

**National Resource Center
on Homelessness and Mental Illness**



**HIV, Homelessness, and Serious Mental Illness:
Implications for Policy and Practice**

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Introduction

By December 1995, more than 513,000 cumulative cases of AIDS (Acquired Immune Deficiency Syndrome) had been diagnosed in the United States, and an estimated 750,000 Americans were infected with the human immunodeficiency virus (HIV) that is a cause of this fatal disease (Centers for Disease Control, 1996). The AIDS epidemic poses one of the greatest challenges ever faced by the modern health care system. Within psychiatric practice, it confronts providers with complex clinical challenges and difficult ethical dilemmas.

Despite a burgeoning literature on the psychiatric and neuropsychiatric aspects of HIV infection, there is surprisingly little literature on the impact of the epidemic on people with serious mental illnesses. At three successive international conferences, where more than 9,000 presentations were made related to HIV and AIDS, only a few focused on people with mental illnesses. Consequently, little is known about the rates of infection and risk behaviors for HIV among this population.

Even less is known about HIV prevalence and risk behaviors for people with mental illnesses who are homeless. Yet, what data does exist indicates that this population is at considerable risk for both contracting and transmitting this infection.

Other groups considered at high risk of HIV infection have generally been directly identified with practices that result in increased risk - for example, anal intercourse among gay men or needle sharing among intravenous drug users. What is somewhat unusual about the high rate of HIV infection among homeless people with serious mental illnesses is the fact that they are not, inherently, at increased risk by virtue of their illness or because of any immediately apparent behavior that they share. This accounts, in part, for the lack of attention paid to the needs and risks in this group.

Yet, there are a number of reasons why homeless people with serious mental illnesses may be particularly vulnerable to HIV infection. Their individual risk behaviors may be impacted by cognitive deficits, vulnerability to coercion by others, and a desperate need for money. In addition, they disproportionately live in urban neighborhoods that have been heavily affected by the AIDS epidemic (Susser, et al., 1994). For clinicians, administrators, and program planners working with this population, there is an urgent need to clarify existing knowledge, identify the gaps in service provision, and devise appropriate preventive and intervention strategies.

This paper provides an overview of available epidemiological data, reviews the literature on the interfaces between HIV/AIDS, homelessness and mental illness, and explores what is known about sexuality and high-risk behaviors in this population. It examines risk reduction programs that have been developed and implemented with homeless people who have serious mental illnesses. Finally, it makes recommendations for appropriate public policy and future research directions.

Identifying a Population at Risk

Current surveillance data on AIDS indicates that it is the eighth leading cause of death in the United States and the leading cause of death for adults ages 25 to 44. It is the third leading cause of death for women in the same age category (Centers for Disease Control, 1996).

A high prevalence of HIV and AIDS has been documented in certain populations and geographical regions. In the United States, such high seroprevalence groups include men who have sex with men and intravenous drug users and their sexual partners. While HIV is spreading to the South and Midwest, most cases are still concentrated in identified urban epicenters, including New York City, San Francisco, and Miami. More than 83,000 AIDS cases have been identified to date in New York City (AIDS Surveillance, 1996), and a recent survey of an African-American community in Harlem documented an 8.4 percent prevalence of HIV infection.

For women, approximately 50 percent of the AIDS cases in 1995 were linked to intravenous drug use and 40 percent to heterosexual contact, whereas for men it is divided almost equally between intravenous drug use and homosexual activity (CDC 1996). The rate of HIV infection among black women is nine times that of white women, while black men have a rate of infection four times greater than that of white men. HIV infection remains a grave threat to men who have unprotected sex with men, but it is rapidly spreading to the poorest and most marginalized sectors of the U.S. population. It is impacting particularly hard on minority African-American and Latino communities.

The Impact of Mental Illness and Homelessness

Studies of domiciled psychiatric inpatients in New York City have documented high prevalence rates of HIV, ranging from 5 percent to 10 percent (Cournos, et al., 1991; Volavka, et al., 1991; Sacks, et al., 1992; Meyer, et al., 1992). Similar findings have been reported among psychiatric patients in other urban centers in the United States (Stewart, et al., 1994; J. Miranda, personal communication), as well as in Europe (De Genio, et al., 1994; Ayuso, et al., 1994).

Few empirical data exist on the prevalence of HIV infection among homeless people, who are often beyond the reach of public health surveillance. However, it is estimated that between one-third and one-half of people with AIDS are either homeless or at imminent risk of homelessness and that, conversely, approximately 15 percent of homeless Americans are infected with HIV (Summers, Testimony on AIDS Housing, 1993).

In a recent cross-sectional survey of 1,226 homeless adults in San Francisco, Zolopa and colleagues (1994) found an 8.5 percent prevalence of HIV infection. On a smaller scale, studies conducted in shelters, clinics, and soup kitchens have demonstrated rates of infection ranging from 9.8 percent to 62 percent (Greer, et al., 1989; Torres, et al., 1990; Allen, et al., 1992). It should be noted that these figures reflect highly selected samples since they come from urban centers that have been hard hit by the epidemic.

While limited, the epidemiological data on HIV/AIDS among people with serious mental illnesses who are also homeless indicates that this population is particularly at risk for HIV transmission and contraction. A study among homeless psychiatric patients at a New York City shelter for men found a 19.4 percent prevalence of HIV infection (Susser, et al., 1993), double that found in men of a similar age group in an inner-city community survey (Brunswick, et al., 1993). Despite the uncertainty in

High rates of HIV infection were also documented among homeless patients admitted to a psychiatric inpatient setting in New York City - 6.4 percent for the sample as a whole and 10.6 percent for a subsample of people ages 18-39 (Empfield, et al., 1993). Similar rates were found among a homeless inpatient sample in San Francisco (Wolfe, 1991).

The extremely high rates of infection for people who are homeless and have serious mental illnesses probably reflect a compounding of risk factors. Many homeless people with serious mental illnesses belong simultaneously to other subcultures that have been disproportionately affected by the AIDS epidemic, including intravenous drug users (Watters, et al., 1994; Des Jarlais, 1988, 1992;), prison inmates (Florio, et al., 1992; Mikl, et al., 1993), crack cocaine users (Chiasson, et al., 1989; Fullilove, et al., 1990, 1992; Kim, et al., 1992), commercial sex traders (Dorfman, et al., 1992), and minority ethnic groups. Behaviors that may place homeless people with serious mental illnesses at particular risk for HIV infection are examined below.

Examining Risk Factors

The primary behavioral modes of transmission and contraction of HIV involve sexual behaviors and drug use practices. Specifically, these are unprotected anal sex, and to a lesser degree unprotected vaginal and oral sex, and the shared use of injection equipment among drug users. Both sexual and drug use practices have been implicated in the transmission of HIV among homeless people with serious mental illnesses. In addition, the presence of sexually transmitted diseases is highly correlated with an increase in HIV transmission.

Sexual behaviors. Although sexual behavior plays a part in the lives of many people with serious mental illnesses, the structure and policies of the psychiatric care delivery system have often been based on the premise that sexuality is not a significant issue for this group. Sexual contact between individuals in the hospital, or in shelters, is usually forbidden. Even in community-based residential programs for people with mental illnesses, shared same-sex bedrooms are the norm, privacy is usually unavailable, and sexual contact is specifically prohibited or assumed to be nonexistent. Historical data and the literature on sexuality among people with mental illnesses, however, seem to contradict these commonly held views.

Early studies examining the sexual histories of psychiatric patients confirm that the majority of patients have been sexually active (Abernathy, 1974; Test and Berlin, 1981). Furthermore, crude indices such as birth rates provide some indication of patients' sexual behavior. Shearer and colleagues (1967) cited a rate of 143 deliveries per 1,000 psychiatric inpatients over a five-year period. Since it is unlikely that each episode of sexual intercourse resulted in a pregnancy, it can be assumed that the frequency of sexual intercourse was far greater, even for patients in a state hospital setting.

