HIV and Chronic Mental Illness
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For the individual with a chronic and serious mental illness, coping with day-to-day life can present an enormously difficult task. When infected with HIV, additional physical and psychosocial stressors produce even greater challenges for the patient as well as the systems and professionals who attempt to provide care. This article defines the needs of chronically mentally ill patients with HIV disease, describes their impact on medical and mental health systems and suggests counseling approaches to treat them.

Who are the chronically mentally ill? Generally, the term refers to those individuals with histories of psychotic illnesses—for example, schizophrenia, schizoaffective disorder, and bipolar affective disorder with psychotic features—that significantly impair daily functioning. Different psychotic conditions have different symptoms but often share common features such as auditory hallucinations, impaired social interactions, and bizarre or delusional thinking.

Years ago, many individuals with chronic mental illness were institutionalized; but, since the 1960s, there has been an enormous reduction in the numbers of long-term and acute psychiatric beds, and individual cities and counties have become responsible for providing outpatient treatment for the chronically mentally ill in their communities. Some patients do very well with outpatient care; they regularly take prescribed medications, attend day programs, receive vocational training, and utilize case management. Others swell the ranks of the homeless without the benefits of psychiatric or medical treatment.

HIV-Related Risk
Seriously mentally ill patients are at high risk for contracting HIV disease for several reasons. Contrary to popular belief, these individuals have sexual feelings, are often sexually active, and some have a tendency towards hypersexuality. The mentally ill, especially the large numbers who are homeless, may trade sex for food, shelter, or drugs. Psychotic processes can impair judgment and impulse control, interfering with decisions about practicing safer sex.

Substance abuse is also common in this population: at the SFGH outpatient HIV clinic and in community-based AIDS residential programs in San Francisco, more than 60 percent of the chronically mentally ill patients are substance abusers. Thus, HIV transmission is increased directly through needle-sharing and indirectly by clouding the judgement necessary to avoid other risks. In addition, people who are chronically mentally ill have minimal access to HIV education and community services and so may lack an understanding of HIV transmission and prevention.

A 1990 study found that 19 percent of acute psychiatric patients had a recent history of at least one HIV-related risk behavior. This study also found that bipolar illness, formerly “manic-depressive illness,” is associated with increased HIV-related risk, probably due to the disinhibiting qualities of manic episodes. Despite these heightened risks, few psychiatric facilities conduct routine HIV-related risk assessments.

Furthermore, only recently have researchers appreciated the high prevalence of HIV infection among psychiatric inpatients. A recent San Francisco General Hospital (SFGH) study found an infection rate of 9 percent among these patients, compared to 4 percent among Bay Area residents and .04 percent in the U.S. popu-
Editorial: Society’s Stepchild

Robert Marks, Editor

Mentally ill people—as do gay men, people of color, women, adolescents, and the poor—add HIV disease to a list that includes other challenges: poverty, stigmatization, a lack of power and limited access to services. But, in some ways, mental illness is a stepchild among the problems that plague society, and society has yet to acknowledge the looming risk of HIV disease among the chronically mentally ill.

As the numbers of the mentally ill continue to grow, the United States continues to reduce funding to this segment of the population increasing HIV-related risk by limiting psychiatric treatment services and exacerbating destructive social conditions, such as homelessness.

A few rough statistics add further shape to the challenge. Currently, 25 percent of the hospital beds in this country are occupied by people with chronic mental illness. In the U.S., the incidence of schizophrenia—a diagnosis that comprises a variety of manifestations—is a whopping 1 percent.

The size of the potential population, however, is less important than its characteristics. Reaching people with chronic mental illness is difficult; they seem to be the ultimate hard-to-reach population, hiding in worlds of their own. Their invisibility, however, is imposed on them: shunned in schools and other public institutions, stuffed into attics and basements, shut away on the locked wards of hospitals and insane asylums, and, now, finally, invisible in the most amazing way, before our eyes—shut tight—on the streets of most American cities. They are hard to reach primarily because we believe we cannot, but mostly because we will not, reach out to them.

