

Mental Health and Substance Abuse Issues Among People with HIV

Lessons from HCSUS

A diagnosis of HIV affects every aspect of a person’s life. Simple awareness of the disease, as well as progression of symptoms, can precipitate new, or exacerbate existing, problems with mental health and substance abuse. In turn, such problems increase an individual’s need for health care services and interfere with his or her ability to comply with complex treatment regimens. What’s more, persons with HIV who struggle with mental health or substance abuse issues may be more likely to engage in unsafe sex and needle-sharing behaviors than others, thus increasing the risk of spreading the disease.

To understand how mental health and substance abuse problems affect those struggling with HIV, the HIV Costs and Services Utilization Study (HCSUS)—the first survey of a nationally representative sample of persons with HIV—gathered information to estimate the prevalence of these problems among persons with HIV, to assess those persons’ access to appropriate care, and to measure how these problems affected their ability to adhere to treatment. A special follow-up survey was conducted on the segment of participants who initially screened positive for mental health problems or substance abuse, and another follow-up survey focused on issues related to the sexual behavior of people living with HIV.

Prevalence of Mental Health and Substance Use Problems Among Persons with HIV

At the beginning of the HCSUS study, the research team screened participants for mental health and substance abuse problems. Nearly half of the participants screened positive for one or more of four psychiatric disorders—major depression, dysthymia, generalized anxiety

Key findings:

- People with HIV are much more likely to experience mental health or substance abuse problems than individuals in the general population.
- Most individuals with HIV who have mental health or substance abuse problems receive the treatment they need, but earlier detection and intervention would likely offset the increased medical costs they often incur.
- More than half of those receiving highly active antiretroviral therapy (HAART), the most effective treatment for HIV, did not take the medications as directed; those struggling with mental health or substance abuse problems were the least likely to comply. Screening and special interventions may help.
- Violence is common in the intimate relationships of people with HIV: A combination of substance use and violence increases the likelihood of engaging in unsafe sex.

disorder (GAD), and panic attacks—far higher proportions than those observed in the general population. When the analysts refined estimates based on this screening with more-comprehensive diagnostic interviews, they found that the prevalence of mental health problems was still higher than for the general population (Figure 1).

Mental Illness

All other factors being equal, the groups most likely to screen positive for a mental illness were individuals under age 35, African Americans,

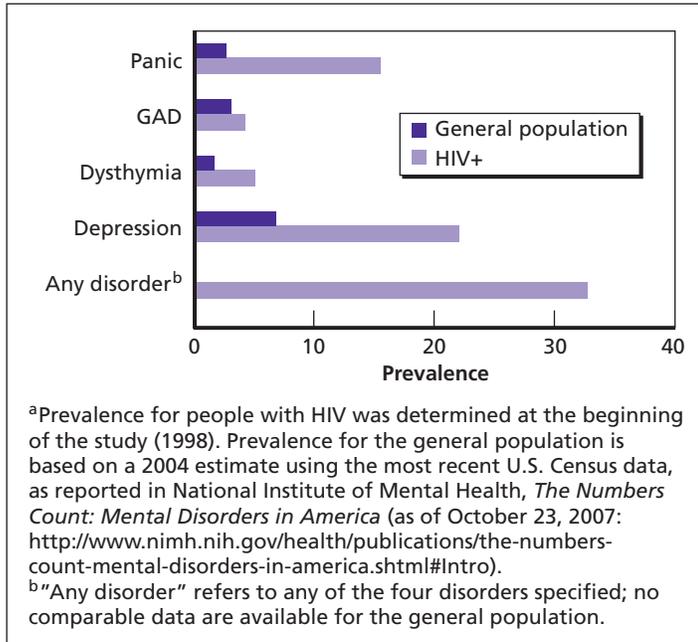
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Figure 1
Prevalence of Mental Health Disorders in Individuals with HIV and in the General Population^a



people who lived alone or with a non-romantic partner, the unemployed or disabled, those with more HIV-related symptoms, and those who reported using illicit drugs other than marijuana. However, disease severity did not play an important role: Individuals with more-advanced HIV were no more likely to have a mental illness than those with less-advanced disease.

In the United States, HIV affects primarily men. Nevertheless, a high proportion of women who were HCSUS participants tested positive for some form of mental illness. Signs of mental illness were more likely to be seen among women who were younger, who had more-advanced disease, and who needed income assistance. Women who attempted to cope with their disease by avoiding others or withdrawing in other ways, who tended to be in conflict with others, who reported prior physical abuse, and who reported putting off going to the doctor because they were caring for someone else also were more likely to show signs of mental illness.

Participants who screened positive for depression or showed signs of having other mental health problems at the beginning of the study had significantly higher medical costs in the following 12 months, even after taking into account the severity of their disease. The increased cost was largely attributable to their greater use of inpatient and emergency services. This finding suggests that early identification and treatment of mental health problems among individuals with HIV might improve their functioning, reduce unnecessary utilization of other health services, and decrease overall treatment costs.

