positive, wherever they may live. (Song, 1999)

Several logistical problems face homeless persons who are ill. Shelters commonly require overnight residents to leave early each morning, with the doors opening again in the late afternoon. Waits in long queues are required to enter the shelter, obtain a bed ticket, and secure a meal. Tuberculosis and other communicable diseases are common in the crowded, poorly ventilated, dormitory-style shelters often found in larger cities. (O'Connell and Lebow, 1992)

While they wander in search of refuge during the days, homeless people are exposed to the extremes of weather and temperature. Fatigue and weakness are common constitutional symptoms that are magnified during the struggle to survive on the streets, especially for those who must carry all their worldly possessions during the daily journey. Inanition and malnutrition render homeless persons with AIDS prey to all manner of violence, especially on the first and third days of the month, when entitlement and Social Security checks arrive. (Ibid.)

Antiretroviral medications frequently have debilitating side effects, such as recurrent and often explosive diarrhea, yet public bathrooms are scarce and often locked to indigents. Some medications require refrigeration, which is unavailable to most homeless individuals. Many of these drugs have a high value on the black market in some areas, and are frequently stolen or sold. (Ibid.)

Despite their disproportionately high risk for HIV infection and transmission, homeless people have limited access to medical care, which delays the identification of HIV and comorbidities, impedes the resolution of behavioral disorders that interfere with HIV risk reduction and treatment, and accelerates the onset of AIDS. Restricted health care access is also a contributing fac-

tor in the higher prevalence of opportunistic infections and other medical conditions, including tuberculosis, among HIV-infected people who are homeless. (Song, 1999)

Adherence to complex HIV treatment regimens presents special challenges for homeless patients and their caregivers. Many homeless people lack regular access to food, water, and other resources needed to facilitate adherence. Mental illness and chemical dependencies present special challenges to developing and adhering to a plan of care. Nevertheless, there are no absolute contraindications to antiretroviral therapy. While it is important to prescribe HIV therapy for homeless patients desiring treatment who have demonstrated regularity in their daily routines, it is just as important to assure the most effective alternative care (i.e., prophylaxis and treatment of comorbidities) for all HIV-infected patients, including those with more chaotic lives, for whom antiretroviral treatment is not yet appropriate. Social support is an essential component of HIV care for all patients who are homeless, many of whom lack family or friends to help them cope with the added stress of serious illness.

Clinical practice guidelines for people with HIV/AIDS who are homeless are fundamentally the same as for those who are housed. Nevertheless, primary care providers who routinely serve homeless patients recognize an increased need to take their living situations and co-occurring disorders into consideration when working with their patients to develop a plan of care. The recommendations in this guide were developed to assist clinicians who provide HIV care for homeless adults and adolescents. It is our expectation that these simple adaptations of established clinical guidelines will maximize opportunities for homeless patients to receive the optimum standard of care.

The Public Health Service's Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, February 2002, and Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States, August 2002 (<http://aidsinfo.nih.gov/guidelines/>) are the primary source documents for these adaptations. Recommendations found in these guidelines are not restated in this document except to clarify a particular adaptation.

CASE STUDY: ADULT HOMELESS MALE WITH HIV

E.W. is a 50-year-old African American man who had been living on the streets of Boston, occasionally sleeping at a night drop-in center where a nurse practitioner (NP) from the Health Care for the Homeless program began to interact with him. Shy, reticent, and withdrawn, he gradually became more comfortable with the NP and complained of pain in his teeth when eating. He agreed to see the dentist at the HCH clinic, who noted oral thrush in addition to marked periodontal disease.

Over the next several months, the NP convinced this gentleman to come to the primary care clinic for HIV testing. When he was found to be HIV positive with a low CD4 count, he was admitted to the medical respite facility. The staff there worked with his primary care clinician to initiate HIV medications.

His response was excellent. He is now housed, volunteers at local AIDS agencies, and continues to have an undetectable viral load.

Carole Hohl PA, Denise Petrella NP, James O'Connell, MD, Boston, Massachusetts

HIV/AIDS

Homeless Adults & Adolescents

Model of Care

SERVICE DELIVERY DESIGN

- Flexible service system Access to care for initial evaluation or ongoing treatment depends on the existence of a flexible service system that homeless individuals can use on a walk-in basis or through outreach workers. “One-size-fits-all” systems of care are inadequate to meet the complex needs of homeless people. Help to identify and resolve system barriers that impede access to care, recognizing that some barriers are not within the patient’s capacity to control. Don’t focus on what the patient is not doing (e.g., on “noncompliance” with a plan of care); instead focus on what service providers can offer to enable homeless patients to obtain effective treatment, such as assuring service flexibility and providing appropriate medical assistance to anyone who walks into the clinic. Be creative; enlist the patient’s assistance, and with his/her permission, utilize everyone in the community with whom s/he has contact to facilitate delivery of care.
- Integrated, interdisciplinary model of care Successful initiation and maintenance of HIV therapy requires a holistic approach to care provided by an interdisciplinary clinical team, including case managers, social workers, medical providers, mental health professionals, and substance abuse counselors who share care planning and coordination. The patient is an essential member of this team. Optimally, medical and psychosocial services should be easily accessible at the same location; fragmented service systems do not work for homeless people. Those with multiple and complex health problems need integrated services that are accessible from multiple points of service, outreach and engagement, and stabilization in short- and long-term housing. Coordinate medical and psychosocial services across multiple disciplines and delivery systems, including the provision of food, housing, and transportation to service sites.
- Access to mainstream health system Ensure that all people with HIV infection have access to the mainstream health care system. HIV care involves multiple medical specialties, including infectious diseases, cardiology, hematology, nephrology, obstetrics/gynecology, psychiatry, neurology, dermatology, and pulmonary medicine. Full collaboration between primary care providers and specialists is the only effective treatment and management strategy. Network with community service providers who are sensitive to the needs of homeless patients to facilitate specialty referrals; assist with transportation and accompany patients to appointments. Problems that distinguish homeless HIV patients from others are primarily system and provider access problems,

rather than client problems or differences in intent or desire to adhere to a plan of care. Treatment readiness is a function of the degree to which the mainstream health care system is accessible and welcoming to these patients.

ENGAGEMENT

- **Outreach** Use outreach workers to locate hard-to-reach individuals and their contacts and encourage them to obtain medical care. View each patient contact as an opportunity for medical and psychosocial evaluation. Offer diagnostic testing and treatment at outreach sites whenever possible. Remember that unmet basic needs may prevent a person from seeking health care. Promote engagement by including nutritious snacks as part of outreach. Offer to bring patients to the grocery store or food bank, and use this as an opportunity to learn about their needs and do a psychosocial history. Homeless HIV-positive youth are often reluctant to seek care on their own. Use a “roving case manager” to help them connect with available health and social services. Work with religious leaders and faith communities (“health ministries”) to encourage their participation in outreach activities. Maintain a consistent presence in places where homeless people congregate.
- **Clinical team** The team should include professionals and paraprofessionals with strong engagement skills who make themselves available to listen to patients and help them address obstacles to care. This is especially important for homeless people who experience extreme social isolation and may have no one else to listen to their concerns. A team member with strong engagement skills should see the patient first. Specifically address psychosocial barriers to health as well as medical issues, employing an intensive case management model.
- **Therapeutic relationship** Engagement involves building mutual trust with people who are alienated from traditional health care systems. Successful HIV care requires effective engagement skills to meet medical as well as psychosocial needs. Nonjudgmental and supportive patient interactions with all members of the clinical team are essential to successful engagement. Recognize that caring for homeless patients is as much about building relationships as about clinical expertise. Spend time getting to know your patients. Listen to their concerns and engage with their interests. Both the quality and frequency of encounters are important in building a therapeutic relationship with homeless people. Realize that seeing the same provider over time facilitates engagement. Take good care of professional staff to promote provider retention and continuity of patient care.

Recognize that engagement of homeless patients often takes a long time. Small, brief conversations may be all a person can tolerate at first, but the length of an encounter will grow as the patient’s comfort level increases. Often clinicians presume that a person isn’t interested after they fail to get very far in one or two contacts. Be patient and persistent; listen well. Measure success in small increments.

CASE STUDY: HOMELESS ADOLESCENT FEMALE WITH HIV

When E. presented to our program in 1999, she was a 16-year old Puerto Rican female with a history of running away from home and sexual activity since around age 11. E. had been tested for HIV in a Staten Island clinic because she thought she was pregnant (she was not). Although newly diagnosed with HIV, her CD4 count was 132 and her viral load was over 100,000. She denied sexual abuse. Her father subsequently died from advanced HIV. Her mother has tested negative for HIV. E. was in touch with her family, but was a most elusive young woman who lived transiently with various boyfriends, her father, her mother, and on the street. She was the tenth of 11 children and had an open ACS (Child Protective Services) case.

Although there were clear medical indications for HAART, because of E.'s elusiveness and transience, we decided not to prescribe antiretroviral medications at that time. She understood the need for medications, but was unable to maintain consistency with anything in her life. She could not even safely adhere to PCP prophylaxis. Our goal was to engage her in our program and provide her with a place to go that was safe and supportive. My goal as her primary care provider was to keep her out of the emergency care system by teaching her to identify symptoms of illness and access medical care early in the course of illness rather than waiting until her health condition had deteriorated.

Initially, E. required our assistance in applying for health insurance. This was difficult because she was an unsupervised minor with no income or stable residence. We also worked on disclosure of her illness to her family and attempted to engage E.'s mother in her daughter's care. We accomplished this in collaboration with her ACS workers. E. was eventually able to obtain housing through the Division of AIDS Services, but not until after her 18th birthday. She was unable to keep this housing, however, because of her violent relationship with a male partner and her inability to pay bills and maintain herself independently in the community. Through extensive outreach, we maintained contact with E. over several years. In July 2002, she became pregnant. She now lives in a rooming house above one of her sisters. She started HAART during her pregnancy and claims to be adhering to the treatment regimen. Her viral load was undetectable for a period, but then rebounded. It is unclear whether E. takes her medications consistently or not. Her baby, born by C-section, is HIV negative. E. has learned to come to clinic appointments on time and is able to identify symptoms of her illness. She calls me frequently and seems to be taking adequate care of her baby. This patient is one of many transient, runaway teens we have seen in our clinic with HIV infection possibly secondary to early sexual abuse, low CD4 counts, and high risk for perinatal transmission.

Alice Myerson, CPNP, Adolescent AIDS Clinic, New York, New York

Diagnosis and Evaluation

HISTORY

- **Current living situation** Lack of stable housing complicates health care and adherence to HIV treatment. At every visit, document the patient's housing status, living conditions, and contact information. Assess residential stability by inquiring, "Where do you live? How long have you lived there? Where did you stay last night and where do you think you will stay tonight?" Ask where the patient spends time during the day and how s/he can be contacted. Ask explicitly about access to basic needs (food, shelter, restrooms, and a place to store medications).
- **History of homelessness** If staying in a shelter, a vehicle, on the street or in any other unstable living situation, ask if this is the first time the patient has been without a home. Recognize that living with a series of friends or family members or with multiple families in housing intended for only one may also indicate residential instability, which is fundamental to homelessness.² If there were prior episodes of homelessness, try to determine whether lack of a stable living situation is chronic or episodic. Assess the patient's resourcefulness by asking what changes enabled him/her to obtain housing or shelter. If currently homeless, try to understand the circumstances that precipitated homelessness (e.g., unemployment, bad luck, poverty, abuse, alcohol or drug problems, mental illness), and explore available housing options that might be acceptable to the patient.
- **Psychosocial history** Lack of social supports, stable housing, and other unmet basic needs can present serious impediments to maintaining reliable communications with caregivers. Obtain a detailed social history; ask about the patient's family, extended family and current social supports (living parents and siblings, marital history or partners, ongoing relationships) to determine the patient's degree of isolation. Many homeless HIV patients aren't in touch with family members or friends. Ask if they have thought about who might make decisions for them if they get very sick and have to go to the hospital. When trust is established, begin to lay the groundwork for a discussion of advance directives and end-of-life care.
- **Regular activities** Awareness of how the patient spends time each day will help service providers identify and address potential barriers to care. Ask if the patient has any sort of schedule or daily routine. ("How many times do you eat each day? How many meals did you eat yesterday? Do you get up at a certain time? Go to the same places or engage in particular activities every day?") Explore evidence of consistency in the patient's life to assess whether a medical regimen can be in-

² A homeless person is an individual without stable or permanent housing, who may live on the streets or stay in a shelter, mission, single-room occupancy facility, abandoned building, vehicle, or "doubled up" with a series of friends and extended family members. Individuals who are to be released from a prison or hospital may be considered homeless if they do not have a stable housing situation to which they can return. Recognition of the instability of an individual's living arrangement is critical to the definition of homelessness. (Bureau of Primary Health Care/HRSA, March 1999)

tegrated into his/her regular schedule of activities. Ask what activities the patient most enjoys and which preferred activities are possible under current circumstances. Improving quality of life can help to increase motivation and capacity for self-care.