The increase in sexual freedom since the mid-1960s, combined with changes in clinical practice, have resulted in far greater possibilities for sexual interaction today. Deinstitutionalization has led more patients to spend greater time in the community, with increased opportunity for sexual contacts. In an outpatient sample, Kelly and colleagues (1992) found that 52 percent of individuals had been sexually active in the past month, and 62 percent in the past year. A recent study done at two outpatient mental health facilities in a medium-sized Canadian city, Calgary, found that 32.9 percent of the clients had been sexually active in the past month, and 52 percent in the past year (Chuang, 1996). Similar results have been documented among inpatient samples. In New York City, a study of inpatients with schizophrenia indicated that 45 percent had engaged in sexual activity in the previous six months (Cournos, et al., 1994).

These studies have also highlighted the importance of the context of such sexual encounters. Kelly and colleagues (1992) note that people with serious mental illnesses often live in poor, urban neighborhoods with high rates of drug abuse and sexually transmitted diseases, including HIV. In addition, many of these individuals meet their partners in public places, such as parks, bars, or on the street. Typically, these encounters are transitory in nature, and the partners do not know each other well (Kalichman, et al., 1994; Cournos, et al., 1994; Susser, et al., 1995). Furthermore, few individuals use condoms regularly.

The patterns of sexual behavior among people with mental illnesses who are homeless remain virtually unknown. There has been one study of risk behaviors among homeless men with mental illnesses in New York City (Susser, et al., 1995). Consistent with the findings for other individuals with mental illnesses, men in this study tended to have relatively few episodes of sex, but they engaged in very high-risk behaviors, including unprotected sex with non-monogamous partners.

It is not known whether there are differences in risk for people with mental illnesses who are homeless compared to those who are domiciled. The fact that many people with serious mental illnesses alternate between housing and periods of homelessness may affect sexual behaviors in ways that are not yet clearly understood.

Preliminary research suggests several factors that may contribute to sexual risk-taking behaviors among homeless people with serious mental illnesses, including social circumstances, psychopathology, medications, and substance use. Each of these is examined in brief below.

Social circumstances. Among homeless people with serious mental illnesses, poverty may be a significant contributor to unsafe sexual behaviors. Many shelters and residential and clinical programs do not make condoms available. For those living at subsistence income levels, condom purchase may pose a significant obstacle to safe sexual practices.

The physical settings of many services - crowded shelters or shared bedrooms - mitigate against the likelihood of pre-planned and leisurely sexual activities. Driven to finding sexual fulfillment in stairways, bathrooms, or parks, such activity may become a furtive, rapid, and largely non-verbal exchange. The deficits in interpersonal skills and planning activities that frequently

accompany major mental illnesses may interact with these external factors to further reduce the likelihood of an individual engaging in protected sex.

A recent study of sexual risk behaviors among homeless men with serious mental illnesses suggests that it is the nature of sexual encounters that place these men and their partners at risk (Susser, et al., 1995). For example, many of the men engage in sex for drugs or money with women in nearby parks. Among psychiatric outpatients, Kelly and colleagues (1992) found similar patterns. Of those individuals who were sexually active, 20 percent met their partners in public places. Understanding the nature of these sexual practices and identifying mediating variables are critical points to address in prevention programs.

Psychopathology. The realization that many people with mental illnesses are sexually active has raised questions about the impact of psychopathology on sexual behaviors. It has been suggested that these individuals are prone to impulsive sexual behavior, hypersexuality, and indiscriminate choice of partners (Cournos, et al., 1994; Sacks, et al., 1992; Kelly, et al., 1992; Cates and Graham, 1993; Steiner, et al., 1992). Carmen and Brady (1989) note that the sexual activities reported to them were often impulsive or coerced.

However, there are few empirical data examining what relationship exists, if any, between psychopathology and sexual behavior, or even about variations in sexual risk-taking behaviors across diagnostic categories (Brady and Carmen, 1990). For example, in regard to schizophrenia, it has been suggested that sexual impulses intensify at the point of onset, gradually diminishing over time (Akhtar and Thompson 1980a, 1980b; Lyketsos, 1983). Recent studies of individuals with persistent schizophrenia, however, demonstrate that a significant number are sexually active (Cournos, et al., 1994; Kelly, et al., 1992; Susser, et al., 1995). Many patients with a history of numerous hospitalizations had remained sexually active well past the initial phase of their illness.

Historically, there have been reports of a disproportionately high incidence of homosexual behavior among individuals with schizophrenia. Lyketsos and colleagues (1983) reported that 14 percent of 113 individuals with chronic schizophrenia had homosexual relations. Klaff (1960) found a 36 percent incidence of homosexual experience among 150 men with paranoid schizophrenia, twice that of the matched, non-psychotic male control group. However, at the time of these studies, those with schizophrenia were much more likely than at present to be in institutional settings, where same-sex activities may be the only available source of sexual contact. In addition, the DSM IV sharpens the diagnostic criteria for schizophrenia and raises additional questions about the purported relationship between schizophrenia and homosexuality.

Some researchers have reported an association between bipolar disorder and sexual hyperactivity (Winokur, et al., 1969; Tsuang, 1975). However, as with the data above, these reports should be regarded with caution as they may reflect obsolete social situations, outdated diagnostic criteria and a lack of the currently available medications that alter the symptoms of these disorders.

Recently, some investigation has been made into the relationship between specific symptoms and diagnostic categories and sexual risk-taking behaviors. Cournos and her colleagues (1994) found an association between positive symptoms of schizophrenia, general psychopathology, and multiple sexual partners. In a comparison across broad diagnostic groups of homeless men

(psychotic versus non-psychotic), Susser and his colleagues (1995) found that a non-psychotic diagnosis was related to an increased risk of unprotected sex with non-monogamous female partners.

These studies show promise in deciphering the dynamics between sexual behavior and mental illness. However, longitudinal research is needed to determine more specifically the ways in which mental health problems impact sexual behaviors.

Medications. Probably the most profound effects of psychiatric medications on potential exposure to HIV have been indirect ones. By reducing symptoms and improving clinical status, these medications have been partly responsible for the shift of people with serious mental illnesses from state hospitals and other psychiatric settings into the community, where they have more opportunity for sexual contact. In addition, symptomatic improvement may result in decreased social withdrawal and an increased likelihood of interpersonal relationships, including sexual ones.

The direct effects of pharmacological agents are more complex and ambiguous. Certainly, some psychiatric medications result in decreased sexual drive and in difficulties with erection and ejaculation in men. Little attention has been paid to the impact of psychiatric medications on women's reproductive health, leaving a huge gap in evaluating risks for HIV. For example, it is not known whether psychiatric medications contribute to increased yeast infections, as such common medications as antibiotics and birth control pills do. The presence of any such infection may increase the likelihood of HIV transmission and contraction.

The few studies that do examine the impact of psychiatric medications on women's reproductive functioning indicate that a common side effect is absence of menstruation. This may have some role in discussions of safe sex with women who have mental illnesses, since they may perceive their risk to be lower based on lack of menstrual discharge.

The overall impact of psychiatric medications on HIV risk is an extremely complicated issue, and one on which further research is needed. Explorations of this matter are complicated by ethical questions about withholding medications and by difficulties in finding untreated populations, as well as by the complex array of intervening variables and the inherent difficulties in measuring specific, high-risk behaviors.

Substance abuse. Research on sexual behaviors has identified a relationship between risky sexual practices and substance abuse (Fullilove, et al., 1990; Chiasson, et al., 1991; Booth, et al., 1993; Susser, et al., 1995; Stall, et al., 1986). In particular, there is growing evidence of a relationship between crack cocaine use and unprotected sex.

For example, Booth and colleagues (1993) note that as crack cocaine use reached epidemic proportions in New York City, a corresponding epidemic of syphilis occurred. Moreover, crack cocaine use has been linked with an increased number of sexual partners and a decreased likelihood of condom use (Chiasson, et al., 1991; Susser, et al., 1995). The fact that sex is often used as a commodity in exchange for crack may contribute to this relationship since these episodes are less likely to be protected.