Alcohol and Other Substance Abuse

Alcohol use by those with HIV is of particular concern because it may exacerbate the effect of the virus on the brain. About 8 percent of the HCSUS participants reported that they drank heavily, about twice the rate in the general population. Heavy drinking was associated with lower education level and with use of cocaine and/or heroin; however, it was less common among those with more-advanced disease. Men who described themselves as gay or bisexual (collectively known as men who have sex with men [MSM]) were more likely to drink and were likely to drink more heavily than any other group.

Nearly two-fifths of the HCSUS participants reported using an illicit drug other than marijuana, and more than 1 in 8 screened positive for drug dependence. Those whose survey responses suggested drug dependence tended to be under 35 and heterosexual, live alone or with someone other than a spouse, have many HIV-related symptoms, and often drink heavily. Eight percent of women were drug-dependent or heavy drinkers. Overall, MSM were more likely to use drugs than were other groups, although they were less likely to be drug-dependent.

Substance abuse by people living with HIV is also of concern because it may lead to unsafe sex—that is, to sexual behavior that risks transmitting HIV to others. HCSUS participants who reported substance use were indeed more likely to have had unprotected sex (sex without a condom)

What Is HCSUS?

The HIV Costs and Services Utilization Study (HCSUS) is the first comprehensive U.S. survey of health care use among a nationally representative sample of HIV-positive persons who were in care for their HIV. The aims of HCSUS were to estimate the costs associated with HIV care; to identify barriers that affect access to HIV treatment, as well as to other health care services; and to assess how HIV-positive status affects quality of life, productivity, and family life. Participants in HCSUS were interviewed several times over a 3-year period, making it possible to assess the effects of changes in HIV treatment.

Since it began in 1996, HCSUS has generated more than 70 original research publications on a wide variety of issues related to HIV infection. The initial findings have been reported widely and featured in several RAND Research Highlights (see research summarized, p. 5). This Research Highlight reports findings from a series of questions posed during the initial interview regarding the need for treatment for mental health and substance abuse. The Highlight is one in a series summarizing HCSUS research. More information on HCSUS, including a list of publications, can be found at www.rand.org/health/hcsus.

with someone of negative or unknown HIV status during the previous 6-month period.

The Effect of Physical Abuse

Episodes of violence in one's close relationships may increase the likelihood that a person with HIV will develop or exacerbate a mental or substance abuse disorder. Violence itself may also be an outcome of mental or substance use disorders. More than 25 percent of the HCSUS participants in close relationships reported the presence of abuse.

All else being equal, African Americans were more likely than whites to be in an abusive relationship, either as the perpetrators or the victims. Younger people, those with psychiatric disorders, and those currently binge-drinking or abusing drugs were all more likely to be either a perpetrator or a victim of violence. Having a partner who was also HIV-positive was associated with a higher risk of abuse than not knowing a partner's HIV status or having a partner who was HIV-negative.

Relationship violence is also a risk factor for transmission of HIV. Victims of abuse were more likely to report having had sex without a condom at least occasionally. HCSUS participants who reported having been violent in their personal relationships were also more likely to have unprotected sex, but only if they also reported using drugs before or during sex. Indeed, this group of violent substance abusers was almost twice as likely to have had unsafe sex as those who did not abuse substances in this way or were not abusing their relationship partners.

Co-Occurring Disorders

About 13 percent of HCSUS participants had psychiatric symptoms and were either drug-dependent, heavy drinkers, or both. Individuals with co-occurring disorders were more likely to be male, heterosexual, white or Hispanic, sexually active, living with someone other than a spouse, under 50 years of age, and lacking private-insurance coverage.

Use of Treatment Services for Mental Health and Substance Abuse

About 70 percent of the participants was estimated to need some type of mental health care (including substance abuse treatment). Of those persons, 30 percent reported that they had gone without such care in the previous 6 months. However, 70 percent did receive care, suggesting that people with HIV who need mental health care are faring better than those in the general population (national studies have estimated that only 25 percent of those with psychiatric diagnoses receives needed care).

People with more-advanced disease and those with more symptoms were more likely to receive some type of mental health treatment than those with less-advanced disease or fewer symptoms. Those who were unable to work because of

disability were more likely to receive mental health services than were those in other employment categories. Gay men were more likely to seek mental health services, but they were much less likely to use substance abuse treatment services than heterosexuals. Those with a college education were more likely to receive mental health services, but they were also much less likely to receive treatment for substance abuse than were those with less education. In contrast, those of lower socioeconomic status and African Americans were less likely to receive treatment for a mental health disorder but more likely to receive treatment for substance abuse. Gender and age did not affect the likelihood of receiving mental health services.