- **Medical history** Request medical records from hospitals and other clinicians to gather information about prior diagnoses and treatments. Obtaining complete medical records may be difficult for migrant and highly mobile patients. If a diagnosis of HIV infection has already been made, inquire about the patient's initial, lowest, and most recent CD4 counts, last viral load, and history of opportunistic infections (OIs). Ask if the patient has ever taken medications for HIV and if so, which ones. Inquire about side effects and reasons for any changes in medication or discontinuations. Ask if the patient is currently receiving antiretroviral therapy and/or OI prophylaxis. If medical records and patient recollection are insufficient to identify specific medications taken, ask if the patient can show you old prescriptions or medicine bottles.

Ask if the patient has ever had active tuberculosis, when and where the last tuberculin test (PPD) and chest X-ray were performed, whether s/he ever received treatment and/or prophylaxis for TB, and if so, what medications were prescribed and how long s/he took them. Ask about a history of/exposure to hepatitis or other sexually transmitted diseases (syphilis, herpes). Ask whether the patient ever had a seizure; if so, try to distinguish a seizure disorder from drug withdrawal symptoms. (Withdrawal from alcohol and benzodiazepenes may result in seizures unrelated to an underlying seizure disorder.)

- **Previous providers** Homeless patients typically see a series of providers in different programs. Since engagement and a therapeutic relationship are very important, explore the patient's past experience with caregivers. ("Tell me about health care providers you have found especially helpful and how they helped you.") Ask why the patient did not return to previous provider(s).
- **Mental health history** Ask whether the patient has ever been treated or hospitalized for a mental health or substance use problem and whether s/he is currently taking psychotropic medications. Explore the patient's strengths and weaknesses, stressing positive assets. ("What do you think are some of your strengths? What do others say about you? What good things are working for you? Tell me something you are looking forward to.") Encouraging patients to talk about their life may provide insight into their emotional status and priorities, and help the clinician understand them better.
- **History of abuse/current risk** Many homeless people have been victims of physical and/or sexual abuse; some have been "self-medicating" with alcohol or drugs for most of their lives to alleviate the residual effects of trauma (posttraumatic stress disorder). These activities may enhance their risk for HIV infection. Assess for a history of emotional, physical or sexual abuse and exploitation; ask all patients if they have ever been physically hurt, afraid of being hurt, or made to do things sexually they didn't want to do. Assess for violence, abusive relationships, and patient safety (i.e., whether knowledge of HIV infection may precipitate abuse against the patient or a partner).

- **Alcohol/drug use** Ask about current and previous use of alcohol and drugs, including nicotine. Focus on obtaining a history of intravenous drug use and alcohol consumption to assess the patient's risk for HIV, hepatitis, and liver damage. If engaging in intravenous drug use, ask about injection practices and access to clean needles. Ask whether the patient has experienced black-outs. Asking questions in a natural, nonjudgmental manner establishes rapport and makes it easier for patients to talk about substance use — e.g., “When was the last time you used/got high? On what? How (injected, smoked or snorted)? Have you ever been in a drug treatment or smoking cessation program? If so, what was the outcome? What is the longest period you have been sober?” Inquire about drug(s) of choice, recognizing that many people are polysubstance users. Ask how periods of sobriety were achieved, and use this information to help guide subsequent interventions and treatment planning.
- **Sexual history/current practices** Ask about sexual orientation, gender, and specific sexual practices that may place the patient or sex partner(s) at risk for HIV infection. Ask whether the patient has sex with men, women or both. Ask the same questions of both males and females in a nonjudgmental way. Ask whether the patient has been forced to have sex against his/her will. Ask whether the patient is currently using contraception, including condoms, to assess risk for pregnancy and/or contracting/transmitting HIV and other sexually transmitted diseases. Introducing topics such as sexual assault and exchanging sex for money, drugs or basic needs gives the patient an opportunity to pursue these issues at the initial interview or when a sufficient level of trust has been established.
- **Reproductive history** Ask female patients about past and/or current pregnancies (number of pregnancies, live births and stillbirths) and any complications, such as preterm birth or eclampsia. Ask HIV-infected women whether any of their children were HIV-infected, whether they received any drugs during pregnancy to prevent perinatal transmission of HIV (antiretroviral prophylaxis), and if so, which ones. Ask about birth control practices and desire for family planning.
- **Work history** Ask what types of work the patient has done and the longest time s/he held a job, to identify abilities and interests, assess stability, and determine risk for co-morbidities associated with toxic exposure (e.g., to asbestos, silica, coal). Ask about work-related illness or injuries.
- **History of detention/incarceration** Ask whether the patient has been detained by police or incarcerated, and if so, whether s/he ever received medical treatment while incarcerated. Housing options may be closed to previously incarcerated people. A history of incarceration is associated with increased risk for HIV and hepatitis.³ Admission to/discharge from criminal justice facilities

³ 70% of the incarcerated population in Texas was reported to have hepatitis C (conversation with Dana Clark, MD, Baylor College of Medicine, 11/04/02). Of 642 subjects detained in Los Angeles County for injection drug use, 3.0% had HIV, 3.1% tested positive for hepatitis B surface antigen marker, and 80.3% for antibody to HBV core antigen (Lopez-Zetina et al, 2001). For more information about known incidence/prevalence rates of HIV among inmates in jails and prisons, see Bartlett, 2001-02 (chapter on HIV in Corrections: www.hopkins-aids.edu/publications/book/cor_prev.html).

may interrupt continuity of care and treatment adherence. In many communities, if a homeless individual is arrested, even for a public nuisance offense such as loitering or public urination, any medications they have with them may be confiscated and not returned.

- **Literacy** A number of homeless people have trouble reading. They may be illiterate or have a low literacy level in their primary language and/or in English, if it is not their native tongue. (A patient may speak but not read English while being literate in Spanish, for example.) Assuming erroneously that the patient can read directions on medicine bottles or an appointment card can lead to serious complications and loss to follow-up. Patients who cannot read may not volunteer this information out of embarrassment or shame. The intake form can serve as a nonthreatening way to evaluate the patient's reading ability. Ask, "Do you want help filling this out?" "Are you comfortable reading?" or "Do you have trouble reading?" This can allow patients to save face, since "trouble reading" can indicate either vision or literacy problems.
- **Nutrition/hydration** Poor nutrition and inadequate hydration are endemic among indigent and homeless people. Recognize that even those who are overweight are at high risk for malnourishment because of diets high in fat, salt and carbohydrates and low in vitamins and minerals. All patients should have an initial nutritional assessment. Special attention to nutritional status and intake is especially important for pregnant patients. Look for signs and symptoms of malnutrition and dehydration. Ask about diet and eating habits. Evaluate the patient's knowledge of proper diet and food resources (pantries, soup kitchens, delivered meals and nutritional supplements including vitamins), as well as cooking skills and availability of cooking facilities. If the patient is not eating well, determine the reasons why—e.g., limited access to nourishing food, poor dentition, use of financial resources to purchase illicit drugs/prescribed medications or shelter instead of food. Inquire about access to water and other liquids, especially in summer months. Adequate hydration is necessary to avoid some medication side effects (e.g., to prevent kidney stones when taking crix-ivan).
- **Community** Ask questions to elicit information about the patient's cultural heritage and religious or spiritual history and affiliation. This information can help the clinical team develop an approach to care that is responsive to the patient's belief and value system. Some patients who are difficult to follow can be contacted through faith communities. Ask about attitudes of the patient's family, friends, community and cultural group toward HIV risk behaviors and persons who contract the virus. Stigmatization of HIV-positive persons is more severe in some cultures than others. For example, it is more shameful in some communities for Latino males than for other homeless men to admit certain behaviors that increase their risk for HIV. Consequently, they may not seek screening as readily as other clients.

PHYSICAL EXAMINATION

- **Comprehensive exam** Because HIV affects so many organ systems, the importance of a thorough physical examination is magnified. Nevertheless, a full-body, unclothed examination of a homeless individual is rarely possible before engagement is achieved. The patient may be too fearful to be examined, indicating the need to build a therapeutic relationship first. Lack of a private setting in which to conduct examinations may also be a challenge, particularly in outreach settings.

Examine patients wherever they are comfortable. To enhance patients' comfort level, some medical providers promote informality by dressing casually and inviting patients to call them by their first name. Once engaged, patients can be seen in a more conventional clinical setting where a more complete examination can be performed. Explain at the first visit what a comprehensive physical examination entails, and ask permission to perform one. Remind patients that they can defer the exam until they feel comfortable. If the patient prefers not to disrobe at the first visit, defer the genital exam until the second visit or whenever the patient's comfort level allows, especially for a young adolescent or if a history of sexual abuse is suspected. Sensitivity to the patient's needs will promote trust and make her/him more at ease at subsequent visits.

- **Serial, focused exams** If the patient is not ready for a comprehensive physical examination, conduct serial, focused examinations until a therapeutic relationship is established (e.g., examine the patient's feet, listen to his/her chest). Ask permission to perform each physical exam. Be attentive to the patient's comfort level and pay attention to nonverbal cues; do whatever s/he can tolerate at the time. Schedule a return visit within a short period of time and plan frequent follow-up encounters to complete the examination. Demonstrating respect in this way and affirming the patient's role as a partner in his/her care will eventually lead to a sufficient level of trust to enable a comprehensive examination.
- **Homeless women** Whenever possible, offer female patients the option of being examined by a health care provider of the same sex. High percentages of poor and homeless women have been victims of physical or sexual abuse.⁴ Routinely assess for domestic/interpersonal violence. A screening tool recommended for this purpose is the Posttraumatic Diagnostic Scale Modified for Use with Extremely Low Income Women (Melnick and Bassuk, 2000). To decrease anxiety, explain at the outset the purpose of each visit and what the patient can expect to happen. Always let her know what you are going to do before you do it. Some patients are more comfortable entering the examination room if a friend or case manager accompanies them. A chaperone should be present during every pelvic exam. Become familiar with relaxation techniques to help patients cope with stressful or uncomfortable procedures.

⁴ Over 90% of surveyed homeless women reported severe physical and sexual assault during their lifetime (Bassuk, 1996); 43% were sexually molested as children (Community Connections, 2002). Homeless women are four times more likely than domiciled women to be raped (Song, 1999). HIV infection is a risk factor for abuse, regardless of housing status. Of surveyed women with HIV, as many as 50% have suffered sexual abuse, and 60% have experienced domestic violence.

HIV-infected women have increased incidence of cervical dysplasia, human papilloma virus, and candida vaginitis infections. The risk of negative outcomes is higher for homeless women, who often resist routine pelvic and breast exams because of a long history of physical/sexual abuse (O'Connell and Lebow, 1992). Close evaluation to detect cervical dysplasia and carcinoma in situ is critical to avoid progression to cancer. This should be accompanied by careful examination of the vulva, vagina and rectum. Women of child-bearing age should also be examined to determine if they are pregnant. If the patient is pregnant, try to determine the gestational age of the fetus and assess for possible complications of pregnancy — e.g., preeclampsia/eclampsia (blood pressure, edema, proteinuria), gestational diabetes.