Alcohol use has also been linked, although less consistently, with sexual risk-taking behaviors (Stall, et al., 1986, 1990; Trocki and Leigh, 1991; Bagnall, et al., 1990; Leigh, 1990). A recent cross-sectional survey of alcohol treatment centers reported a 5 percent HIV prevalence rate among heterosexual inpatients. Similar findings have been reported in smaller studies of individuals in alcohol treatment programs (Mahler, et al., 1994; Jacobson, et al., 1992).

The fact that alcohol is generally regarded as decreasing a person's inhibitions may explain its role in sexual risk taking in some populations. This may be of even greater significance for people with mental illnesses, whose vulnerability to alcohol's effects can be particularly profound (Westermeyer, 1992).

Recent data gathered as part of a Federal demonstration program that served nearly 900 homeless adults with serious mental illnesses provides some indication of the extent of substance abuse within this population (Center for Mental Health Services, 1994). Levels of co-occurring drug and alcohol use ranged from a low of 47 percent in one of the five projects to a high of 77.6 percent in another, for an average rate of 58 percent. Alcohol and cocaine were the most commonly abused drugs. Although study participants were not necessarily representative of all homeless people with serious mental illnesses, these numbers are nonetheless alarmingly high and are many times those found in the general population.

Gender differences. Differences in sexual behavior according to gender may have important implications for the spread of HIV. It has been established that in the United States, women are more vulnerable than men to contracting HIV through penile-vaginal intercourse. Beyond physiological vulnerability, however, there may be differences in the behaviors that place homeless men and women with mental illnesses at varying risk for HIV infection.

Early studies provide evidence of unprotected sexual activity among women with mental illnesses, as indicated by the tripling of the birth rate among women with psychotic disorders since deinstitutionalization. Studies of family planning in the 1970s and early 1980s further substantiate this, indicating that most women with mental illnesses who are sexually active do not use contraceptives. (Abernathy, 1974; Test and Berlin, 1981; Grunebaum, et al., 1971). This may relate in part to their lack of access to family planning services and gynecological care.

In studies of sexual behavior related directly to HIV and AIDS, there is some indication that women tend to have more partners than men. Among psychiatric outpatients, 42 percent of the sexually active women reported more than one partner, as compared to 19 percent of the men (Kelly, et al., 1992). Kim and colleagues (1992) found that, among a sample of psychiatric inpatients with a history of crack cocaine use, women continued to have more partners than men despite a reduced sex drive following regular crack use. This may relate to the fact that these women exchange sex for drugs or the money to buy them.

Sexually transmitted diseases. Sexually transmitted diseases have been identified as critical co-factors in the spread of HIV. Wasserheit (1992), in her comprehensive review of the literature, notes that an association has been documented between both ulcerative and non-ulcerative sexually transmitted diseases and HIV. Donovan (1993) notes that sexually

transmitted diseases disproportionately affect women, because they are easier for women to contract and the symptoms are more difficult to diagnosis. In a single act of unprotected sex with an infected partner, an uninfected woman may be twice as likely to contract gonorrhea, chlamydia, chancroid, or Hepatitis B than an uninfected man.

Several studies suggest that sexually transmitted diseases are common among psychiatric patients and homeless people (Kim, et al., 1992; Shalwitz, et al., 1990; Kelly, et al., 1992). Among psychiatric outpatients, Kelly and colleagues (1992) found that 33 percent had been treated for a sexually transmitted disease.

In a study of the physical and mental health problems of homeless men and women, Breakey and his colleagues (1989) found that two-thirds of the women had gynecological problems, including 34 percent with genital infections. Nearly one-third of participants reported prior sexually transmitted diseases, with 8 percent of the men and 11 percent of the women testing positive for gonorrhea and syphilis at the time of the study. The fact that other sexually transmitted diseases are common within this population may have implications for implementing HIV prevention programs.

Intravenous drug use. Much has been written about the relationship between intravenous drug use and the transmission of HIV (Des Jarlais, et al., 1988, 1990, 1992; Kaplan, et al., 1992; Watters, et al., 1994). Data on risk behaviors among homeless men with serious mental illnesses in New York City indicate that a past history of intravenous drug use accounted for at least half of the cases that were HIV positive (Susser, et al., 1993).

Moreover, a recent study of homeless men with serious mental illnesses found that 20 percent had a history of intravenous drug use (Susser and Miller, 1996). Of these, the majority of men (76 percent) reported sharing or renting needles. Furthermore, these men were more likely to engage in sexual risk-taking behaviors, most often with women. Of those who had a history of intravenous drug use, 84 percent reported having unprotected sex with women in the prior six months.

The fact that these men tend to share needles and engage in unprotected sex warrants immediate attention. However, prevention efforts are complicated by their pattern of intermittent, rather than regular, drug use. In the studies noted above, few of the men reported current use of intravenous drugs. As periodic users, they may be less invested in such harm reduction practices as needle exchange programs. Moreover, they may not perceive themselves to be at risk due to episodic use and thus not recognize the need for risk reduction in their sexual practices as well.

In summary, there is a substantial body of epidemiological evidence that homeless people with severe mental illness, specifically those in large urban centers, have a high prevalence of HIV infection. Risk behaviors include unprotected sex with multiple partners, sex in exchange for drugs or money, men having unprotected anal sex with men, and sharing of injection drug use equipment. Factors that may contribute to these risk-taking behaviors include a high rate of substance use disorders, various social circumstances, and psychopathology.

Assessing HIV Risk

Many people with serious mental illnesses are unable to independently schedule and/or follow through on obtaining the medical care they need. Often, they rely on their psychiatrists or other mental health professionals to serve as their primary physicians or principal medical contact. Those who are also homeless often spend extended periods of time in shelters or other community-based services, where psychiatric care frequently extends beyond mental health interventions to the provision of food, clothing, shelter, rehabilitative services, and medical care. Efforts at detecting HIV infection and offering preventive education and early treatment must be seen by service providers as part of this expanded role.

A key issue in the development of interventions to address HIV infection has been the absence of reliable data on risk behaviors. In clinical settings, practitioners seldom explore sexual and drug use histories for patients, particularly those who have mental illnesses. The marginalized status of individuals who are homeless, coupled with inadequate access to health care, has also left a considerable gap in gathering such data.

Recent research among homeless people with mental illnesses has given rise to the development of structured research instruments focusing on risk behaviors. The SERBAS - Sexual Risk Behavior Assessment Schedule - assesses sexual behavior for lifetime and over the past six months (Meyer-Bahlburg, 1991). This instrument has been tested in a reliability study of psychiatric inpatients (McKinnon, unpublished). A modified version, the SERBAS-ARM, adapted for use with homeless people who have mental illnesses, has been evaluated and found reliable (Susser, et al., in press; in preparation). This version includes variables that are specific to sexual behavior within transient living situations, particularly shelters for homeless people. Although developed as a research instrument, a shortened version of the SERBAS could be incorporated into clinical practice and provide invaluable information for both treatment and prevention efforts.

Clinical and medical interviews are ideal settings for taking a patient's sexual history, however, few physicians or clinicians do so (Seidman and Rieder, 1994). A 1991 study of practitioners at a teaching hospital found that only 11 percent routinely asked patients about risk behaviors (Ferguson, et al., 1991). A telephone survey of 1,350 adults determined that only 19 percent of these patients had ever had a discussion about AIDS with their physician. Furthermore, the majority of these were initiated by the patient (AIDS Alert, 1992).

It is imperative that health professionals, including those in mental health, incorporate a comprehensive sexual history in their assessment interviews. Understanding that discrepancies may exist between sexual identity and behavior is an important aspect of the sexual history interview. For example, Susser and his colleagues (1995) report that individuals who engage in same-sex sexual activity may not identify themselves as homosexual or even bisexual.