Emily Leavitt and Patricia Sullivan in their overview of HIV disease and chronic mental illness and Ronald Hattis in an article focusing on inpatient HIV education acknowledge the stepchild among the problems that plague society, and society has yet to acknowledge the looming risk of HIV disease among the chronically mentally ill.

In their work as counselors and educators, Leavitt, Sullivan, and Hattis are reaching people with chronic mental illness. They and their colleagues are successfully communicating about the dangers of HIV disease and are helping people with chronic mental illness make life-saving decisions about behavior, antibody testing, and treatment.

The message of this issue of FOCUS is that HIV prevention education and counseling can be successfully performed with the chronically mentally ill. The challenge is for those providing care to this population to take up the call.

The Clinical Picture

HIV disease can affect the clinical picture of pre-existing mental illness in several ways. For example, thoughts regarding AIDS can become the focus of psychotic delusions. A patient might say, "Spirits gave me AIDS," or "I've cured myself of AIDS and can now cure others."

In addition, chronically mentally ill patients faced with HIV-related fears, pain, and physical decline may experience an overlay of new psychiatric symptoms, such as depression, anxiety, or rage. Psychiatric intervention—whether psychotherapy or psychiatric medication—can greatly enhance quality of life for these patients, but sometimes is not available. Even if treatment options do exist, these patients may be too afraid or confused to seek proper treatment and may instead "self-medicate" with alcohol, opiates, or other drugs.

HIV infection can also directly affect brain functioning, and HIV-related organic disorders, like dementia or mania, can worsen or further complicate the psychotic process. Conversely, when a provider overlooks pre-existing psychiatric history, psychotic patients with HIV disease are frequently misdiagnosed as having HIV-related dementia, and such misdiagnosis often leads to inappropriate treatment.

Psychiatric medications for HIV-infected patients need to be carefully evaluated and monitored, since these patients are more susceptible to side effects than are their uninfected counterparts. Potential side effects, such as dry mouth, diarrhea, or restlessness and pacing can cause further debilitation in immune-compromised patients. Finally, patients with advanced HIV disease may require less psychotropic medication than they previously needed to control their symptoms.
HIV-Related Counseling and Concerns

Most counselors with HIV-related experience are used to treating clients with psychological problems stemming from the psychosocial and physical stressors of HIV disease, but they are generally less familiar with patients whose major psychological problems predate HIV infection. Some counseling approaches effective with the normal population of HIV-infected patients can be ineffective and possibly damaging to patients with serious mental illness. For example, many chronically mentally ill individuals are socially and emotionally withdrawn. Counselors who focus on establishing warm, close relationships and eliciting emotional responses may frighten patients into further withdrawal or escalate them into increased psychosis.

Patients who present as actively psychotic—that is, responding to auditory hallucinations, exhibiting bizarre speech and behavior, acting out of touch with reality—will not benefit from "counseling" in the traditional sense. Rather, counseling staff need to maintain a calm, quiet demeanor to comfort and deescalate these patients, while making arrangements for any necessary psychiatric intervention. It is important for counselors to realize that, generally, psychotic symptoms will not simply go away without appropriate psychiatric medication.

How does the counselor best assist such patients in coping with the new stressors of medical visits, declining health, and fears regarding death and dying? Assess the patient’s ability to deal with emotional content. For the patient who is extremely withdrawn or out of touch with reality, supportive, nonjudgmental comments such as, "It’s usually scary to be in the hospital," or "We’re going to help you learn what medicines to take" can be helpful. For the higher functioning patient who is stabilized on psychiatric medication, the counselor can ask more direct questions: "Do you want to talk about what this diagnosis means?" or "Are you scared?"

As the discussion continues, address the patient’s concerns in a concrete, calm manner. Again, avoid emotional confrontation or pushing for “feelings” while acknowledging any feelings that the patient brings up: “I understand that you’re very sad about your friend’s death. It’s normal to be sad when friends die. Do you want to talk about it more?” On the other hand, it is important for the counselor to recognize his or her own discomfort in discussing difficult issues so as to avoid ignoring the patient’s desire to address painful feelings.