- **Sexual minorities** Recognize that homeless people with a non-traditional sexual orientation or gender identity (gay, lesbian, bisexual, transgender) experience even greater obstacles to health care than do other homeless people, and may not have seen a primary care provider for years. Many clinicians are uncomfortable examining individuals whose gender expression diverges from cultural norms. A male taking estrogen needs to have mammograms; a female taking testosterone still requires a Pap smear and breast exam/ mammogram. Any patient who has had a silicon or other implant, regardless of gender or sexual orientation, should receive both physical and radiological examinations and be carefully monitored. Patients who have had sexual reassignment surgery require genital examination as part of regular health care maintenance. Listen to these patients' concerns nonjudgmentally. Treat each client as a unique individual and provide respectful, compassionate care.
- **“Touch therapy”** Many homeless persons with HIV have not been touched for a long time and may be shunned or physically/emotionally abused by other homeless people and service providers if their condition is disclosed. Shake hands to ameliorate the patient's sense of being an “untouchable” because s/he is dirty or has HIV. Once trust is established, “touch therapy” can be an important part of caring for patients (e.g., touch the patient's shoulder when listening with a stethoscope; ask if s/he would like a hug). But pay attention to nonverbal signals and recognize that some patients, particularly those experiencing paranoia, may find touching threatening, even outside the examining room. Be careful about using “touch therapy” unless another member of the clinical team is present.
- **Signs & symptoms of HIV** Recognize the signs and symptoms of HIV complications and a failing immune system. These may include oral thrush, shingles, dermatitis, Kaposi's sarcoma, tuberculosis, chronic diarrhea, dementia, and recurrent fevers. Realize that the onset of symptoms such as weight loss and dehydration can be hastened and exacerbated by homelessness, and that HIV symptoms may be difficult to differentiate from comorbidities in multiply diagnosed patients. For example, weight loss in a homeless individual may be the result of primary malnutrition rather than HIV wasting syndrome; dementia may be secondary to chronic mental illness/substance abuse, opportunistic infection, and/or neurological changes associated with AIDS. Maintain good linkage with specialists for assistance with differential diagnoses.

- **Dermatological exam** Do a thorough examination of the patient's skin and oral mucosa on a regular basis. Look for skin cancers, rashes, and fungal infections in the mouth, groin, and feet, which may indicate that disease is not being adequately managed in a patient with a known HIV diagnosis. Oral candidiasis ("thrush") and tinea pedis ("athlete's foot") are common fungal infections seen in homeless patients. Many skin diseases such as seborrheic dermatitis are exacerbated by HIV. Dirty skin may complicate the assessment, as many homeless people have no place to bathe. Pay special attention to genital and rectal warts, skin problems associated with injection drug use, and foot care. Corns, blisters, and ulcers are other common problems.

Associated morbidities, such as diabetes and peripheral vascular disease, exacerbate foot problems. Venous stasis ulcers carry a risk of cellulitis and/or sepsis and their management is difficult. Their appearance and smell may contribute to the cool reception that homeless persons often get in mainstream medical facilities. Ill-fitting shoes, hours on their feet without the protection of clean socks, and limited access to good hygiene create a perfect environment for infection in homeless people. Understand that if homeless persons can't get around, their lives may be in jeopardy; helping them care for their feet shows sensitivity to their problems and helps to promote engagement.

- **Neurological/psychiatric evaluation** Perform a thorough neurological examination and mental health evaluation, as the patient's comfort level allows. It is often necessary to explore only briefly at the first encounter and continue the evaluation at subsequent visits. Assess for mental illness, substance abuse, and evidence of cognitive impairment. Screen for domestic violence and posttraumatic stress disorder. Effects of HIV on the central nervous system may be confused with those of substance use, psychiatric disorders, or medication side effects. HIV infection and treatment can also trigger and exacerbate underlying mental illness. Be aware that the first signs and symptoms of serious mental illness may coincide with the discovery of HIV infection.

Normalize discussion of mental health issues in the primary care setting by asking about "stress" rather than "mental illness." If emotional problems are suspected, ask if the patient would like an appointment with someone (preferably a mental health professional on the clinical team) to discuss his/her concerns further. People with underlying psychiatric disorders, especially PTSD, may be self-medicating with alcohol or street drugs; it is important to explore this during the psychiatric evaluation.

- **Dental/vision exams** Dental problems secondary to HIV are difficult to distinguish from bad dentition in homeless individuals, whose access to oral health and vision care is often limited. Every effort should be made to include a dentist on the clinical team, as well as an optometrist or ophthalmologist to do retinal exams. Portable equipment allows for dental outreach in soup kitchens and other homeless service sites. All HIV-positive patients should receive a dilated ophthalmological exam every 3–6 months, especially those with CD4 counts < 100, to screen for cytomegalovirus (CMV) retinitis.

DIAGNOSTIC TESTS

- **HIV test** Conduct an HIV antibody test only if you will educate the patient, protect public health, and engage the patient in care. A homeless client should be engaged in care with appropriate social supports before HIV testing is done. “Because many of the conditions that accompany HIV infection can be treated, it is ethically unacceptable to provide HIV testing in the absence of adequate and accessible medical services”(Goldfinger et al., 1998). Engaging in care is important to provide support, reduce HIV transmission, and initiate prophylaxis, if needed, even if the patient is not ready for HIV therapy.

Don't offer testing in a setting where facilities, expertise, or support are lacking to provide HIV care. Testing by mobile units that can only refer elsewhere for medical care does not work well for homeless people and can present challenges to preserving client confidentiality. Facilities that do only outreach and HIV testing must provide direct linkage to care providers and assertive case management to assure that homeless individuals actually receive care. Offer testing to partner(s) of HIV-positive patients; provide an incentive (e.g., grocery store voucher) to the patient who brings a partner in for testing. Offer testing of an HIV-infected person's children, regardless of age, if they haven't already been tested. Infants under 15–18 months born to HIV-infected women require virologic testing (e.g., HIV DNA PCR) instead of antibody testing due to transplacental maternal antibody.

- **Pre-test counseling** Pre-test counseling is essential. Before testing for HIV infection, explore the patient's perceptions of what being HIV positive means. Identify the patient's support systems; ensure support from the clinical team and others. Ask what the patient will do when HIV test results are known. If the response is that s/he will harm him/herself or others if HIV-positive, more counseling is needed before testing is done. Make a clinical decision regarding social stability as a prerequisite for HIV testing on a case-by-case basis. For some patients, having HIV test results immediately is clinically necessary.
- **Screening test** Many patients prefer oral testing to standard blood testing for HIV because it is less invasive. With proper use, oral mucosal testing (OraSure®) has comparable specificity and sensitivity, and has been shown to increase patient willingness to be tested. Oral testing is especially useful in outreach settings, and is strongly recommended for homeless /runaway youth (since many adolescents resist invasive procedures).

Rapid diagnostic testing options may also provide preferable alternatives for many patients. For example, the OraQuick Rapid HIV-1 Antibody Test (FDA approved in November 2002) utilizes a fingerstick blood sample. Results are available in 20 minutes or less, compared to up to two weeks for standard blood tests and the oral mucosal test, and can be read by a trained staff member without the necessity of a laboratory, making this test ideal for use in most homeless clinics. Much care must be taken during pretest counseling to assess the patient's readiness for the test

result when using the rapid test. In outreach settings, it is best not to use the rapid test if support staff are not available to assist the counselor and the patient in the event of a positive test result. Train clinical staff in the proper use of diagnostic modalities likely to make HIV testing more acceptable to homeless patients.

- **Confirmatory test** A negative HIV screening test does not require further testing (although retesting is recommended for persons with known or possible exposure to HIV within the last 3 months), but a positive test should be confirmed before the individual is told that he or she is infected. If an initial screening test (oral mucosal, rapid test or standard blood test) is positive, do a confirmatory test (Western blot or immunofluorescence assay). (CDC, 2001)
- **Post-test counseling** Be sure the patient is engaged in care when a positive test result is communicated. Receiving an HIV diagnosis is as devastating to someone who is homeless as to someone who is not, but a homeless individual has fewer social supports. The same individual who conducts pre-test counseling and HIV testing should conduct post-test counseling for that patient. Be personally available when the patient returns for test results, and maintain contact with him/her. If the test result is positive, normalize emotions the patient will go through and address stigmatization against HIV. Use peer counselors (HIV-infected homeless or formerly homeless individuals) who have done well to talk to the patient and provide social support.
- **Baseline labs** Perform baseline laboratory tests as specified in standard clinical guidelines, including a CBC, electrolytes with glucose as well as BUN and creatinine, liver function tests, lipid studies, and a urinalysis. Perform diagnostic tests at the first visit and review lab results at the next encounter. Pay more attention to liver function tests in a homeless patient whose risk for liver damage (secondary to hepatitis, alcoholic cirrhosis) is high. Patients on hormones should also have regular monitoring of liver functions. Recognize that the serum albumin test cannot be reliably used to differentiate wasting syndrome (cachexia) associated with HIV/AIDS from dietary inadequacy/ malnutrition often seen in homeless individuals with co-occurring substance use disorders who do not obtain regular meals from shelter-based meal programs or soup kitchens (free food sources).
- **Viral load** Perform a virologic test (e.g., HIV RNA) to determine viral load only in patients known to be HIV positive. Avoid doing an HIV RNA assay following a single positive rapid antibody test (which may be a false positive) unless the patient reports a prior positive HIV test.
- **Resistance assay** Drug resistance testing (genotyping or phenotyping) should be considered for patients with acute HIV infection, for those who have failed or not responded optimally to anti-retroviral treatment regimens, or for “treatment naïve” patients (who haven’t had prior HIV treatment) from areas with a high incidence of resistant HIV strains. In areas where drug resistance is high, do resistance testing for every new HIV patient. Some clinicians with large HIV practices report that many homeless patients are treatment naïve because of limited access to

health care or prior refusal of mainstream medical care. For this reason, they can be much easier to manage medically because of less underlying antiviral resistance.

- **Tuberculosis** Although standard practice guidelines recommend purified protein derivative (PPD) tuberculin skin testing annually for high-risk patients (US PHS, June 2000), a number of practitioners recommend testing homeless patients every six months because of their higher risk for contact with active TB cases and unpredictable follow-up.⁵ For patients with a negative PPD, re-check every six months; for those with a positive PPD, do a baseline chest X-ray and symptom screen every six months. TB specialists recommend regular tuberculin skin testing even for patients with CD4 counts < 200, who may not be as reactive to the PPD test due to immunosuppression. For persons with TB symptoms or a history of exposure to tuberculosis, a chest X-ray is recommended, regardless of the skin test reaction. Realize that a negative chest X-ray does not rule out active tuberculosis, including non-pulmonary TB, in an HIV-positive patient.

A new blood test to detect latent tuberculosis, called the QuantiFERON (QFT) test, may be helpful with this population in the future. Although recently approved for use in other high-risk groups (CDC, January 2003), it has not yet been approved for use in HIV-infected persons.

Tuberculosis surveillance techniques may vary according to the prevalence of TB in the community. Collaborate with your local health department for TB surveillance, screening and referrals, to help decrease barriers to care for homeless patients. Various agencies (including shelters) require proof of TB testing. It is not unusual for a homeless person to have been tested multiple times for TB by different providers. Help the patient maintain a “medical home” where documentation of services is maintained. Provide a written record of TB testing results on a wallet-sized card that patients can carry with them.

- **Hepatitis C** Testing for hepatitis C (HCV) is especially recommended for injection drug users and their partners, and should be part of initial screening for every HIV-infected person. High prevalence rates of injection drug use and hepatitis C have been reported among people experiencing homelessness.⁶
- **Pap smear** The 2002 US PHS guidelines for the treatment of sexually transmitted diseases recommend that a Papanicolaou (Pap) smear be obtained twice in the first year after diagnosis of HIV and if normal, yearly after that (US PHS May 10, 2002). Many practitioners recommend a Pap test every six months for HIV-infected homeless women, especially if they are severely immunocompromised. Women who have frequent STI's, multiple partners, or who exchange sex

⁵ In New York City, health care workers in settings at high risk for TB exposure, including homeless shelters, receive a tuberculin (PPD) test every three months, following CDC guidelines (MMWR October 28, 1994; 43(RR13)).