HIV testing. HIV antibody testing has been surrounded by controversy virtually from its introduction. However, on strictly scientific grounds, it is a highly specific and reliable means of determining HIV infection.

For those who, by virtue of their history or current symptoms are likely to have been exposed to the virus, antibody testing is the only sure way of determining whether the individual is infected. When offered, voluntary HIV testing has been successful. Among homeless individuals in a shelter-based mental health clinic, the majority chose to be tested for HIV (Susser, et al., 1993).

Early in the epidemic, there were no available interventions that directly affected viral replication, and few effective treatments for the opportunistic infections that result from immunosuppression. Antibody testing was primarily used for diagnostic purposes alone. Over the past decade, evidence is mounting that new treatments can significantly prolong life and reduce morbidity. Under these circumstances, antibody testing can be seen as an element of preventive health care, with early diagnosis allowing the physician to prescribe both medications and changes in patient behavior that can improve survival and enhance the individual's quality of life.

Antibody testing, however, should not be undertaken lightly. Its appropriateness, the context in which it is done, and issues of confidentiality and the use of results raise profound questions for clinical policy and professional practice. These are discussed in greater length in the final chapter.

Designing Preventive Efforts

Like other groups, homeless people with serious mental illnesses are at risk for HIV infection due to high-risk sexual practices and unsafe injection drug use practices. However, this population is particularly vulnerable for a number of reasons, including personal and environmental obstacles to safe sexual practices, inadequate or inappropriate medical care, and co-occurring alcohol and other substance use disorders. Effective prevention programs need to address both the general obstacles to behavioral change that exist for all populations and the problems that are more specific to those who are homeless and mentally ill. A general approach to such prevention efforts and an effective intervention to reduce high risk sexual behaviors are highlighted in the next chapter.

Reducing Risk Through Prevention

Education about HIV infection remains the cornerstone of prevention efforts; this is no less the case for homeless people who have serious mental illnesses. However, just as education efforts in general must be targeted to the needs and cultural expectations of particular groups, HIV education for homeless people with serious mental illnesses will necessitate specialized approaches.

In particular, providers must be sensitive to the social nature and context of sexual behaviors for this population. Also, prevention programs may need to be individualized to take into account cognitive and neurological deficits and co-occurring substance use disorders. Specialized educational approaches to reduce high-risk sexual practices and unsafe drug use among homeless people with serious mental illnesses are examined in the sections that follow.

Reducing High-Risk Sexual Behaviors

Early efforts to introduce sex education programs for people with mental illnesses met with some resistance from mental health clinicians. This often reflected staff discomfort with discussing sexuality in general, as well as specific anxieties raised by HIV infection and AIDS.

A common worry is the belief that, by discussing sexual behaviors, staff will be promoting sexual contact between clients. Despite the persistence of negative assumptions by staff about sexuality and psychiatric patients, however, sex education curricula have generally been successful when introduced (Friedman, 1975; Wasow, 1980; Lukoff, et al., 1986; Pepper, 1988). Programs that address staff concerns, in addition to providing information and education techniques, maybe especially important (e.g., Roemers-Kleven, 1991).

Fears about dealing with HIV infection reach striking proportions among medical and surgical staff (Wallack, 1989; Link, et al., 1988). Such "AIDS anxiety" (Wallack, 1989) has also been well documented among mental health practitioners, despite the far lower chance of transmission of HIV infection in the mental health setting (Polan, et al., 1985; Cummings, 1986; Rosse, 1985). However, as HIV becomes more ubiquitous, and the need for client education more obvious, prevention programs are in fact proliferating despite such concerns.

Programs for people with mental illnesses. Initial efforts to introduce AIDS education among people with mental illnesses focused on a standard instructional format (Sladyk, 1990; Carmen and Brady, 1990; Cates and Graham, 1993). However, such programs may be more effective in increasing knowledge about HIV than in influencing behavioral change. Recent studies have, in fact, documented a high level of awareness about HIV and AIDS, even among people with serious mental illnesses (Chuang et al., 1996).

Generally, individuals are most knowledgeable about specific, high-risk behaviors. Thus, 83 percent of one inpatient sample and 100 percent of another knew that condom use helps decrease the risk of getting AIDS (Baer, et al., 1988; Steiner, et al., 1992). Such knowledge of high-risk behaviors was also found among homeless populations (e.g., Schutt, et al., 1992; Susser, et al.,

unpublished data). Individuals who are homeless and have mental illnesses are generally less knowledgeable about "low-risk behaviors," often ascribing risk to such activities as mosquito bites, sharing toilet seats, or giving blood (Schutt, et al., 1992; Steiner, et al., 1992; Goldfinger and Schutt, 1992).

Ultimately, reducing the spread of HIV infection must result from changes in behavior rather than merely increased knowledge. Thus, behavioral specialists and mental health providers have begun to develop prevention interventions for people with mental illnesses that employ a more interactive format, emphasizing the use of interpersonal and psychiatric rehabilitation techniques such as role playing and behavior modeling (Meyer, et al., 1992; Susser, et al., 1994; Goisman, et al., 1991).

It is generally agreed that successful HIV prevention programs for individuals with serious mental illnesses must have certain characteristics. In particular:

- Information should be presented clearly, using simple language and straightforward descriptions.
- Repetition of material is essential, given the frequent attention deficit and cognitive processing disorders in this population.
- Approaches should address the social and physical skills necessary for safe sex practices through role playing and participation in physical activities, such as putting a condom on an inanimate object.
- The attitude of staff must be nonjudgmental and accepting of a wide variety of sexual practices, including abstinence and same-sex exchanges.
- Programs must be sensitive to the cultural, linguistic, and personal needs and situations of the target audience.
- Participation should be encouraged; however, it can be expected that some participants may not be willing or able to stay for entire sessions.

Behavior change programs designed for domiciled populations may need to be significantly altered for use with homeless people. Life in shelters and on the streets rarely affords privacy, and sexual interaction is often furtive and of short duration. In addition, much of the sex in homeless settings is predicated on the exchange of cigarettes, money, or drugs for sexual favors. Traditional approaches that focus primarily on "getting to know one's partner," taking a sexual history prior to engagement, or other such recommendations are frequently neither appropriate nor useful with this group.

Developing HIV prevention programs that are both culturally familiar and entertaining can enhance learning and foster participation among homeless people with serious mental illnesses. For example, the "Sex, Games, and Videotapes" curriculum described below makes use of the

social activities of the target audience by incorporating games, skits, and videos in a way that is both fun and educational.

"Sex, Games, and Videotapes." The "Sex, Games, and Videotapes" curriculum was developed as an HIV sexual risk reduction intervention for homeless men with mental illnesses in a New York City municipal shelter (Susser, et al., 1994). This curriculum addresses the life circumstances of participants through a blending of proven skills development strategies, including social learning theory and psychiatric rehabilitation, and culturally appropriate techniques. While the intervention does not adhere to any one approach, it uses key principles from several programs and adapts them to the shelter setting.

One of the curriculum's greatest strengths is the fact that the program is built around activities that are familiar to the men, who spend much of their time in competitive games (e.g., dice or cards - often for money), and watching television and videos. The inclusion of fast-paced games in the curriculum, such as a variation of the game show Jeopardy, provides an opportunity for the men to learn in a way that is both familiar and entertaining.

In addition, the program capitalizes on the participants' strengths. Homeless men with mental illnesses have developed and refined communication skills necessary for survival in shelters and on the streets. In particular, their use of a rich and descriptive "street" language and strong sense of theater are used in the curriculum through storytelling and role-playing exercises.

Finally, the program uses role models with whom the men can identify. Videotaped role-playing sessions feature other shelter residents as actors. Also, men who have graduated from the program are recruited as peer group leaders.

Structured in five modules and presented over 15 sessions, the curriculum covers a range of issues including sex with prostitutes, sex with a special partner, and sex with other men, as well as information on the proper use of condoms and the nature of sexually transmitted diseases (Figure 1). In addition, participants undergo pre- and post-intervention assessments of their attitudes and knowledge about sexual behaviors and sexually transmitted diseases, including HIV, and survey their social skills, psychopathology, and personal history.