As noted above, patients with serious mental illness can develop depression and anxiety in relation to new stressors such as HIV disease, and this can be difficult to assess. If patients present with new symptoms such as appetite change, insomnia, or thoughts of death, gently explore these symptoms and arrange for psychiatric consultation based on their severity.

Finally, treatment goals with the chronically mentally ill patient should include compliance with and understanding of both psychotropic and HIV-related medications. For the individual who is unable to manage his or her own medications, arrange professional assistance such as case management or supervised residential programs. Patients may also need focused behavioral counseling regarding appropriate behaviors in outpatient and inpatient medical settings, including help in learning to adhere to clinic rules.

Mental Health and Medical Systems

Traditionally, mental health and medical programs have not worked closely together; even within a single hospital, relationships between the departments of psychiatry and medicine can be distant. In such settings, the care of patients who require both medical and psychiatric expertise may be compromised.

Mental health clinics, day treatment programs, and psychiatric residential facilities frequently lack knowledge, awareness, and perhaps willingness to work with patients who have HIV disease. These programs are not designed to deal with patients with declining health or chronic medical problems such as fevers, diarrhea, acute pain, or wasting. Inpatient nursing staff may be unfamiliar with infusion or other HIV-related medical procedures. Psychiatrists may lack knowledge regarding HIV-related medications, especially when used in conjunction with psychotropic medications.

HIV risk assessment is critical in psychiatric settings. A recent study concluded that mental health providers are hesitant to discuss risk factors for a variety of reasons, including the belief that HIV infection is not related to psychiatric...
Concerns, the fear that the topic may distress patients or increase suicide risk, and the reluctance to deal with the ethical and legal implications of patients practicing unsafe sex. Perhaps the most common reason why psychiatric staff members fail to deal with HIV-related risk is their discomfort taking sexual histories and discussing sexual practices. A recent study conducted at five publicly funded, university-affiliated county mental health clinics found that 82 percent of clinical staff believed the anxiety levels of patients would be heightened if patients disclosed information about their sexual practices. In fact, only 27 percent of patients reported such feelings.

Medical settings are usually not well-equipped to work with patients with serious mental illness. These patients are not usually connected to primary or preventative medical care, and may be initiated into the health care system as a result of their HIV disease. Medical providers, often reflecting the general indifference of society toward chronic mental illness, may lack awareness or sensitivity, for example, believing that all psychotic patients are dangerous and should be institutionalized.

It is true that these patients can be difficult to treat. They may have serious problems complying both with medication regimens and appointment schedules. In addition, they may exhibit substance abuse and drug-seeking behavior, have difficulty localizing and describing symptoms, and engage in obtrusive and disinhibited behaviors, which can be particularly difficult in a waiting room full of medically compromised patients.

The unwillingness of many medical personnel to work with HIV-infected patients has been well-documented in the media; the chronically mentally ill are perhaps considered less newsworthy, but are equally shunned by many professionals. Thus, the patient who suffers both HIV disease and major mental illness may suffer professional disdain on two fronts. Education and training are probably the best tools to counter staff resistance.

**Conclusion**

HIV-infected patients with chronic mental illness benefit from programs that can address both their psychiatric and medical needs, and there are successful residential programs in various communities that provide medical, mental health, and substance abuse services. Ideally, new adult day health programs—traditionally developed to respond to the needs of the elderly—will now address the complicated physical and psychological needs of HIV-infected patients.

On-site mental health services can have a tremendous impact on HIV-related outpatient and inpatient medical care, both through direct patient contact and through consultation and training for staff. Specialized inpatient psychiatric units can provide treatment and discharge planning for the patient with concurrent HIV disease and mental illness, and all psychiatric facilities should be encouraged to incorporate HIV-related risk assessment into their intake procedures.

The chronically mentally ill are often overlooked as a high-risk group for HIV infection. They present special challenges both to the systems with which they interface and to individual providers counseling and treating them. People with chronic mental illness, whose lives are often characterized by emotional turmoil and social instability, are in need of multiple services: HIV prevention and treatment counseling now clearly must be among them.