⁶ A study of 884 homeless adults in Los Angeles found that 22% were HCV infected; injection drug users and persons reporting lifetime alcohol abuse were more likely than others to be HCV infected (Nyamathi, 2002). A study of administrative databases in Philadelphia revealed that residents of public shelters were nine times more likely to have an AIDS diagnosis than the general population; and among persons with AIDS, admission to a shelter was significantly related to injection drug use (Culhane, 2001).

for goods (drugs, money, basic needs) should also have a Pap test every six months. HIV-infected women with abnormal Pap smears — e.g., atypical squamous cells of undetermined significance (ASCUS), atypical glandular cells of undetermined significance (AGUS), low-grade or high-grade squamous intraepithelial lesions (SIL) — or inflammation that does not respond to treatment should be referred for colposcopy. Providing an advocate/escort can make an often uncomfortable and/or frightening test more manageable and improve treatment adherence.

- **Pregnancy test** Offer pregnancy testing (UCG urine test) to heterosexually active female patients of childbearing age.

CASE STUDY: ADULT HOMELESS FEMALE WITH AIDS

A.B. is a 41-year-old Hispanic female who reports a first diagnosis of AIDS in November 2000. In December 2001, her viral load was 90,538 and her CD4 count was 644. This client reports a significant history of poly-substance abuse (25+ years), a history of childhood sexual abuse, recent adult sexual assault, and psychiatric instability. Assisting this client with treatment adherence involved educating her primary social supports (her daughter, sister and partner) about her HIV and mental health issues.

In September 2001, A.B. was diagnosed with high-grade cervical dysplasia while incarcerated. Coordination of her medical visits with the correctional facility during incarceration was necessary to maintain continuity of HIV care. She did not receive treatment for cancer of the cervix until January 2002 because of failure to keep medical appointments during a period of relapse in addiction recovery. Although the client's whereabouts were unknown during this period, she was able to maintain contact with our medical and mental health team by paging her social worker.

Our primary objective was meeting the client's basic needs while homeless, so that she could continue to address her medical issues. Coordination of care was provided by the Dade County Homeless Assistance Center. The client is currently awaiting transfer to a dual diagnosis residential facility. She has been provided with bus tokens and food vouchers to facilitate her return to the clinic for medical care. To further support treatment adherence, an initial mental health assessment was conducted; rec-ommendations included a psychiatric evaluation and psychotropic medications. Our multidisciplinary team has coordinated care provided to this client during medical visits, in group therapy, and in HIV educational groups.

Due to her significant instability over the last 17 months, the client did not begin antiretroviral therapy until March 2003.

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Plan and Management

PLAN OF CARE

- **Next steps** Explain the need to develop an agreed-upon plan of care with the patient's active involvement. Emphasize next steps the patient should expect, while reassuring him/her that everything need not be done right away.
- **Interdisciplinary team** Establish an interdisciplinary clinical team managed by the patient, including addiction/mental health counselors, a medical care manager, and a treatment advocate. Every member of the clinical team should engage in care planning and coordination and patient education about HIV. A team approach increases the likelihood that the patient will develop strong rapport with at least one caregiver.
- **Basic needs** Understand that HIV usually will not be the most important problem for a homeless patient unless s/he is acutely ill; food, clothing, housing and mental health issues may be perceived as more important. Develop an individualized plan of care with the patient that incorporates strategies to meet these needs. This will strengthen the therapeutic relationship, increase patient stability, and promote successful treatment.
- **Patient priorities & goals** Carefully assess the patient's immediate and long-term needs and what the *patient* identifies as priorities. Ask what s/he would like you to do. Address immediate medical needs first (the patient's reason for the visit) rather than underlying causes. (For example, provide cough medicine, pain relief, or hormones, where indicated, even if you don't think they are medical priorities.) The patient will be more receptive to discussion of underlying causes if immediate needs are met. Encourage the patient to specify his/her own goals and prioritize issues to be addressed. Meeting small, manageable objectives and keeping follow-up appointments are evidence of the patient's willingness and capacity to adhere to treatment.
- **Governmental assistance** Help the patient apply for Ryan White Comprehensive AIDS Resources Emergency Act (CARE) services, Housing Opportunities for Persons with AIDS (HOPWA), disability assistance (SSI/SSDI), Medicaid, Food Stamps, and any other programs that facilitate access to health and social services.
- **Communication** Frequent discussion, explanation in simple language, and feedback regarding the patient's understanding of the plan of care are critical to adherence. Recognize that patient forgetfulness may be a symptom of cognitive impairment secondary to HIV, medication side effects, or co-morbidities. Do not criticize the patient; speak in a straightforward and nonjudgmental manner. Avoid medical jargon and euphemisms, which can be confusing and perceived as "talking down" to the patient (e.g., with an adolescent, talk about "having sex," not "intercourse"). Use an interpreter and/or lay educator (*promotoras*) to facilitate communication and

ensure culturally competent care for patients with limited English proficiency.

EDUCATION, SELF-MANAGEMENT

- **Basic education about HIV** Learning about HIV and how to control it can help homeless patients regain a sense of control over their lives and provide an impetus for change and incentive to work on other issues (e.g., begin drug treatment, reunite with family). Begin at the first visit and provide ongoing education, support and reinforcement at each subsequent visit. Provide answers to basic questions about HIV: What is the virus? What is it doing to your body? Why do you need medication? Educate patients about the natural course of the disease. Provide printed information in language they can understand.

Teach homeless patients how to know if they are sick, how to tell if the illness is more serious than a cold, how to care for themselves when sick, and when to seek urgent or emergent care. Educate them about warning signs of HIV complications (fevers, coughs that won't go away, exhaustion) and what you can do to help alleviate these symptoms. Tell patients where they can go to get medicine and where they can go to recuperate when ill. Explain that the more advanced their disease is, the more preventive medications will be required to keep them from getting sicker.

- **HIV transmission** Explain that the HIV virus can be passed through intravenous drug use (IVDU), sexually, perinatally, and via breast milk from an HIV-positive mother to her baby. Stress the need for protection, even after beginning HIV treatment, in sexual relationships (condoms and other contraception, abstinence) and with self-administered injections (cessation of any sharing of drug paraphernalia, participation in a needle exchange program).

Counsel HIV-infected pregnant women about how to reduce the risk of transmitting HIV infection to their babies. Stress the importance of antiretroviral prophylaxis to reduce perinatal transmission of infection. Breastfeeding is not recommended for HIV-positive mothers if there is a safe alternative — i.e., if infant formula is available, if there is access to clean water to prepare formula milk and cleanse bottles and nipples, if refrigeration is available to store prepared formula, and if the mother can manage formula feeding with appropriate hygiene (Heymann SJ and Vo P, 2003; CDC, 2001).⁷

- **Prevention** Discuss ways to reduce HIV risks for the patient and others. To effect behavioral change, use individual, small group, and community interventions based on careful investigation

⁷ The CDC guidelines presume formula feeding to be a safe alternative for babies born in the United States, versus in the developing world. Nevertheless, experienced HCH providers attest that for homeless families without access to refrigeration, appropriate hygiene, and/or Women Infant Child (WIC) services, use of breastmilk substitutes may not be a feasible or safe alternative, even in the US. The rate of HIV transmission via breastfeeding, which ranges from 14% to 26%, has been reduced to 8.3% following antiretroviral treatment (Heymann SJ and VO P, 2003).

of actual patient behaviors and an intimate understanding of their daily life—how they spend their time, what activities interest them, and potential structural barriers to desired change. Use motivational interviewing,⁸ risk reduction techniques, and social skills training.

Teach safer practices to injection drug users unwilling or unable to stop using drugs (e.g., abscess reduction, use of tourniquets). Provide general sexual/reproductive health education and counsel the patient about safer sex practices (contraceptive use for pregnancy prevention and STI protection, fewer sex partners or abstinence). Reinforce this information with interactive activities that involve repetition, positive feedback, and acting out new skills, such as proper condom use (Susser, 1998) and role playing (how to talk to a partner). All members of the clinical team should participate in patient education. At every visit, provide male/female condoms or information about where the patient can obtain them. Know what is really happening in the patient's life; then try to figure out how you can help behavioral change occur within that context (HCH Clinicians' Network, 2000).

- **Addiction management** Try to find out how patients with chemical dependencies use psychoactive substances—whether they engage in erratic substance use (“binging”) or are regular users. People who binge have more problems with treatment adherence than do regular users; they forget to take their medications while bingeing and often forego food and sleep, which also interferes with disease prevention and health promotion. Some people with chemical dependencies are already experienced at organizing their time to accommodate regular drug use and avoid withdrawal symptoms.

Work with these patients to identify strategies already employed to manage illicit drug or alcohol use and apply them to HIV treatment adherence, substituting HIV medications for other drugs. For patients with demonstrated regularity in their daily routine who are unable or unwilling to stop drug/alcohol use, consider advising that HIV medications be taken prior to other drugs, if no adverse drug interactions are likely. Recognize that many homeless people use alcohol or drugs to cope with underlying emotional problems. Facilitate access to appropriate behavioral health care to promote recovery and readiness for HIV treatment.

- **HIV therapy** Inquire about the patient's understanding of HIV therapy. Some patients refuse treatment because they don't understand it, have lost hope, and don't think treatment will matter. Emphasize the positive; assure HIV-infected homeless patients that they are candidates for treatment and can manage it successfully. Highly-active antiretroviral therapy (HAART) can be as effective for highly motivated persons who are homeless as for those who are housed, as confirmed by comparative measurement of viral loads following treatment.⁹ Explain what CD4 counts and

⁸ Motivational interviewing is a goal-directed, client-centered counseling style for eliciting behavioral change by helping clients explore and resolve ambivalence (Miller and Rollnick, 2002). For more information, see: www.motivationalinterview.org.

⁹ The percentage of homeless patients seen at Boston Health Care for the Homeless Program with successful treatment outcomes (viral loads decreasing to below detectable limits and CD4 counts increasing by more than 50%) was similar to that of housed patients treated at Massachusetts General Hospital (conversation with Jim O'Connell, MD, April 2002).

viral loads are, and how these measurements are used to help determine how advanced the patient's disease is, predict risk of complications, and monitor treatment adherence.

- **Written instructions/reminders** Write down instructions about when to take medications each day, at what times. Use graphic illustrations and color coding to clarify and reinforce verbal instructions. Then make sure that instructions are understood. Ask the patient, “What medications are you going to take this morning and how?” Instruct the patient to “keep written instructions with you.” If a patient discloses that s/he has trouble reading, designate someone on the clinical team who can spend extra time to help him/her understand instructions, and offer referral to a literacy program or instruction in English as a second language. Specify any dietary restrictions associated with antiretroviral therapy or other treatment (i.e., whether medications must be taken with food or on an empty stomach). It is sometimes possible to enlist the help of shelter staff in reminding patients to take medications.
- **Drug resistance** Explain the risk of developing resistance to HIV medications if they are not taken consistently or appropriately. Acknowledge that for all persons taking antiretrovirals, as for persons receiving treatment for tuberculosis, development and spread of drug-resistant infection is a serious concern; but stress that lack of treatment is no more acceptable an alternative for HIV than it is for TB.
- **Treatment advocates** Use social workers, nurses, or case managers as treatment advocates, serving as liaisons between the patient and providers to promote successful adherence to HIV therapy. The patient may feel more comfortable discussing side effects of treatment with social workers or other advocates who have more time to explain than medical providers. Treatment advocates should be part of an integrated clinical team and treated as peers by medical providers. Consider using consumer advocates (formerly homeless persons) to accompany homeless HIV patients to appointments with specialists and attend clinic sessions with the patient and primary caregivers. This can help homeless patients overcome communication barriers sometimes experienced in encounters with mainstream health care providers.