A randomized clinical trial of "Sex, Games and Videotapes," with an 18-month follow-up, has recently been completed (Susser, Valencia, and Torres, 1994). Sexually active men assigned to the test intervention had a highly significant three-fold reduction in their sexual risk behaviors after six months of follow-up; the impact declined with time but was still present after 18 months. The success achieved in this study is grounds for optimism that a similar approach can be effective in changing the sexual risk behaviors of a broader spectrum of homeless people with mental illness.

One criticism of "Sex, Games, and Videotapes" was that it might promote sexual activity by men who had been sexually inactive. To examine that issue, the randomized clinical trial included men who had been sexually inactive for at least six months prior to the start of the intervention; these men were followed for 18 months as well. A similar percentage of the sexually inactive men in both the control and test groups became active during the follow-up period; they showed

no significant difference in their sexual risk behaviors. The conclusion that was drawn was that the intervention did not appear to stimulate sexual activity among those who were inactive compared to controls. It was also noted that the intervention did not appear to be effective in modifying sexual risk behaviors among those who were sexually inactive shortly before and during the intervention.

A second criticism is that this intervention stresses the use of condoms. Although condom use is essential if the men intend to continue insertive sexual practices, most HIV education programs propose alternative means of sexual gratification. Abstinence and masturbation are absolutely "safe" sexual practices, as are other activities with a consenting partner that do not involve the exchange of bodily fluids. Prevention efforts could highlight these as well.

Finally, this program serves men only. It is widely recognized that appropriate interventions for women in general, and homeless women in particular, are likely to require quite different approaches. Efforts using the same general approach as that employed in "Sex, Games, and Videotapes" are currently underway to develop an HIV prevention intervention for severely mentally ill women.

FIGURE 1 - "Sex, Games, and Videotapes" Curriculum

Sessions 1 & 2
INTRODUCTION: SAY THE WORD The group establishes a "street" dictionary of common words for use in the sessions. Other topics include the correct use of condoms and facts about sexually transmitted diseases.
Sessions 3 to 6
A QUICK FIX The focus of these sessions is on sex with women, usually for drugs or money.
Sessions 7 to 10
ALL YOU NEED IS LOVE This module focuses on sex with special partners and skills in negotiating condom use.
Sessions 11 to 14
PEANUT BUTTER The focus is on same-sex sexual activity (e.g. between men in the shelter) and the exchange of sex for money and/or drugs.
Session 15
GRADUATION The men are recognized for their participation. They receive diplomas and ID cards as HIV Prevention Specialists.

Adapting models for different settings. Other HIV prevention programs demonstrate the need to adapt these basic paradigms for use in different settings and situations. Although most would agree that a multi-session course is likely to be more effective, clinicians and staff working on

inpatient units, or in outpatient mental health settings and emergency shelters with brief lengths of stay, may need alternative program guidelines.

Thus, for example, Meyer and colleagues (1992) report on a seven-week program, using 75-minute sessions once a week. As with "Sex, Games, and Videotapes," the sessions use a combination of informational material, conversation, videotapes, role playing, and other interactive games. Discussions of intravenous drug use and HIV testing are also included. They found significant improvement in both knowledge and attitudes in those who attended the program; behaviors were not assessed.

Carmen and Brady (1990) used a semi-structured, drop-in group approach for people with mental illnesses and co-occurring substance use disorders. Stevenson and colleagues (1994) implemented a brief behavioral intervention to change sexual behaviors among mental health outpatients. The four-session, skills training program addressed sexual assertiveness, problem solving skills, and self-management of risk, in addition to standard risk-reduction strategies. Results show reduced rates of unprotected sex and increased condom use after a one-month follow-up period.

Kelly and colleagues (1991) have tested a unique model of HIV risk reduction among gay men that uses peer leaders to endorse behavior change within community settings. The leaders are instructed in HIV prevention methods and social skills training. The results indicate that participants increased their use of condoms by 16 percent and decreased their number of partners by 18 percent as compared to baseline reports. This approach to AIDS education shows great promise as a model that facilitates community empowerment and promotes the dissemination of information in culturally relevant ways.

Treating sexually transmitted diseases. Prevention of other sexually transmitted diseases may serve as an effective means of changing sexual behaviors, as well. Symptoms of other sexually transmitted diseases manifest earlier and more blatantly than those of HIV, thus making them a more immediate concern for individuals and, possibly, a more relevant target for intervention. The early treatment of sexually transmitted diseases may substantially reduce the potential for contraction of HIV (Wasserheit, 1992; Namssenmo, et al., 1993; Ndoye, et al., 1993).

Addressing Unsafe Drug Use Practices

HIV prevention efforts for homeless people with serious mental illnesses have focused almost exclusively on high-risk sexual behaviors. However, there is an urgent need to develop and test effective strategies to address drug use in this population, particularly unsafe drug practices which are common before individuals are fully engaged in treatment.

Placing active substance abusers in treatment programs is the optimal alternative. Residential programs for mentally ill and chemically addicted (MICA) clients address homelessness, as well as offer treatment for both the psychiatric and substance abuse disorders. These programs often utilize a modification of the traditional 12-step programs offered by AA and NA, along with individual therapy sessions, and, in some instances, non-verbal modalities, such as acupuncture.

Unfortunately, the number of available beds in such programs is much below the need in most large urban centers.

Methadone maintenance programs have been shown to reduce injection drug use and high risk injection practices among their clients, but no studies have specifically addressed homeless people with severe mental illness. The fact that only a small percentage of homeless people with severe mental illness are active injection drug users at any one time will likely limit the usefulness of such programs in this population.

The implementation of needle exchange programs throughout Europe, and more recently in parts of the United States, has been effective in slowing the spread of AIDS among intravenous drug users. In particular, recent research has shown considerable declines in behaviors such as the use of shared or contaminated needles (from 51 percent to 7 percent), as well as an increase in the use of non-intravenous drugs, such as intranasal heroin (Des Jarlais, et al., 1994).

As noted earlier, the intravenous drug use seen among homeless people with serious mental illnesses tends to be intermittent and situationally driven. They tend to frequent shooting galleries or to share injection equipment with a group of friends. Therefore, needle exchange programs, predicated on the expectation that individuals will own, and trade in, drug-injecting paraphernalia, may be difficult to implement with this group. Mental illness may interfere with the ability of individuals to access and maintain a relationship with either a needle exchange or methadone maintenance program, thereby requiring the mental health provider to act as a liaison.

Incorporating Prevention in Treatment Settings

It is important to underscore the fact that increased knowledge about HIV, in the absence of behavioral change, is not a sufficient outcome. Further research is needed to assess the effectiveness of AIDS education activities, both for their impact on sexual and drug-use behavior and, perhaps more critically, for their ultimate effect on HIV prevalence rates.

In addition, education in HIV prevention must be provided as part of the overall treatment of people with serious mental illnesses in both institutional and community-based settings. Likewise, for individuals who are homeless, there is a need to incorporate prevention information into the range of services offered in shelters or through outreach programs. Specific recommendations for policymakers and providers working with this population are featured in the next chapter.

Adapting Policy and Practice

Once a problem faced only by those clinicians working in large, "first-wave" cities, addressing the realities of HIV infection and AIDS has now become a part of virtually all work in shelter and mental health programs. The care of individuals infected with HIV in community settings creates both administrative and clinical challenges.

What is critical, regardless of one's role or work setting, is a broad understanding of the special risks and vulnerabilities of homeless people with serious mental illnesses. These must lead to a planned approach to provide infection control, AIDS education, and clinical interventions specifically tailored to client needs, and to a close collaboration with colleagues in public health, medicine, and HIV/AIDS organizations in the community. At least five broad areas need to be addressed: (1) staff education and training, (2) client education and behavior change, (3) client care and clinical management, (4) antibody testing, and (5) housing.