**Clearinghouse: Psychiatric Issues**

**References**


Several studies have shown that psychiatric inpatients have a higher HIV seroprevalence than the general population. Education and behavior change for these patients may require special efforts because of delusions, confusion, compulsive behavior, poor impulse control, and poor self-esteem. Although such patients have daily contact with health professionals who could make these efforts, many psychiatric hospitals have not yet introduced systematic HIV education, antibody testing, and risk-related counseling.

In 1987, the California Department of Mental Health instituted a three-step program for inpatient HIV education and a process for inpatient HIV antibody testing. These were implemented at the five California state hospitals for mentally disabled people. The programs described below are those in effect at one of these institutions, Patton State Hospital, and include both mandatory statewide components and additional elements, such as risk factor interviews and condom availability.

Patton is a coeducational, forensic, psychiatric facility with almost 1,000 beds. Court commitments ranging from a few months to several years permit adequate time for several HIV-related contacts with each patient, and most patients become stable enough prior to discharge to comprehend health-related information.

HIV Education and Condom Distribution
Patient education and antibody test counseling at Patton are provided by specially-trained HIV Counselors. Staff designated as counselors—including registered nurses, psychiatric technicians, social workers, and psychologists—receive a minimum of seven hours of training covering general information about HIV disease, specific information on training steps and materials, and hospital policies on condom use and antibody testing. There are two to four counselors from each unit of 40 to 50 patients. Educational materials are selected for simplicity in concepts and language—for example, no attempt is made to explain T-helper cells—and emphasize behaviors necessary to prevent HIV transmission.

Education begins with Level 1, during which a single-sided handout containing basic HIV-related information is reviewed with each patient shortly after admission. Patients are also told that further information and a blood test will be available through HIV Counselors. Within one month of admission, HIV Counselors present Level 2 group education, including a videotape and pamphlets about HIV disease, hands-on training about condoms, and a discussion of safer sex.

Later in the hospital stay, HIV Counselors provide more details in Level 3 training to individuals or very small groups mentally capable of absorbing further HIV-related information. Counselors note whether patients have understood each topic. In addition, they conduct confidential one-on-one risk factor interviews—the records of which are saved for analysis, but not filed in patient charts—to help patients appreciate personal risk and avoid high-risk behaviors.

Patton makes clear to patients its policy towards patient sexual activity: it is neither approved nor condoned. Furthermore, patients are told that sexual activity can be risky, but if it occurs, condoms are available to make it safer. Condoms may be obtained by patients from HIV...
Counselors and from staff at the medication room. Some units make condoms freely available in patient restrooms or permit ward government leaders to distribute them. Units order condoms from the pharmacy, but condom distribution does not require any charting or sign out on drug sheets.

HIV Antibody Testing

To encourage risk reduction and early medical intervention, the hospital provides voluntary, confidential HIV antibody testing after the completion of Level 3 education and additional pre-test counseling. Patients must sign a simply-worded consent form, and hospital psychiatrists must verify in writing that their patients are capable of informed consent and that there is no contraindication to testing due to suicide risk. Post-test counseling for patients who test antibody negative helps further to personalize HIV-related risk and reinforce risk reduction behavior.

Patients who test antibody positive are treated according to a detailed protocol covering psychological support, behavioral counseling, and HIV-specific medical care. There are no segregated units for HIV-infected patients, however if they behave in sexually irresponsible ways, they may be subject to special observation such as one-to-one nursing care.

Program Utilization and Experience

The majority of Patton patients have received Levels 1 and 2 education, but some units have required periodic reminders to keep the program active. Many patients have failed to receive Level 3, partly due to mental status, but variation by unit suggests that the motivation and available time of HIV Counselors are also factors. Delusional thinking has sometimes interfered with learning about HIV disease. However, key concepts have been communicated even to acutely psychotic patients.