Use of consumer advocates to explain information conveyed by the medical provider to other consumers is often helpful, but must be done with sensitivity to patient privacy and confidentiality and in compliance with requirements of the Health Insurance Portability and Accountability Act (HIPAA). (For information about HIPAA privacy requirements, see www.hhs.gov/ocr/hipaa/whatsnew.html.)

- **Directly observed therapy** Good results have been reported with directly observed therapy (DOT) when homeless patients come to the clinic once daily to take medications (Mitty, 2003). DOT is recommended for patients with co-occurring tuberculosis, substance use disorders, and/or mental illness, but can present staffing and transportation challenges when patients must take psychiatric medications 2–3 times per day. Provide transportation or carfare to assure feasibility

of this treatment option. Some communities are exploring the possibility of directly observed HIV therapy at methadone clinics. Although some patients may benefit from an adherence program that provides medication storage and directly observed therapy, others are quite capable of managing medications on their own. Homelessness has enabled them to develop a fairly rigid routine. (Some schizophrenic clients can adhere well to treatment regimens and other routines.)

- **Side effects management** Recognize that medication side effects are a primary reason for lack of adherence to HAART. Be candid about possible side effects of antiretroviral treatment, such as diarrhea, and how long they will last, so the patient knows what to expect and can identify and better describe side effects that do occur. Explain that nausea may result if medications are taken without food. Provide snacks (e.g., peanut butter crackers, individual boxes of cereal with Parmalat milk, individual containers of juice, granola bars, high energy bars) to help the patient avoid this side effect and promote adherence to treatment. Ask what side effects the patient has noticed; if there is no medical alternative with fewer/less severe side effects, explore strategies to minimize and/or accommodate them within the patient's lifestyle.
- **Urgent medical problems** Help patients understand the difference between common medication side effects (e.g., diarrhea from nelfinavir) and symptoms of life-threatening toxicities (such as nevirapine or abacavir hypersensitivity, pancreatitis, hepatitis, or lactic acidosis). Patients need to know what side effects to expect with HAART that may be mild and go away over time, so they don't stop their medications; but they also need to know how to recognize a potentially fatal drug reaction, so they will seek early medical care. Other medical emergencies include late-stage opportunistic infections such as *Pneumocystis carinii* pneumonia (PCP), toxoplasmosis, and crypto-coccal meningitis — major complications of HIV that are usually lethal if not treated. Stress the need for prompt evaluation if the following symptoms occur: fever, new rash, difficulty breathing, abdominal or back pain, vomiting, headache, vision changes.
- **Supportive relationships** Reluctance to inform others about their illness results in lack of supportive feedback for individuals with HIV. Encourage a supportive relationship with a social worker, provider, or friend — someone in whom the patient can confide fears, questions and concerns, including problems with medication side effects. Advise the patient, "If your doctor doesn't have time to listen and discuss your concerns, find someone who does." Link the patient with a support person or "sponsor" through HIV/substance abuse treatment programs or other community-based programs. Network with law schools to provide *pro bono* legal assistance with child custody, drug arrest, or immigration issues as part of substance use treatment programs.
- **Support groups** For patients who experience extreme stigmatization or isolation, create a support group where they can share concerns and learn how others are coping with their disease. Members of ethnic/sexual minorities and migrant workers may experience more marginalization and isolation than other homeless individuals with HIV. Help such patients find each other for mutual support. Offer social support groups, not just groups for therapy or counseling. Help

patients moving into transitional housing learn how to live successfully in a community setting (e.g., respect personal boundaries).

- **Nutrition counseling** Educate patients about nutritional health, diet, and dietary supplements. If possible, include a nutritionist familiar with the issues of homelessness on the interdisciplinary health team to do screening and frequent consultation. Some practitioners recommend the use of bioelectrical impedance analysis (BIA), which measures body composition (fat and lean body mass), to educate patients about their nutritional status and promote early detection and management of HIV-associated nutritional changes (Swanson, 1998). Prescribe multivitamins with minerals. Assure that pregnant patients receive appropriate vitamin supplements (with folate). Consider prescribing nutritional supplements with less familiar brand names and lower resale value to reduce risk of theft.
- **Medical home** Many homeless people have never had a regular medical provider and only receive medical care episodically from hospital emergency room staff. Discuss benefits of forming relationships with care providers who can help the patient avoid becoming acutely ill. Explain what primary care is and how to use a regular source of care (“medical home”). Present regular primary care as an opportunity to be in charge of one’s own health. Many medical problems, including those related to HIV, are preventable.
- **Education of service providers** Educate medical providers about the special needs of homeless patients. Explain how treatment adherence and successful outcomes are possible even for homeless individuals with mental health/substance use problems. Stress the importance of developing a nonjudgmental, therapeutic relationship based on unconditional acceptance of the patient and harm reduction. Understand your own feelings about substance use, sex work, and mental illness. Take time in a safe setting to explore your feelings about people who are homeless. Talk about your experience, biases, and stereotypes with other providers who are more experienced in caring for homeless patients.

Help specialists understand that homeless people may not be able to follow the treatment plan they prescribe, and how to modify the plan of care so homeless patients can better adhere. Educate primary care providers about chronic pain management and addiction medicine. Educate all homeless service providers about HIV, including prevention measures and the need for nonjudgmental, compassionate care. Provide basic education about the natural history of the disease, what to expect if the patient is or is not treated, transmissibility of infection, and universal precautions. Help pastors learn how to talk about HIV with members of their faith community. Work with food services at shelters and soup kitchens to provide appropriate meals.

CASE STUDY: HAART THERAPY FOR A HOMELESS MAN

Samuel is a 32-year-old Caucasian man who entered our therapeutic community for alcohol abuse treatment. He had tested positive for HIV two years previously. He was begun on HAART with AZT, Efavir, and Viracept. He was instructed to take Viracept 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.

The problem was solved when I spoke to the shelter staff and explained the need for the morning meal, which was subsequently provided on Saturday and Sunday mornings, in addition to brunch and dinner.

Elizabeth Lutas, M.D., New York City

MEDICATIONS

- **Medical priorities** If acute retroviral syndrome is not suspected or if early HIV treatment is not warranted for other reasons, deal with other medical priorities first— e.g., psychotropics for severe mental illness, methadone for heroin addiction, prophylaxis for opportunistic infections and tuberculosis (if +PPD), treatment and management of uncontrolled hypertension, diabetes, and seizures — any of which can undermine a patient's ability to adhere to HIV treatment. With all HIV-infected patients, weigh benefits against potential risks of early antiretroviral treatment.
- **Prophylaxis** Start prophylaxis for opportunistic infections as soon as indicated by standard clinical guidelines (US PHS/IDSA, November 2001). Explain the importance of OI prophylaxis at each visit, if the patient is not initially interested or willing to accept preventive treatment. Antiretroviral prophylaxis to reduce perinatal transmission of infection should include antenatal AZT therapy and intrapartum intravenous AZT therapy for the mother, and 6 weeks of AZT for the infant. Use of antenatal HAART is recommended if the maternal antenatal HIV RNA level is >1,000 copies/ml and treatment adherence is likely.
- **Immunizations** Given their high risk for exposure to respiratory infections in congregate living situations, all homeless patients should receive influenzae vaccine annually and be immunized against pneumococcus according to standard clinical guidelines. Also provide hepatitis B and A vaccines and update tetanus (Td) if the last immunization was more than 10 years ago. (See Quick Reference Vaccines Chart at: www.cdc.gov/nip/vaccine/vac-chart-hcp.htm.) Lacking reliable food and shelter, most homeless people welcome immunizations as a way to prevent illness.
- **HIV treatment readiness** Never rush to antiretroviral treatment; build a therapeutic relationship first. Encourage more frequent visits to prepare homeless/formerly homeless patients for treatment. Evaluate patient readiness for treatment and ability to adhere to a plan of care by first attempting to understand the patient's current behavior in light of his/her life story. Elicit this information in a nonjudgmental way; understand the patient's lifestyle and how basic needs are met. If the patient desires treatment, look for evidence of a daily routine to discover how to prescribe medications that can fit into that routine. (A patient who must leave the shelter at 5:00 a.m. may not be able to take medications at that time.)

Ask what the patient does after leaving the shelter—e.g., go to a drop-in center or the library? have breakfast? Ask if there a “private time” when the patient can take medications. Privacy is frequently an issue for homeless individuals, who worry about taking medications that have street value or that reveal their diagnosis. (If others discover they have HIV, some may refuse to sit near them or talk to them, and they may be at increased risk for abuse.) Ask the patient, “Who can help you take your medicines and keep track of them?” Outreach provides a unique opportunity to observe patients in their own environment and assess stability, evidence of regularity and capacity to follow a schedule (sleep pattern, access to food/water/clock, daily activities,

regular appointments with parole officer/methadone program, etc.), in order to assess their potential for treatment adherence. For best outcomes, engage patients and assure that they have a comfortable medical home before beginning treatment. Address issues that may complicate treatment adherence. The patient should be part of the team that helps to decide when to begin treatment.

- **“Practice” medications** For a patient desiring HIV therapy whose ability to adhere to treatment is questionable, consider using placebos or vitamins as “practice medications” for a week or two. Put medications of the same size and number to be prescribed for HIV in a pillbox; follow up in a week. Ask the patient how many pills were taken, how many missed. This may convince the patient that s/he is not yet ready for HIV therapy (e.g., needs to work on substance abuse issues first). Realize that some patients may not take practice medications seriously, possibly confirming their lack of readiness for HAART.
- **Antiretroviral medications** Be knowledgeable about HIV treatment alternatives and when to use them.¹⁰ Although treatment may be provided at the initial visit if medically warranted or if refilling a prescription, most providers recommend waiting 3–6 months before beginning HAART. Working on prophylaxis, immunizations, and obtaining housing and access to other health and social services before initiating HIV therapy can strengthen the therapeutic relationship, help the provider decide on the best medical regimen, and result in more successful treatment. Individualize initiation of HIV therapy and continually re-assess treatment adherence and effectiveness. Ensure access to medications that can be taken once or twice daily.
- **HIV specialist** HIV is a primary care disease that requires special knowledge to treat. Partner with an HIV specialist (a certified clinician who follows at least 26–50 HIV patients every six months and pursues continuing education) in prescribing treatment through consultation or referral. The team approach to care for homeless individuals is optimal; an HIV specialist, primary care provider, case manager, nutritionist, mental health professional, and outreach worker should all be part of the team. A primary care provider serving a community with a fairly high incidence/prevalence of HIV should develop HIV treatment skills. The critical mass of patients with HIV is key — if fewer than 5, refer; if 5–10 or more, develop expertise in primary HIV care. Consult with an infectious disease specialist and other specialists in planning medications for patients with co-morbidities. Consultation is a two-way street; specialists may consult primary care providers with expertise in serving homeless patients.
- **Simple regimen** The simplest treatment, tailored to individual needs, is best for all HIV patients. Pill count, frequency and dosing are extremely important for homeless patients; once-a-day dosing will increase adherence. For some patients, it will help to dispense medications a

¹⁰ See current HIV treatment guidelines at www.aidsinfo.nih.gov/. See perinatal guidelines for information about the safety and efficacy of particular HAART medications in pregnancy. Information about recent research findings is available at www.hopkins-aids.edu/publications/book/book_toc.html.

day or a week at a time, recognizing that this is feasible only if transportation to and from the clinic is available and affordable for the patient. (If possible, provide transportation or carfare for homeless patients.) If giving trimethoprim/sulfamethoxazole (TMP/SMX) for PCP prophylaxis, one dose per day is best and probably easiest for most homeless patients, but 2–3 times per week is acceptable; it's better to take some of the medication than none. The opposite is true for anti-retrovirals: it's better not to take medications at all than to take them only some of the time. Overcome the common perception that HAART medications are too complicated. Don't under-treat HIV or opportunistic infections, just because a patient is homeless.