Training Staff

Given the growing rate of HIV infection among homeless people with serious mental illnesses, it is critical that individuals working in shelters and mental health settings be familiar with basic facts about this virus and the conditions it may cause. General knowledge about the means of HIV transmission, the usefulness and implications of HIV testing, and some familiarity with the primary and secondary diseases caused by this virus should be part of basic staff inservice education. Such information can help combat the AIDS anxiety previously mentioned. Naturally, the types and complexity of information will vary depending on staff background and role; however, fundamental knowledge should be required of all those working with such a high-risk population. Local and state Departments of Health, as well as the federal Centers for Disease Control, have written materials and videotapes that can be helpful in developing such training programs.

As part of this effort, staff should be trained in the proper and safe handling of infected material. Universal Body Substance precautions have been instituted at virtually all medical and mental health centers, and it is essential that detailed infection control procedures be implemented and monitored. Although the risk of HIV infection is far less in such settings as shelters, workers should be made aware of what does, and does not, constitute infective material. Administrators must be familiar with existing federal and state guidelines, and policy manuals specific to each facility should be developed.

In addition to providing information, it is critical that staff attitudes be addressed. Individuals who are homeless, and those who have serious mental illnesses, have been stigmatized by society. To further discriminate against them because of their HIV status has profound consequences for their psychological state and their willingness to comply with treatment. Tolerance of alternative lifestyles and a sensitivity to the despair often experienced by individuals with HIV infection should be encouraged in frontline and managerial staff. Early reports indicate that, after initial anxiety and awkwardness, most staff are both willing and able to work with HIV-infected individuals in mental health settings (Baer, 1987; Polan, et al., 1985; Cummings, et al., 1986).

Educating Clients

As previously noted, the best way to decrease the spread of HIV infection is by reducing those behaviors that provide for its transmission, and the most effective method of doing that is through regular, ongoing education of those at risk. Shelters, day programs, residential programs, and inpatient services must develop education groups that include attention to "safe sex" and "clean needle" issues.

As educators, staff must become familiar with existing knowledge about the AIDS virus and be comfortable talking about sexual behaviors, the use of condoms, alternative low-risk sexual activity, substance use, and needle sterilization techniques. Although it is useful to have an identified AIDS coordinator at each facility, participation by all staff is necessary for effective infection prevention.

Staff should recognize that, despite widely held beliefs to the contrary, many individuals with mental illnesses are sexually active, and are likely to remain so even if living on inpatient units or in shelters, halfway houses, or other community residences. Misperceptions that HIV education or the availability of condoms will cause otherwise abstinent individuals to become sexually active must be overcome (Susser, Valencia, and Torres, 1994). However, while condoms should be available in both institutional and community settings, their distribution alone is not a replacement for aggressive, risk reduction education. Clients should be offered information about an array of alternative safe sex options, including abstinence and sexual activities that do not involve the exchange of bodily fluids.

Many of the models of AIDS education currently in use were predominantly designed for gay men and people who use intravenous drugs. Work with ethnic and cultural minority populations has demonstrated that such approaches will likely need to be modified to be effective with other groups, including homeless people who have serious mental illnesses (Freudenberg et al.1995). Characteristics of successful HIV prevention programs for this population are noted in the previous chapter.

Managing Client Care

There is an absence of literature that explicitly addresses the management of HIV infection in people with serious mental illnesses, including those who are homeless, and of treating serious mental illnesses in homeless people who are infected with HIV. Individually, HIV infection, homelessness, and serious mental illnesses pose complex and multi-dimensional clinical demands. When they co-occur, they pose a challenge to the full range and extent of the mental health provider's and case manager's technical skills and personal strengths.

A comprehensive approach to such treatment would require expertise in psychiatry and neuropsychiatry, psychopharmacology and infectious disease, and clinical medicine and social casework, and would range from counseling at the time of HIV testing to terminal and hospice care (Goldfinger and Robinowitz, 1990). Although a thorough discussion of the multiplicity of issues involved in the treatment of serious mental illnesses, HIV infection and AIDS, and

approaches to homelessness are beyond the scope of this paper, some of the key areas that must be addressed are outlined below.

Treating mental illnesses in homeless people with HIV infection. Traditional psychological and pharmacological interventions with homeless people who have serious mental illnesses have been discussed in detail elsewhere (Goldfinger, 1990; Susser, et al., 1990). In the face of comorbid HIV infection, special concerns are raised in making an adequate diagnosis, and in planning appropriate treatment, including the use of various therapies, medications, and rehabilitative activities.

HIV infection has been associated with primary neurological impairments that can present as both dementia and syndromes that mimic mania and hypomania (Brady and Carmen, 1990). In addition, reaction to learning that one is HIV positive, and adapting to the conditions that result, frequently lead to both transitory and longer lasting affective disorders ranging across a broad array of diagnostic categories (Schaffner, 1990).

Secondary infections and toxic and metabolic disturbances, both related to the disorder and to treatment interventions, may produce symptoms of confusion, disorientation, anxiety, lethargy, and frank delirium (Beckett, 1990). Appropriate clinical evaluation must, therefore, include a comprehensive list of possible differential diagnoses. In individuals with pre-existing psychiatric disorders, a careful history taking and mental status examination must often be combined with laboratory and radiologic studies.

Psychological issues raised by HIV infection should be addressed in any ongoing therapy. Reactions of anxiety, loss, depression, and hopelessness are common and must be handled as realistic concerns. Educational efforts have to be expanded beyond teaching about mental illness to include information about the course of treatment for HIV infection. Often, such activities are best shared with an individual's primary physician, although clear delineation of the responsibilities and shared expectations of each professional must be established.

Interactions between psychiatric medications and those used to treat primary HIV infection, opportunistic infections, and other complications of immunosuppression are not well studied. In many cases, dosages of neuroleptic and anti-depressant medications may have to be reduced, and particular attention must be paid to anticholinergic side effects (Fernandez, 1990). Such pharmacological interactions are yet another critical reason for developing a close working relationship with medical colleagues providing care for individuals with HIV infection.

The implications of homelessness. The difficulties in engaging homeless people into services and assuring their compliance with a treatment plan are well established in the literature. The very same instability and uncertainty that compromise a homeless individual's psychiatric care becomes even more critical in the treatment of HIV infection.

Early in the course of the virus, individuals may remain physically robust, apparently suffering few physical consequences of infection. A growing array of medications which, introduced at differing points after infection but before overt symptomatology — including Zidovudine (AZT)

and dDI — require regular compliance and careful monitoring, which is highly problematic with people who remain homeless.

Later in the course of the illness, as individuals begin to experience compromised immunity, it is critical that they avoid situations that put them at risk for potentially lethal infections. For individuals living on the streets or in crowded shelters, it is especially difficult to isolate them from sources of tuberculosis and other infective microorganisms or to insure that they continue treatment for existing infections.

Often, individuals experience acute episodes requiring care in inpatient settings, followed by remissions. At such times, discharge options that provide greater stability, support, and medical attention than that available in typical shelters are often needed. Finally, many people with AIDS become sufficiently debilitated that care in a hospital, nursing home, or hospice is necessary.

The special problem of tuberculosis. HIV infection among homeless people, including those with serious mental illnesses, poses the additional public health risk of an increased susceptibility to tuberculosis (TB). Classically, TB is not an easy infection to transmit. However, with the immunosuppression that characterizes HIV infection, individuals with the virus are particularly vulnerable to contracting tuberculosis.

In addition, the overcrowded and often unsanitary conditions found in shelters can serve as a breeding ground for such contagious diseases, leading to much higher rates of TB among homeless individuals as compared to the general population (McAdam, et al., 1990; Imperato, 1992; Paul, et al., in press). Finally, higher rates of TB are also associated with many of the groups considered at particular risk for HIV infection, including people who use intravenous drugs and racial and ethnic minorities (McAdam, et al., 1990).