The ultimate criterion of the success of an HIV program is behavior change to reduce HIV exposure among high-risk patients. For example, after HIV-related and drug counseling, a seropositive, female heroin addict was elected to lead a hospital Narcotics Anonymous group, shared her story to encourage others to be tested for HIV antibody and to avoid injection drug abuse, and remains drug-free since her discharge. On the other hand, another seropositive patient could hardly wait to be released and to resume drug abuse.

In 1992, Patton purchased enough condoms to supply the average patient with three per month. The number actually used, however, is unknown. Some patients do not sufficiently plan their sexual activities to take these precautions, while others are too embarrassed to seek out condoms. Problems initially feared by many staff members—for example, unsanitary disposal, hoarding, “water balloon” fights—have by and large not materialized.

From March 1987 through December 1992, 824 Patton patients had confidential antibody tests and 2.4 percent tested positive. This rate was more than twice as high as the hospital’s blind seroprevalence found through studies in 1987-88 and 1990, suggesting that voluntary testing following HIV education was successful in reaching individuals with higher than average risk.

Conclusion

Several lessons can be learned from the Patton State Hospital experience. These include:

- The level of information patients can integrate depends on their mental status and duration of stay.
- Key HIV prevention messages—such as the need for safer sex and avoidance of needle sharing—must be presented in simple terms and repeatedly reinforced.
- HIV counseling can lead to voluntary antibody testing by patients with histories of high-risk behavior.

Most importantly, our experience shows that HIV education can be successfully imparted to patients with chronic mental illnesses. We have achieved success both in identifying HIV-infected patients who can then be appropriately monitored and treated, and in modifying HIV-related risk behaviors in at least some of our patients.

Comments and Submissions

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

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**Recent Reports**

**HIV Education for the Chronic Mentally Ill**

A group of 50 Massachusetts community mental health outpatients considerably improved their HIV-related knowledge, following participation in a pilot AIDS education program. Despite the sexually explicit nature of the information provided, no instances of aggressive or other maladaptive behavior occurred during or after the program. In addition, six months later, 50 percent of study participants approached the center for condoms and more information.

Subjects participated in three one-hour HIV education classes that focused on sex education, HIV-related information, and proper condom use. Subsequently, the clinic developed other sessions relating to assertiveness skills and to needle sharing. The curriculum was multidimensional and made use of audiovisual aids, models and handouts.

Despite the intervention, there were significant gaps in HIV-related knowledge, a denial of substance use, and high levels of risk behavior. The report included only general and qualitative findings, because the sample was small and researchers did not collect data from all participants.

**Risk Behaviors in Wisconsin**

A small group of chronic mentally ill people reported high levels of HIV-related risk behaviors and low levels of HIV-related knowledge, and frequently found themselves in situations that led to risk-taking.

Researchers administered questionnaires to 60 chronic mentally ill patients who visited community mental health clinics in Wisconsin. Eighty-five percent had diagnoses of schizophrenia or other psychoses. Of the 32 men and 28 women, 57 percent were African American and 40 percent were White, 57 percent lived in apartments and 25 percent lived with their families, and 93 percent were unmarried and 62 percent were sexually active in the prior year. The mean age of participants was 36.

The respondents incorrectly answered many basic questions about HIV infection: 43 percent stated that heterosexual women were not at risk, and 45 percent stated that people with AIDS always appear to be ill. The sexually active men reported an average of 13.2 different female partners within the prior year, and 11 percent also had engaged in sex with other men. Among sexually active men, condoms were used regularly less than 20 percent of the time.

Eighty-three percent of study participants reported that they had encountered at least one HIV-related risk situation in the prior year. Twenty percent reported having had sex after using alcohol or drugs, and 15 percent had been pressured into having unwanted sex. In addition, 33 percent had also been diagnosed with STDs other than HIV.

**Risk Behaviors and HIV Knowledge**

An exploratory survey of 50 subjects, dually diagnosed with chronic mental disorders and substance abuse, found that although they possessed a moderate amount of HIV knowledge, they were misinformed in some crucial areas, especially about condom use. The interviewees also regularly engaged in high-risk heterosexual practices, and younger subjects engaged in significantly more of these behaviors than did older subjects.