Once-a-day therapy is preferable for homeless patients if clinically indicated, especially for those who may be unable to adhere to a more complex regimen. Antiretrovirals that can be taken once a day include: nucleosides – lamivudine (Epivir® or 3TC), didanosine (ddI or Videx®), tenofovir (Viread®), stavudine (D4T or Zerit®); non-nucleosides – nevirapine (Viramune®) and efavirenz (Sustiva®). A protease inhibitor that can be taken once daily is expected to be available soon. Trizivir (combination of AZT, 3TC and abacavir in one pill, taken twice daily) offers a low pill burden that is easy to tolerate. However, recent data suggest that Trizivir alone does not completely suppress the virus, so it must be taken either with a NNRTI such as efavirenz or with a protease inhibitor.¹¹

- **Dietary restrictions** Awareness of the patient's access to regular meals is important because some HIV medications must be taken with food. Other medications must be taken on an empty stomach. If possible, prescribe medications without dietary restrictions.
- **Side effects** Prescribe medications with fewer/less severe GI and other side effects. (Some NNRTIs and protease inhibitors have fewer GI side effects.) The severity of side effects experienced by the patient may not be apparent to the provider. Diarrhea creates an added burden for a homeless person with limited access to toilets and bathing facilities. Address the likelihood of diarrhea with certain protease inhibitors (e.g., nelfinavir) and provide anti-diarrhea medication for patients with symptoms. Nausea, which often results from taking medications on an empty stomach, may also be incapacitating; providing nutritious snacks can prevent this side effect. Be more aggressive with homeless patients in treating side effects or changing medication, if an equally effective alternative is available.
- **Drug toxicities** Be aware of serious toxicities that can occur with HAART.¹² Abacavir hypersensitivity reaction (rash, fever) occurs in a small number of patients taking this medication

¹¹ Preliminary data from a recent study (ACTG A5095) showed that patients taking AZT/3TC/abacavir (Trizivir) alone had a higher rate of virologic failure than did patients taking Trizivir with efavirenz or those taking AZT/3TC/ efavirenz. The Trizivir-only arm of the study was stopped in March 2003 after an interim review because that group had a 21% failure rate, compared to 10% in the other two groups. Virologic failure also occurred sooner in the Trizivir arm. Based on these findings, many experts advise that for patients receiving Trizivir alone, strong consideration be given to intensifying or changing the regimen.

¹² A summary of severe, life-threatening symptoms of antiretroviral drug toxicities and recommendations for monitoring and management, prepared by Dr. Lynne Mofenson of NIH for the World Health Organization (WHO, 2003), is available at: www.who.int/docstore/hiv/scaling/anex11b.html.

(Ziagen[®] or as part of Trizivir (3TC, AZT, and abvacavir)). In a few cases, Nevirapine (NVP) has been associated with hepatic necrosis or a severe skin reaction called Stevens Johnson Syndrome. Pancreatitis, lactic acidosis, and severe anemia are other medical emergencies that can be caused by antiretroviral medications.

- **Drug interactions/contraindications** Chronic illness may complicate HIV treatment because of the potential for drug-drug interactions. Awareness of drug interactions is important when prescribing HIV medications. Some medications may be contraindicated if the patient has history of pancreatitis or alcoholism, or should be used with caution and more frequent monitoring with co-occurring mental illness, hepatitis C, high cholesterol, or diabetes. Some HIV medications and HIV itself may cause metabolic changes, which can include diabetes, hyperlipidemia, changes in body fat distribution, osteoporosis, and lactic acidosis. HAART can also exacerbate pre-existing diabetes. All persons on antiretrovirals for HIV should be carefully monitored for the development of glucose intolerance and diabetes, as well as for lipid abnormalities and lipodystrophy, and treated according to accepted guidelines and standards of care.

- **Efavirenz** (Sustiva[®]) can be a good choice for homeless patients because it is one pill once a day. However, it does have neuropsychiatric effects. Efavirenz causes sedation, which can be dangerous for street dwellers, and can exacerbate underlying mental illness. If already treating a patient with a severe psychiatric disorder, monitor him/her closely or avoid using this drug, which in some areas has a high “street value” because of these effects (induces a “dream-like state”). Because of the potential for birth defects, pregnancy should be avoided in women receiving efavirenz; counseling women about this is important. For women of childbearing age for whom this drug is clinically preferable, prescribe double contraceptives (a barrier method in addition to an oral or injected contraceptive) to prevent pregnancy. It is recommended that efavirenz not be given to pregnant women except when there are no therapeutic alternatives (AIDSinfo Drugs Database, NIH: <http://aidsinfo.nih.gov>). Before initiating therapy with efavirenz, women of childbearing potential should undergo pregnancy testing. If a woman receiving efavirenz should become pregnant and the pregnancy is recognized during the first trimester, efavirenz should be discontinued (nevirapine could be substituted), at least for the first 12–14 weeks of pregnancy.

- **Methadone** Recognize that alcohol and drug use is common among homeless people, and prescribe medications that are compatible with substances used. Evaluate use of methadone by patients on HAART. Be aware that non-nucleoside reverse transcriptase inhibitors (e.g., nevirapine and efavirenz) and certain protease inhibitors (particularly ritonavir) can reduce the efficacy of methadone by as much as 50%. Avoid these medications, if possible, in any patient with opioid dependence; consider using a ritonavir-boosted protease inhibitor instead (Mitty, 2003). If this is not feasible for a patient on methadone, it is essential to work directly with the patient’s methadone maintenance treatment program to adjust the dosage upward. (Many

practitioners begin with a 20% increase in methadone dosage when HAART is initiated). Recognize that successful adherence to methadone therapy for persons addicted to heroin can increase adherence to HAART (Clarke, 2003). Some patients won't begin HIV treatment or may stop taking medications because of the misconception that all prescription drugs are incompatible with alcohol or other drug use. Most antiretrovirals are chemically compatible with commonly used street drugs, although use of psychoactive substances, including prescribed psychotropics, can interfere with remembering to take medications. Address these issues candidly with the patient to promote adherence.

- **Drug resistance** Be cautious about prescribing HAART for homeless adolescents and youth because of their higher risk for drug resistance if unable to adhere to treatment. Many are in denial and fail at the first treatment attempt. Recognize that drug resistance can be conveyed to others via blood, semen, or sexual contact; the higher the viral load, the more likely infection will spread in any given contact. Although antiretrovirals decrease infectivity (an argument for treatment despite the risk of instability), they are never 100% effective, even if the patient is adherent. Resistance is not always indicative of nonadherence; mutation of the organism can occur even if the patient adheres to treatment.

Homeless individuals should have the same access to HIV medications as others. If the patient requests HIV therapy, is willing to begin treatment, and is medically appropriate for treatment, select an initial regimen to which the patient can adhere, preferring medications with a low pill burden where possible. Consider avoiding NNRTI's and 3TC in patients suspected to have trouble with adherence. (Resistance to NNRTI drugs can be induced by a single mutation, and there is cross-resistance. Therefore, poor adherence to a NNRTI regimen may easily induce resistance to the whole NNRTI drug class. 3TC resistance can also result from a single mutation.)

- **HIV treatment & substance use** An automatic assumption that people with substance use disorders cannot adhere to HIV treatment is inappropriate. The primary challenge is determining when to initiate therapy. Patients can learn how to organize their lives so they can keep appointments and take medications while actively using psychoactive substances. Indicators of readiness include keeping regularly scheduled appointments with medical and ancillary staff. If patients desire HIV therapy and there is evidence that patients can adhere to a regular schedule despite substance use, consider advising them to take HIV medications *before* using other drugs.

If appointments are missed, seek patients out and explore in a nonjudgmental manner what has changed in their lives to motivate a change in behavior (common triggers of relapse: contact with/rejection by a family member, anniversary of a painful event). Look for indications of new stresses and difficulty coping; help patients find ways to cope. Most important, maintain communication with them. Many actively using, chronically homeless people have successful treatment outcomes. Knowing that medications can prolong life can give patients hope and motivate lifestyle changes to promote health. Successful HIV treatment is not only possible, but extremely desir-

able for homeless people with chemical dependencies.

- **Pain relief** Recognize that HIV and hepatitis C can be painful diseases, and that other common co-morbidities in homeless patients, including traumatic injuries, can result in chronic pain. It is important to remember that some HIV medications can decrease or increase the efficacy of pain medications, including methadone and other narcotics. Work with the patient to understand the underlying cause of pain, prescribe appropriate pain medication, and document why you prescribe it. Understand chronic pain management; if you don't, the patient may seek relief from practitioners known to provide pain medications indiscriminately, without understanding HIV care or monitoring for possible misuse. If necessary, refer to a pain management specialist and maintain open communications with the patient and other providers. To avoid overmedicating or contributing to drug-seeking behavior, inform and encourage cooperation from the patient with a contract that specifies the plan of care and designates a single provider for pain prescription refills.
- **Adherence monitoring** To facilitate adherence, use a harm reduction approach, outreach, intensive case management, directly observed therapy, and medication monitoring. Provide incentives (e.g., carfare, meal vouchers), and don't require clients to be drug and alcohol free to receive them. Aggressive outreach and case management will contribute to successful outcomes for active substance users. Address obstacles to taking medications appropriately. Ask the patient, "Who can help you take your medicine and keep track of it?" Some patients will benefit from treatment and a reduced risk of transmission even if viral loads are not entirely suppressed. Monitor adherence by measuring CD4 counts and viral load every 3 months; if the patient's viral load increases and the CD4 count decreases, find out why and address the reasons. (Reduced treatment adherence is often triggered by depression or a relapse in recovery). Explore barriers to adherence and problem solve with the patient.
 - **Pill packs** Consider providing "blister packs" for all medications, labeled for each day of the week, each meal per day. Some pharmacies provide pre-packaged pill boxes with handles or "easy packs" — a cellophane roll with perforated sections that enable patients to tear off morning and evening doses and carry them in a pocket or bag. This helps patients with memory loss keep track of their medications and makes resale more difficult. Some people prefer using their own system to remember what pills to take when.
 - **Pagers** Some pharmacies provide patients with pagers that vibrate when it's time to take medications and allow caregivers to page them with toll-free number. This can be a helpful aid to promote treatment adherence and clinical follow-up.
- **Medication storage/DOT** Allow homeless patients to store HAART medications at the clinic and come there daily for treatment. This protects against having medications stolen or confiscated by police if arrested for public nuisance offenses, and assures that they are taken as prescribed. If medications are not stored in the clinic and the patient does not have access to refrigeration, avoid prescribing medications that require it. Shelter residents may be required to turn in all

medications to shelter staff, who sometimes lose/misplace them or fail to return medications to the patient when needed. Lack of privacy/confidentiality is a major problem for shelter residents, who may be reluctant to complain to shelter staff for fear of disclosing their diagnosis and too embarrassed to tell the provider if medications are lost repeatedly. Educate shelter staff about the importance of making stored medications easily available to patients; explain that medications are costly and necessary for the patients' health.

- **Financial barriers** The availability of free or low-cost HIV medications may be limited, particularly in smaller communities and rural areas. For homeless patients, even a small co-payment can be excessive, and for those without health insurance or access to programs that provide free medications, the cost of antiretroviral therapy may be prohibitive. Before initiating treatment, assure continuous access to medications.
- **Pharmacy access** In some cities, homeless patients are restricted to use of one clinic or pharmacy, to prevent misuse of medications. Lack of transportation to this or other pharmacies can present barriers to getting prescriptions filled. Since homeless people do not have regular access to telephones, coordinating delivery of medications to these patients can be difficult. Provide transportation to pick up medications or arrange for delivery of medications to a location where the patient can obtain them reliably and wants to receive them (e.g., a friend's home, social work center or clinic). Delivery of medications to a clinic for pick up and distribution can provide another opportunity for hands-on education about treatment adherence.