An alarming growth of TB rates in shelter populations since the widespread dissemination of the AIDS virus provides clear corroboration of this risk. Paul and colleagues (in press) report a 79 percent tuberculosis infection rate among the residents at the Fort Washington men's shelter in New York City. In a study of homeless people population in San Francisco, Zolopa and colleagues (1994) found an overall TB rate of 28 percent, with a 10 percent rate of HIV in the same population. Those who tested positive for HIV were twice as likely to test positive for TB, and those living in public shelters had twice the prevalence of TB as those living on the streets.

While tuberculosis infection is a curable condition in both those with and without HIV, effective treatment is predicated on compliance with an ongoing regimen of antibiotic agents. Failure to complete a full course of treatment has implications both for the individual and for society at large. At the personal level, untreated infection can result in increased morbidity and mortality. Partial treatment has been demonstrated to result in an increasing incidence of drug-resistant tuberculosis, a phenomenon now well documented in the shelter and prison systems.

Remaining in treatment can be particularly problematic for homeless people, especially those with serious mental illnesses. In 1990, McAdam and colleagues reported that men in a New York City shelter had only a 36 percent completion rate for TB infection, compared with 55 percent

for individuals residing in New York who had permanent residences. This was despite the fact that the shelter offered a very active follow-up program for treatment. Confronted with an expanding epidemic, the New York City Department of Health initiated an aggressive program of case finding and directly observed therapy that included daily computerized tracking of all those living in the shelter system. This allowed for monitoring of moves between shelters and significantly increased the treatment completion rate. There have been no recent reports of shelter-based outbreaks, and incidence of tuberculosis in the city as a whole has dropped by 28 percent (Frieden, 1996).

Although tuberculosis infection is not a primary focus of this paper, it is critical to raise these findings. Unlike the risk of infection with the human immunodeficiency virus, which can be eliminated through individual behavioral choices and actions, tuberculosis, as an airborne infection, cannot. Overcrowded and unsanitary conditions, and the inability to isolate people with active infection, are not within an individual's control. Active case finding, appropriate initial interventions, and ongoing treatment are necessary to preserve the health of the individual and protect the public at large.

Fragmented services as barriers to care. The lack of integration of housing, mental health, substance abuse, and health services often is the most difficult barrier to appropriate care for homeless people who have serious mental illnesses and HIV infection. Frequently, the presence of HIV infection compromises access to mental health services or shelters; a diagnosis of mental illness may invoke barriers to HIV care or housing; and the poverty and instability that accompany homelessness may make access to, and follow-up for, psychiatric and medical care more difficult. Providers dedicated to serving individuals with one of these concerns may lack the skills and expertise to meet the needs that accompany the others, even if they want to be helpful.

In many communities, case managers are seen as the primary individuals responsible for the identification, coordination and sometimes provision of services to individuals who are homeless and mentally ill. What is meant by case management however, and the expectable levels of training and experience of local case managers is highly variable. Often, case managers are either seen as generalists, or come with specific training in one specialty area. Those with substance abuse training, for example, may not be familiar with the specialized problems of those with severe psychiatric illness, or with the physical health problems associated with HIV. Similarly, given the diverse, and often specialized and exclusionary nature of many services targeted for discrete problems and populations, no case manager can be expected to be familiar with all programs locally available. What may be more useful is an increasing reliance on teams of case managers with expertise in substance abuse, mental illness, HIV and housing, especially when access to well-trained psychiatric and nursing supports are made available.

Certainly, as we have seen, familiarity with basic issues of HIV transmission and prevention must be part of all case managers knowledge base. Given the strong association of homelessness, mental illness and substance abuse, at least one chemical dependency specialist is a necessary part of any service team. Incorporating substance abuse prevention and treatment efforts in mental healthcare is, fortunately, becoming more common, but its importance is particularly noteworthy in those at highest risk for this lethal infection.

In programs where those with HIV infection make up a large percentage of those treated, including a well-trained medical social worker or nurse, who may be better able to evaluate, and advocate for, needed medical services can be extremely helpful. Any agency which works extensively with homeless individuals has come to recognize the high level of medical morbidity among this population. Familiarity not only with HIV infection, but with such common problems as simple trauma, cellulitis, frostbite and respiratory problems will often be needed. There is a great deal of controversy over whether homeless individuals are better served in specialized programs such as local Health Care for the Homeless projects, or should be mainstreamed into more traditional health care services. In many communities, there will be no choice...mainstream services will often either actively or passively reject homeless mentally ill individuals, or case management programs will have established ties with a specific health care provider. What may be more important than which program an individual is sent to is the nature of the interpersonal and interagency ties of the responsible case management resource with the provider.

Ultimately, the multiple needs of this group can best be served by developing a comprehensive, community-based system of care that integrates mental health services, medical care, and housing (Randolph, et al., 1997; NIMH, 1990). Such integration may only be possible if traditional boundaries between housing, medical, and mental health service delivery systems are transcended by either a coordinated team approach or enriched case management. The federal government and local planning agencies have begun to fund model programs that create a continuum of care for homeless people with mental illness and comorbid HIV infection, but it appears unlikely that such programs will be adopted on a scale proportionate to the growing need.

Understanding the Implications of HIV Testing

Controversy surrounds the use of HIV antibody testing as a screening tool; its use in various communities reflect different community standards and state statutes. It is therefore essential that shelter and mental health service administrators be familiar with the applicable laws governing HIV testing in their locale. Many significant and controversial questions remain. These include: What should be the indications for recommending or requiring HIV antibody testing? Should it be made generally available to all shelter residents or psychiatric patients? Should individuals be tested at shelter-based clinics or their local mental health centers, or should they be referred to anonymous testing sites?

The extent to which HIV antibody testing is used as a diagnostic procedure varies dramatically. Some programs restrict its use only to inexplicable presentations of organic deficits or, even more narrowly, to the evaluation of such patients who are also likely to have been exposed to the virus. Other providers require antibody testing as part of the standard admission procedure, although this approach is controversial and widely criticized. Representatives from 11 national mental health organizations, convened by the National Institute of Mental Health to discuss policies and issues related to HIV infection among people with serious mental illnesses, were unable to reach consensus about whether there was any circumstance in which "an individual, other than the patient, has a legitimate right to require testing" (NIMH Proceedings, 1990).

Because effective agents are available to reduce the course and severity of primary and secondary infections that result from HIV, antibody testing is considered an effective tool to allow appropriate treatment decisions to be made. Most clinicians agree that access to HIV antibody testing should be offered as part of regular ongoing medical care, perhaps in conjunction with an annual physical examination. For those individuals whose clinical presentation or prior behavior places them at high risk of HIV infection, but who are deemed incompetent to consent for treatment or are under legal guardianship, requests for testing should be obtained from the court appointed guardian.

Given the profound implications of a positive test, it is currently deemed sound clinical practice to offer HIV testing only when both pre- and post-test counseling are available. In addition, 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. Despite data that clearly demonstrates a high prevalence of HIV infection in people with serious mental illnesses, and particularly those who are homeless, there remains a significant lack of such follow-up care in most localities.

Confidentiality. The degree to which HIV test results should, or must, be held confidential is a frequently changing and complex area that is primarily regulated by state specific statutes. All facilities must have careful and specific guidelines describing where and how such results should be recorded in the medical record, and it is incumbent on practitioners to become familiar with local statutes concerning the dissemination of HIV antibody test results. Written and witnessed consent forms are highly recommended and are required in most states.

The question of sharing HIV test results, particularly when positive, with other clinicians or staff is a controversial issue. Here again, a clear and comprehensive agency-specific policy is essential. The criteria under which individuals on the staff and in referral agencies will have access to such data must be clearly specified. Sharing information about HIV status with family members or other individuals poses additional challenges and must similarly be addressed through a clearly articulated policy.¹

Breaches of confidentiality should not be undertaken lightly. Whether it is appropriate to share a client's HIV status with other individuals who may be exposed via sexual relations is a commonly raised concern, and each clinical situation must be considered individually. Naturally, obtaining the client's cooperation in notifying sexual partners him or herself must be the first step, and seeking consent for partner notification should be attempted and documented. When such permission is denied, sharing such information may be acceptable in certain circumstances.