The study population was drawn from attendees of a hospital-based clinic for dually disordered adults located in central Brooklyn. Researchers questioned subjects regarding their HIV knowledge and risk behaviors. Eighty-eight percent were African American, and 86 percent were men, a majority of whom had never been married. The average age was 32. Subjects were primarily unemployed and living on public assistance.

Psychiatric diagnoses included 30 percent paranoid schizophrenia, 42 percent other schizophrenia, and 28 percent...
other mental disorders. Fifty-two percent had a secondary diagnosis of alcohol abuse or dependence, and 48 percent were diagnosed with another psychoactive substance use disorder. Nearly all had a history of multiple substance use.

Although an average of 62 percent of the subjects answered questions about HIV disease correctly, the responses varied and were not consistent. Subjects were misinformed in key areas, with less than half answering questions about condoms correctly. In terms of high-risk sexual practices, 38 percent had unprotected oral sex, 28 percent had sex with drug users, 22 percent had sex with prostitutes, 16 percent engaged in anal sex, 12 percent traded sex for drugs, and 6 percent had sex with bisexuals.

There was a moderate association between educational level and knowledge of HIV disease, and educational level and condom use. Similarly, subjects with more severe drug problems had greater HIV-related knowledge. In terms of sexual practices, there was a significant correlation between age and unsafe sex, with younger adults engaging in more unsafe sex. The study also found that accurate HIV-related knowledge did not result in safer sex practices.

Prevention on an Adolescent Psych Unit

Following participation in an HIV prevention program, adolescent psychiatric inpatients with a history of HIV-related risk behaviors reported reduced intentions to engage in these behaviors, particularly in sexual risk taking. Subjects also indicated a significant decline in misconceptions about the casual spread of HIV. Sixty-two adolescents, admitted to a locked hospital psychiatric unit in San Francisco for a six-month period, participated in an HIV prevention program that lasted eight days over four weeks. Of the adolescents, 62 percent were White, 16 percent Black, and 60 percent had been sexually active. The personal histories of the participants included high incidences of sexual abuse, self-mutilation, multiple risk-taking behaviors, infrequent condom use, and substance abuse.

Held in conjunction with a sex education program, the HIV prevention program consisted of a didactic classroom component, creative art therapy sessions, and biweekly “lifestyle” discussion groups. Two key components of the program were a presentation by a person with AIDS and peer group support.

There was a significant change from pre- to post-intervention in the understanding that casual contact was not a major means of HIV transmission. However, there was no significant change in response to questions about HIV-related knowledge and perceived risk of infection. An overwhelming majority (87 percent) of participants endorsed the concept of HIV education in psychiatric hospitals.

Sexual risk-taking intentions declined significantly after the intervention. For example, 75 percent of those who had engaged in sex with a gay man and 50 percent of those who had engaged in unprotected sex reported that they did not intend to do so in the future. Those likely to engage in anal intercourse declined from 50 percent to 33 percent and those who would engage in sex with an injection drug user fell from 80 percent to 20 percent. The percentage of reduction was less for drug-related behaviors, however, suggesting that special efforts are required to change these risk behaviors in this population.

Next Month
The most common and perhaps the most difficult AIDS legal and ethical issue relates to the duty to protect, specifically, the counselor’s potential obligation to inform identifiable sexual partners if seropositive clients pose an imminent danger of transmitting HIV. In the April issue of FOCUS, Craig Georgianna, MA, a counselor working with high-risk adolescents, and Michael W. Johnston, EdD, an adjunct assistant professor of educational psychology at California State University, Long Beach, present data on a survey of the client’s response to the duty to protect. They found that clients overwhelmingly disapproved of counselors breaching the confidentiality of the therapeutic relationship.

Also in the April issue, Peter Daniolos, MD, a psychiatry resident at Duke University Medical Center in North Carolina, discusses the response of professional organizations to the HIV-related duty to protect.
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