ASSOCIATED PROBLEMS, COMPLICATIONS

- **Medication side effects** Side effects are a primary reason for nonadherence to antiretroviral treatment. Medications that interfere with survival on the streets, making people feel sicker or more fatigued, will not be acceptable. Common side effects of HAART include diarrhea (particularly from some protease inhibitors), nausea (if taken on an empty stomach), peripheral neuropathy (numbness/tingling in extremities, exacerbated by poor nutrition and constant walking), and nightmares. Living in a shelter or on the streets is especially difficult for patients with these symptoms, which are exacerbated by chronic sleep deprivation and depression. If alternative medications with fewer negative side effects are not medically indicated, treat side effects symptomatically. Some clinicians recommend the medical use of marijuana to help control pain and nausea and reduce alcohol or other drug use. Some medications (e.g., TMP/SMX (Bactrim), commonly prescribed for PCP prophylaxis) increase sensitivity to sun exposure; homeless patients who spend most of their time outdoors should be advised to wear long sleeves and sunscreen to avoid sunburn. Be more aggressive with homeless patients in treating side effects or changing medication, if an equally effective alternative is available.

- **Severe drug toxicities** Some HIV-infected patients receiving antiretroviral therapy experience symptoms of life-threatening toxicity, which would be fatal if the drugs associated with the reactions were continued. Abacavir hypersensitivity reaction, hepatic necrosis, Stevens Johnson Syndrome, pancreatitis, and lactic acidosis are among the drug reactions that should be considered medical emergencies. (For a comprehensive summary of severe drug toxicities associated with particular antiretroviral drugs, see: www.who.int/docstore/hiv/scaling/anex11b.html.)
- **Masked symptoms** Lactic acidosis may be harder to diagnose in a homeless patient because symptoms (abdominal pain, shortness of breath) may be present for other reasons (e.g., diabetes, COPD).
- **More acute illness** Because homeless people with HIV may not seek care until their disease is advanced and symptomatic, they often present with more acute illness. Even in areas with free access to exceptional HIV care, new patients with advanced AIDS are not unusual, and many of them are homeless. Patients with advanced disease require complicated treatment regimens. Opportunistic infections and diseases unrelated to HIV may increase the severity of illness. Major complications of HIV include late-stage opportunistic infections such as *Pneumocystis carinii* pneumonia (PCP), invasive candidal infection, toxoplasmosis, and cryptococcal meningitis, and CMV retinitis (which can lead to blindness if untreated). Provide respite care facilities where homeless patients can convalesce when ill or following hospitalization. A medical respite facility may be the only place a homeless patient can get end-of-life care. Develop close linkages with inpatient service providers and facilities.
- **Mental illness/substance use** Mental illness, substance use and HIV are frequently linked. A large proportion of mentally ill homeless people use psychoactive substances that result in loss of inhibition, which can result in unsafe behaviors that increase their risk of exposure to HIV, tuberculosis, and hepatitis. Mental illness (both Axis I and Axis II disorders) and drug-induced psychosis can interfere with treatment adherence. Optimally, co-occurring mental illness and substance abuse should be treated simultaneously within the same program. Underlying mental illness is often the issue that keeps homeless patients out of care; or if in care, may be their most pronounced disorder. Involve a psychiatrist who is interested in the co-occurrence of these disorders with HIV in the assessment and management of homeless patients. A key issue is pharmacodynamics (the cumulative side effects of polypharmacy). In practice, overlapping side effects are more problematic than drug interactions. Some mental health problems can be treated by a primary care provider. Refer more complicated cases to a dedicated mental health program while maintaining good coordination of mental health and primary care.
- **Cognitive impairment** If patients have difficulty remembering appointments, don't automatically assume nonadherence; question their cognition. Cognitive impairment may be associated with mental illness, chronic substance abuse, AIDS-related dementia, and/or opportunistic infections. Accurate diagnosis may require specialty evaluation.

- **Tuberculosis** The association between TB, HIV infection, and homelessness is well documented (McElroy, 2003; Moss, 2000; Zolopa, 1994; US PHS, 1992). Homeless shelters are among the most likely sites of TB transmission, and growing numbers of HIV-infected persons have contributed to the resurgence of tuberculosis in the United States. HIV coinfection increases the risk of progression from latent TB infection to active tuberculosis. Recommended control measures include more frequently screening of HIV-infected homeless persons for TB infection, initiation of isoniazid prophylaxis in any HIV-infected person with a positive tuberculin skin test, and directly observed TB/HIV therapy to promote treatment adherence and reduce the risk of drug resistant organisms (Moss et al, 2000).
- **Hepatitis** Some homeless persons (especially injection drug users) are at increased risk for hepatitis. Hepatitis C (HCV), hepatitis B (HBV), and HIV are chronic, potentially fatal diseases that can be symbiotic. In patients with co-occurring HIV, treatment of HCV/HBV is important. “Although all antiretroviral drugs are associated with hepatotoxicity, . . . antiretroviral therapy should generally not be avoided, and specific agents should not be avoided in patients with HBV/HCV co-infection. Nevertheless, these patients should have careful monitoring of liver enzymes during therapy” (Bartlett and Gallant, 2001–2002).¹³ Always consult a specialist experienced in the treatment of hepatitis when planning HIV care for patients with HCV or HBV co-infection. A psychiatric consult is recommended prior to initiating HCV treatment, which may have depression as a side effect. For patients with co-occurring alcoholism, behavioral contracts and/or other treatment/rehabilitation strategies should be used concurrently with HCV treatment to promote sobriety and reduce the risk of liver damage.

Two antiretroviral agents, lamivudine (3TC) and tenofovir, are active against HBV. When initiating HAART in an HBV-infected person, one of these drugs should be considered as part of the regimen. However, lamivudine or tenofovir should only be used as part of a fully suppressive antiretroviral regimen in an HIV-infected person. In general, treatment of these patients requires careful follow-up and consultation with a specialist, as they may be more likely to develop drug-related liver complications. Ensure that all patients are immunized against HBV (especially injection drug users) and hepatitis A (HAV), if seronegative. Recognize that the cost of HBV/HAV vaccines and HCV/HBV treatment may be prohibitive for uninsured patients.

- **Abuse** Homeless individuals with HIV may be at risk for various kinds of abuse from other homeless people and shelter staff who find out they are infected. A significant number of these patients also have a history of physical or sexual abuse that may have precipitated homelessness. Work with all service providers in clinics and shelters to protect homeless patients from physical assault and verbal abuse.
- **Pregnancy** HIV-positive pregnant women should receive HAART for themselves and to prevent transmission of infection to the fetus. Many are highly motivated to protect their baby, but

¹³ Bartlett JG and Gallant JE, 2001–2002: www.hopkinsaids.edu/publications/book/ch4_agents_react.html#class

women with other children may not agree to treatment that includes residential care. (Family-based treatment centers that permit substance-using mothers to bring one or more children to live with them in a therapeutic residential drug treatment community are disappearing for lack of funding.) Develop good consulting relationships with obstetricians (including academic departments of obstetrics) to help pregnant homeless patients with HIV. Be knowledgeable about national guidelines for the treatment of HIV-infected pregnant women (perinatal guidelines: <http://aidsinfo.nih.gov/>).

- **Lack of transportation** Many poor and homeless people cannot access health services because they lack transportation for trips to and from appointments. This can present serious barriers to HIV testing and care. Become familiar with transportation resources in your community. All state Medicaid programs are required to provide non-emergency medical transportation (NEMT) to approved health services. Each state is responsible for designing and operating its own NEMT, and programs differ from state to state. (For a list of Medicaid transportation contacts in each state, see: <http://www.ctaa.org/ntrc/medical/contacts.asp>.)
- **Lack of stable housing** HIV treatment is extremely difficult for individuals without stable housing. Meeting needs for food and shelter leaves little time for medical appointments. Lack of privacy, risk of abuse, theft of medications with street value, and no place to lie down during the day compound discomforts associated with HIV and HAART. Homeless persons need a stable residence and routine in order to begin the process of recovery. In many communities, housing is simply not available for homeless persons with HIV. Conversely, in some places, the only way for homeless adults unaccompanied by children to get housing is if they are HIV positive. Sometimes the partner of an HIV-positive person who is HIV-negative or untested desperately tries to get infected in order to qualify for housing and other benefits. Individuals with HIV may sleep outside to be with a partner, at risk to their own health.

Despite some availability of transitional housing for HIV-infected individuals in larger metropolitan areas, insufficient housing stock, long waiting lists, and policies that exclude active substance users or ex-inmates limit access for homeless people in many communities. Most housing, rehabilitation, or transitional programs available to homeless persons with HIV infection require sobriety for admission or continued residence. Unfortunately, such supports become attainable only when homeless individuals with co-occurring addiction disorders become too ill to support a habit, often at a time far advanced in the course of HIV infection (O'Connell and Lebow, 1992).

The federal Fair Housing Act prevents discrimination based on health history, including mental illness and addiction. Nevertheless, some local communities and permanent housing programs, however, continue to use "housing readiness" as a subjective measure of appropriateness for housing. Strongly advocate for "low demand" housing models in your community that serve people coming directly from the streets or shelters, without clean and sober requirements or other standards for housing readiness.

- **Barriers to health insurance/disability assistance** Efforts to deliver quality health care are hampered by barriers to obtaining public benefits, including health insurance and disability assistance.
 - **Insufficient documentation** Entitlement programs in many states and localities require extensive documentation, including photo identification, birth certificates, Social Security cards, pay stubs, etc., to verify eligibility. Proof of identity, residence and income is difficult to come by for someone without a home, a car or continuous employment. Obtaining required documentation is often costly, time-consuming, and intimidating. Homeless people may have trouble obtaining transportation to various agencies where required documents are available, or cannot get there during working hours without losing their jobs, or are unable to pay fees required for copies. Even if they are able to get required documentation, homeless individuals may have no safe place to keep it. Personal papers are often stolen or lost in moving from place to place on foot. Lack of required documentation to verify eligibility is the most frequently cited obstacle to Medicaid enrollment for eligible homeless people (Post, 2001).
 - **Denied disability claims** It is important to realize that most homeless people (particularly adults unaccompanied by children) do not qualify for Medicaid under current policy. Few state Medicaid programs cover nondisabled adults, and those that do may not cover needed services. For many homeless people, SSI (Federal disability assistance) is the only door to Medicaid. SSI regulations still exclude persons with asymptomatic HIV or those with disabling addictions without evidence of underlying mental illness. Only CDC's AIDS-defining diagnoses are considered sufficient evidence of permanent disability (O'Connell, 1997), despite the fact that many persons with chronic fatigue and other constitutional symptoms are too incapacitated to engage in gainful employment. There is evidence that homeless disability claimants have higher denial rates than other claimants. Insufficient medical evidence of functional disability (inadequate documentation by medical providers) and failure of homeless patients to show up at consultative evaluations partially explain this discrepancy (Post, 2001).

Realize that in most states, except for pregnant women and children, Medicaid eligibility is linked to SSI for persons with disabling conditions including HIV/AIDS. Facilitate applications for disability assistance and SSI-related Medicaid. Keep detailed records of all functional impairments.¹⁴ Develop a working relationship with your local SSA Disability Services office. Secure a representative for homeless disability claimants. Ensure that consultative examinations are conducted by physicians with significant experience in treating homeless patients. Advocate for all patients to obtain needed health care, regardless of their insurance status.

- **Stigmatization** Strong stigmas against HIV and homelessness, particularly in smaller communities and rural areas, result in extreme marginalization of HIV-positive homeless individuals and reduced self-esteem, often exacerbating self-destructive behaviors (e.g., substance abuse, sex

¹⁴ For guidance in documenting diagnoses and functional impairments appropriately to expedite SSI/SSDI claims, see O'Connell J. Determining Disability: Simple Strategies for Clinicians. HCH Clinicians' Network, December 1997: www.nhchc.org/Publications/.

work). Sexual minorities and immigrants with limited English proficiency are especially vulnerable to stigmatization and low self-esteem. Fear of abuse and eviction from shelter motivates many HIV-infected homeless patients to conceal their diagnosis.