The ethical concerns about the uses and abuses of antibody testing become heightened when one considers the "home testing" systems that have recently been approved for use. Under such a system, the individual prepares a blood or saliva sample in the privacy of his or her home and

¹ The American Psychiatric Association's (APA) Commission on AIDS addresses these issues for psychiatric settings clearly and in great detail. Copies of these guidelines are available from the APA Office, 1400 K St., NW, Washington, D.C. 20005.

submits the sample to a central lab. The results are available over the phone (negative results get a recording, and positive ones are transferred to a counselor). For individuals who are dealing with a serious mental illness, such services may be highly detrimental.

Staff testing. Given the extraordinarily low risk of infection transmission to providers in shelter or psychiatric settings, it is certainly not recommended that staff be tested as part of their routine physical examination, or that HIV-positive individuals be restricted from practicing in such settings. However, it is becoming increasingly common to recommend testing and prophylactic treatment with antiretrovirals after accidental exposure to blood through needlestick or other injury.

Segregation of HIV-positive individuals. Early in the epidemic, there were numerous proposals calling for the segregation of individuals who were HIV positive to reduce transmission within such settings as hospitals and shelters. Both the feasibility and usefulness of such a strategy have come into question, and current practice stresses the desirability of "mainstreaming" people with HIV infection as long as their physical condition permits.

Individuals who refuse to change their sexual behaviors while knowing they are infected with HIV are an ongoing concern. Most discussions of residential quarantine (e.g., Carlson, et al., 1989) ignore the fact that sex occurs in such places as prisons, supervised residences, and hospitals, and they disregard issues of non-consensual sex, "malicious intent," and the practicalities of monitoring and enforcement. Arguments for quarantine are countered with the need to retain civil liberty and the recognition that large-scale segregation of people has never, historically, been successful (Musto, 1986).

There are no absolute or correct answers to these questions about disclosure and involuntary detention, and it is strongly recommended that administrators provide a forum for staff to discuss these complex and difficult matters. Asking a bioethicist to join such a discussion can be especially useful.

Providing Housing

It is no secret that the current stock of housing does not meet the needs of homeless individuals without disabilities, let alone those with serious mental illnesses. Housing options for those with HIV infection who are unable to maintain their regular residences are becoming a growing problem, as well (National Commission on AIDS, 1992).

Funding of housing for people with AIDS has consistently been inadequate. Thus, in 1992, when 500 units of federally-funded housing were available for homeless people with HIV/AIDS nationally, more than 500 units were needed to meet the needs of homeless individuals with HIV infection in Boston alone (Summers, 1993). Federal and local housing agencies have been criticized for imposing bureaucratic barriers to placement of those with either serious mental illnesses or HIV infection, and for failing to effectively integrate the housing stock available to them with local organizations providing care to these individuals.

Those with mental illness, substance abuse and HIV infection have all faced discrimination in access to safe and affordable housing. Those who are newly diagnosed with AIDS have found themselves denied access to market housing when their medical condition is disclosed; those with mental illness have long been the subject of overt and covert exclusion. Often, advocacy efforts have targeted one or another of these disabilities, with little attention being paid to those who are multiply affected. Often, this discrimination is irrational and merely reflects the stigma attached to these conditions. Sometimes, landlords and housing providers fear that the physical and architectural features of their buildings will make them unsafe for those who are mentally or physically impaired.

For example, single-room-occupancy (SRO) housing, frequently used as part of supportive housing programs for people with serious mental illnesses, may prove inappropriate for those with HIV/AIDS. Shared bathrooms increase the risk of opportunistic infections. Building design may make it difficult or impossible for chairlifts, elevators, or in-home medical care; and funding for modifications and rehabilitation may be insufficient to address the specialized needs of this population.

Housing providers often express concern that, should an individual's physical condition deteriorate, he or she will be unable to access appropriate, more highly-staffed housing, and rather than run the risk of being "stuck" with the person at that time, will refuse admission to their programs even when the individual is still ambulatory and relatively healthy. Memorandums of understanding between housing and appropriate service providers are an achievable remedy to this type of expectation.

Agencies used to providing housing for people with mental illnesses, or for people with HIV infection, may lack the expertise to coordinate their activities and to seek funding for the special needs of people with both serious mental illnesses and HIV infection. Finally, restrictive definitions of who is homeless, who is seriously mentally ill, and who qualifies for supported AIDS housing may eliminate from consideration individuals whose clinical picture, nonetheless, puts them at great risk if housing that meets their special needs is unavailable. However, programs such as The Times Square Hotel in New York, which provides 650 units of housing for people with AIDS, homeless mentally ill individuals and low-income members of the community is evidence that, with proper planning, supports and leadership, high quality housing can be provided and maintained (White, personal communication).

Over the last several years, a number of similar small-scale, collaborative projects and improved working relationships have been developed in various localities. Selected federal programs, including housing programs sponsored by the U.S. Department of Housing and Urban Development under the Stewart B. McKinney Homeless Assistance Act, and the ACCESS (Access to Community Care and Effective Services and Supports) Program administered by the Center for Mental Health Services, will inevitably serve an increasing number of homeless people with serious mental illnesses and HIV infection (Randolph, 1995).

No single housing model or individual organization can effectively address the myriad and changing needs of this population. Rather, an array of housing choices must be developed, and multiple agencies have to work together across service system boundaries. The development of

housing with physical care supports of varying intensity, from occasional assistance to hospice-like settings, are likely to be needed. Further research is needed to establish the costs, and benefits, of various housing options and their impact on morbidity and quality of life. In the interim, collaborations among the relevant service providers can do much to redress the problems of access experienced by people with these multiple problems.

Meeting the Challenge

Working with homeless people who have serious mental illnesses and HIV infection poses complex ethical, clinical, and systems integration challenges. Staff need to be both sensitive and well informed; clinical care must accommodate a wide variety of needs and possibilities; and the full array of medical, mental health, and housing services has to be coordinated effectively to serve this population.

None of these are easy tasks, yet all are essential to addressing HIV infection in homeless people with serious mental illnesses. AIDS is a fatal disease, and the special vulnerabilities of this population cannot be ignored.

Conclusion

The epidemic of the human immunodeficiency virus has profoundly altered the context of medical care throughout the world. The extremely high rates of infection among people with serious mental illnesses, especially those who are homeless, are striking, and they demand appropriate responses.

A more complete understanding of the nature and course of HIV infection, the special vulnerabilities of people with serious mental illnesses who are homeless, and the impact of the virus on psychiatric treatment and residential supports must become a part of the knowledge base of all clinicians and program planners. Approaches to preventing the spread of infection - through education about sexual behaviors and intravenous drug use - must be integrated into both overall clinical strategies and daily practice. Those responsible for planning and implementing policy at all levels must develop thoughtful and ethically sound strategies for HIV testing, clinical treatment, residential alternatives, and ongoing care.

In the long-term, provision of appropriate services for homeless people who have serious mental illnesses and HIV infection may involve substantial changes in existing service delivery systems. The need for close collaboration between programs that serve homeless people, mental health practitioners, health care personnel, and housing providers is crucial. Broad systems planning must include appropriate staff education, the development and funding for an array of outpatient and residential services, and multidisciplinary teams with the capability to address this group's diverse needs.

The complexity of the social, personal, and ethical issues raised by the HIV epidemic are multifaceted and profound. Yet the failure to address these issues results in the suffering and death of hundreds of thousands of vulnerable individuals in the U.S. alone. In mental health care, as in the general health care system in America and worldwide, HIV and AIDS cannot be ignored. Incorporating plans to address the epidemic are difficult and burdensome; they are, however, imperative.

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