- **Incarceration** Many homeless people are frequently arrested or incarcerated for loitering, sleeping, urinating or drinking in public places—activities that are permissible in the privacy of a home. A number of them contract HIV and hepatitis while in prison. Periods of detention or incarceration can also interrupt continuity of care for pre-existing conditions.
- **Special populations:**
 - **Homeless women** The overwhelming majority of homeless patients in most clinic settings are male, which can be intimidating for homeless women, many of whom have a history of physical/sexual abuse. Increasing heterosexual transmission of HIV associated with sexual abuse, sex work, and IV drug use warrants programs specifically targeted to homeless women, who can be harder to reach than men and may require more intensive services. Offer social support and counseling through a weekly women's group. If high-risk sexual behavior is perceived as necessary to meet basic survival needs, try to engage the patient for services and find another way of meeting underlying needs. If high-risk behavior is used to obtain a drug on which the patient is dependent, continually offer detoxification/substance abuse treatment as an alternative.
 - **Homeless youth** Most homeless adolescents and youth (ages 14–24) have been abused or neglected. HIV infection, usually identified in 18–20 year olds (ages when most willing to be tested), is often seen as an asset by homeless youth because it may increase their access to services (substance abuse treatment and shelter). Adolescents and youth tend to be more recently infected than older adults, who are likely to be more acutely ill when identified. Younger patients have more time to address psychosocial problems; treatment is not as urgent. Homeless adolescents and youth are often developmentally less advanced than peers of the same chronological age; concrete thinking predominates over abstract reasoning skills, according to providers who are experienced with this population. When discussing behavioral change with these patients, focus on immediate concerns rather than possible future consequences.
 - **Sexual minorities** Homeless sexual minorities (gay, lesbian, bisexual, transgender (GLBT) persons) need special support to counteract extreme marginalization, victimization, and frequent exclusion from mainstream health care systems. A significant number of homeless adolescents and youth are sexual minorities who have been rejected by their families and communities. Victimization, psychopathology, use of addictive substances, and multiple sexual partners increase their risk for HIV infection.¹⁵ Create a safe and nondiscriminatory clinical environment for all GLBT patients; build trust and rapport with these patients, and assure their access

¹⁵ A study in Seattle, Washington, found that GLBT adolescents left home more frequently, were victimized more often, used highly addictive substances more frequently, had higher rates of psychopathology, and had more sexual partners than heterosexual adolescents (Cochron BT et al, 2002).

to comprehensive health care.

Transgender adults and adolescents (male-to-females and female-to-males) comprise a significant proportion of the homeless population in some areas. Injection of hormones or other drugs with nonsterile needles and unprotected sex with infected partners place some of these individuals at especially high risk for HIV.¹⁶ Among sexual minorities, persons with gender variance are least likely to receive appropriate medical care; many have been denied screening and treatment for life-threatening diseases such as cervical cancer and HIV infection. Give these patients the information they need to make informed choices. Educate patients using injected hormones about clean needle exchange, and explain gender-related health risks — e.g., a male taking estrogen may have increased risk for thromboembolic disease and cervical cancer; a female taking testosterone still requires screening for breast and cervical cancer, and runs the risk of hair loss and early cardiac disease. This information should be conveyed to promote informed choices, not to frighten or dissuade.

- **Immigrants** Although homeless immigrants from certain areas may be at high risk for HIV (e.g., Africa) and tuberculosis (Mexico, the Philippines, and Southeast Asia), their access to prophylaxis and treatment may be limited. Undocumented immigrants may be reluctant to seek care for fear of being deported. Language and cultural barriers often compound financial barriers to health care. (For guidance in providing linguistically appropriate and culturally competent health services to homeless individuals, see Holzwarth, 2002). Recognize that some of these patients may qualify for Medicaid as refugees, and that many immigrants, undocumented or not, are explicitly barred from the Medicaid program by Federal law (Post, 2001).

¹⁶ A study in San Francisco found that 32% of 515 transgender participants had prior exposure to injected, illicit drugs excluding hormones, over 50% had used injected hormones outside conventional medical settings, and 48% had engaged in sex work. In addition, 35% of MTF participants were infected with HIV, and among African Americans, almost two-thirds (63%) were HIV positive (Clements, 2000). Other studies corroborate high rates of HIV infection among transgender women in California, even surpassing those for bisexual and homosexual men (Lombardi, 2001).

CASE STUDY: HOMELESS TRANSGENDER YOUTH WITH HIV

S.A. was a 21-year-old Hispanic woman, recently released from jail for prostitution, when first brought to our urgent care clinic by an outreach worker in 1997. She was residing in a city shelter with one of our satellite clinics. S.A. is a male-to-female transgender who had tested HIV-positive a year before. She faced rejection from her family in Mexico and came to the U.S. two years ago with a boyfriend.

Shortly after arriving in the U.S., S.A. became dependent on sex work for income. She had multiple sexual encounters without protection, and was smoking methamphetamines and additionally was using injectable estrogens procured on the street to develop her feminine characteristics. At the time of her first visit, she complained of rectal pain and bleeding. On physical examination, there were large condyloma in her rectum that required surgical removal. Our social work team was able to place her with a special grant program that provides housing and ancillary services to HIV-positive patients with dual diagnoses.

S.A. successfully recovered from rectal surgery, was seen by social services, and kept medical follow-up appointments. Her initial viral load was 350,000; her CD4 count was 73. Prophylaxis against opportunistic infections and vitamin supplements were prescribed, which S.A. took regularly. Oral estrogen was also prescribed to discourage self-administered IM hormones purchased on the street. Physically she was feeling well and did not want to start antiretroviral therapy.

Her CD4 continued to decrease. When it reached 23, S.A. agreed to start treatment. She started on AZT/3TC and nelfinavir, which caused only minimal diarrhea. After a month, her viral load was 16,000 and her CD4 doubled. After three months, her viral load was again over 300,000. She stopped the medications because there were “too many pills” and erroneous information from friends. Physically she was feeling well and did not want to try another antiretroviral regimen. She kept taking her prophylaxis medications and continued her regular visit to our clinic where she felt welcome, since her gender status was not a discriminatory issue. Without treatment, her CD4 count dropped to 10, she became acetic, and was admitted to the hospital twice with bacterial pneumonia and viral meningitis. It was after this last admission that she was willing to re-start antiretroviral therapy. Because of the short prior exposure, I prescribed AZT/3TC plus nevirapine, with concern for the possibility of developing rapid resistance to this combination with poor adherence. However, at this time it seemed to be the most realistic regimen because of its low pill burden. Since oral estrogens are important to A.B. and are also taken twice daily, taking the HIV medications with the estrogens improves her adherence.

Once-a-day therapies are currently available, but S.A. is now comfortable with her treatment regimen. Her last labs revealed a CD4 count of 240 and an undetectable viral load. I see her frequently. In the past few months, she has enrolled in an English class and has gained 24 pounds. She still faces many obstacles, however. Her job and education prospects are minimal. The housing program is for a limited period of time. Her immigration status makes her ineligible for SSI unless she is able to qualify for asylum because of persecution for being transgender. Nevertheless, she is receiving lifesaving medication and is content with her quality of life, which has improved significantly under our care.

Linette Martinez, MD, San Francisco, California

FOLLOW-UP

- **Contact information** At every visit, seek contact information (telephone/cell phone numbers and/or mailing/email addresses) for the patient, a family member or friend with a stable address, the shelter where the patient is currently staying or other location where s/he might be found, and the patient's case manager and health care providers. A clinician should be available to the patient via beeper or other means 24 hours a day.
- **More frequent follow-up** Try to see homeless patients more frequently, especially early in the course of treatment. (Most HIV patients are told to return monthly; homeless patients should return within 1–2 weeks.) Follow-up intervals also depend on co-morbidities. Contact the patient a few days after starting medications and schedule a return visit within a week. Review adherence; give the patient a pillbox, if desired. At the beginning of a therapeutic relationship, reinforce the patient's understanding of the plan of care repeatedly. Ask if medications were missed and if so, why they were missed and what happened (e.g., stolen, forgot to take them while bingeing). Frequent contact encourages patient bonding and willingness to return to the clinic on a drop-in basis. Let homeless clients come back as frequently as is comfortable for them.
- **Drop-in system** Create a routine drop-in time at primary care clinics (e.g., every Tuesday afternoon) with no appointment required for new patients. Encourage routine follow-up for established patients, supplemented by an open-door policy for drop-ins. A drop-in system is far more effective than appointments for people who are disorganized or whose lives are chaotic.
- **Help with appointments** Help patients make and keep clinical appointments and routinely remind them of their appointments. Find out what their regular commitments are (e.g., when and where they receive wages or disability checks) and at what time(s) of day they can come to the clinic. Recognize that a homeless patient may be forced to miss a meal at a soup kitchen if the clinic appointment runs past serving hours.
- **Incentives** Give the patient "carefare" (carfare plus a meal voucher) for every kept appointment or group meeting attended. Escort each patient to the first clinic appointment; explain how to obtain carfare for the next visit, and take them to the cafeteria to demonstrate how to use the meal voucher. Provide a client advocate to accompany the patient to appointments for MRI, culposcopy, or ambulatory surgery. Be the family member or friend most people call on if they have to do something frightening or unpleasant.
- **Transportation** Provide transportation to and from specialty referrals; arrange to pick up new patients and those unable to come to the primary care clinic on their own.
- **Intensive case management** Use a clinical team to support the patient and promote continuity of care, which is essential for good HIV care. Visit inpatients daily to reinforce engagement, facilitate discharge planning, and promote better follow-up (e.g., call the library, help patients

get methadone/nicotine patches, talk with patients about where to go after they leave the hospital). Encourage discharge to a nursing/recuperative care facility, if available. Establish and maintain contact with other service providers who know your patient (make phone calls and have lunch from time to time). Ask the patient to sign a release, in compliance with HIPAA requirements, so that you can share health information with other clinicians and service providers when s/he leaves your care. Information sharing is important, particularly during transition from homelessness to transitional housing, to identify any variations in the patient's behavior that may indicate a change in health status or problems with adherence. Be compassionate and caring.

- **Peer support** Start a “breakfast club” for patients having difficulty with HAART medications, to create positive peer support. Provide food and encourage members to take medications together. Include staff to work with clients on medical and social issues in a social setting. This helps patients to establish a regular wake-up time, begin the day with food and medications, share resources and coping strategies, and receive both medical and social support.

PRIMARY SOURCES

U.S. Public Health Services (US PHS) guidance documents for the medical management of HIV infection and other issues surrounding HIV infection (<http://aidsinfo.nih.gov/guidelines/>):

Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, February 2002;

Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States, 2002.

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WEBSITES

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HIV/AIDS guidelines US Dept. of Health and Human Services	http://aidsinfo.nih.gov/guidelines
Centers for Disease Control and Prevention	www.cdc.gov
Health Care for the Homeless Information Resource Center	www.bphc.hrsa.gov/hchirc
HIV/AIDS Bureau, HRSA	http://hab.hrsa.gov/
Housing Opportunities for Persons with AIDS (HOPWA)	www.hud.gov/offices/cpd/ aidshousing/index.cfm
National Health Care for the Homeless Council & Health Care for the Homeless Clinicians' Network	www.nhchc.org
National Resource Center AIDS Education & Training Centers, HRSA	www.aids-ed.org/
World Health Organization HIV/AIDS site	www.who.int/hiv/en/

ABOUT THE HCH CLINICIANS' NETWORK

Founded in 1994, the Health Care for the Homeless Clinicians' Network is a national membership association that unites care providers from many disciplines who are committed to improving the health and quality of life of homeless people. The Network is engaged in a broad range of activities including publications, training, research and peer support. The Network is operated by the National Health Care for the Homeless Council, and our efforts are supported by the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and member dues. The Network is governed by a Steering Committee representing diverse community and professional interests.

To become a member or order Network materials, call 615 226-2292 or write network@nhchc.org. Please visit our Web site at www.nhchc.org.