Because mental health treatment provided by a specialist may be of higher quality than that provided by a primary care physician, the research team also assessed the kinds of practitioners seen by the participants. Some 77 percent of individuals who were receiving care received it from a mental health specialist; the rest received care only from primary care physicians. People who saw specialists had more visits and were more likely to receive psychotherapeutic medications and to have been hospitalized than those who saw only generalists. (These findings could indicate more-thorough treatment, or they might simply mean that those who saw specialists had more-severe problems.) Insurance status did not affect the likelihood of receiving care, but those with private health insurance were half as likely to have seen a specialist as those with Medicaid or Medicare. The disabled and the college-educated were more likely to receive care from specialists.

Study participants with major depression were more likely to be taking antidepressant medications than were persons with major depression in the general population. Nevertheless, the kinds of treatment people with HIV received for mood disorders showed some racial and ethnic differences. Among patients with diagnosed mood disorders, African Americans were significantly less likely than whites or Hispanics to use antidepressants but more likely to have received some type of psychosocial intervention.

Mental Health, Substance Abuse, and Use of Highly Active Antiretroviral Therapy (HAART)

Another reason for particular concern about mental illness and substance abuse among people with HIV is that these conditions might lessen the likelihood of receiving HAART or, if they receive it, of following the treatment instructions. Poor adherence to treatment is common. Medication schedules are complex and inconvenient, the drugs often produce side effects, and, to work properly, the drugs must be taken consistently for long periods of time. (The reason for concern about failure to follow treatment instructions is that so-called nonadherence is associated with acquiring and spreading a more virulent, drug-resistant form of the disease.) The

HCSUS researchers examined whether substance use and mental health problems affect the likelihood that an individual receives HAART or follows treatment instructions.

The research team found that individuals with mental illness, substance abuse, or addiction, as well as those who contracted HIV through injection drug use, were less likely to have received HAART than other participants (for a more complete discussion of access to care, see the research highlight *Disparities in Care for HIV Patients: Results of the HCSUS Study*, RB-9171, 2006).

During the first follow-up survey, more than half of participants taking HAART were nonadherent (that is, they reported missing at least one treatment in the previous week). All other factors being equal, the nonadherent were more likely to be heavy drinkers, use drugs, or have a probable psychiatric disorder, such as depression, generalized anxiety, or panic disorder. Nearly half of the participants without a psychiatric disorder or drug use were adherent. But adherence declined to 36 percent for those with a psychiatric disorder, and it dropped lower still for those who used illicit drugs or alcohol (Figure 2). Adherence declined steadily with increasing alcohol use, including moderate use.

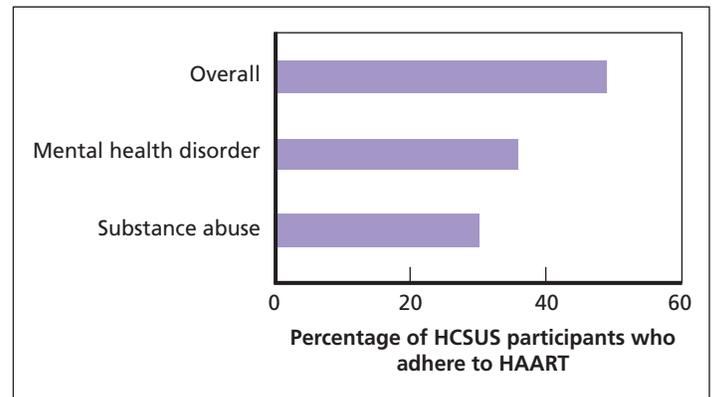
When asked what factors interfered most with adherence to HAART, people with mental health and substance use problems most often cited the time and effort it takes to get the medications, as well as the challenges of integrating the complex treatment regimen into one's lifestyle. Other potential factors, such as negative attitudes toward the medications and lack of instruction from health care providers in using the medications, did not turn out to be important. These findings suggest a need to screen and provide treatment for mental health problems and to help patients deal with HAART's complex medication schedules.

The Good News

While the HCSUS study revealed many challenges of mental health and substance abuse problems among people with HIV, there was also good news. In addition to the relatively high access of people with HIV to mental health and substance abuse treatment, most of the HCSUS participants reported having made some positive changes in health behaviors since their diagnosis: Some 80 percent of substance users reported having quit or curtailed their drinking or use of other substances.

In addition, from the beginning of HCSUS to the first follow-up questionnaire—about 8 months—symptoms of mental disorders generally decreased among HCSUS participants. This improvement was reported not only by those who were actively taking HAART but also by those who had been on HAART but stopped, as well as by those who had never used HAART. The decrease in symptoms of mental

Figure 2
Proportion of Participants Who Adhere to HAART



disorder reported by those who were taking or had ever taken HAART was accompanied by higher CD4 (a type of white blood cell) counts—an indicator of better physical health (or less-advanced disease)—and fewer opportunistic infections, which are responsible for much of the morbidity and some of the mortality associated with AIDS.

This finding suggests that HAART might improve mental health in two different ways: by some treatment-specific effect, which was observed in those who took the drugs, and by a more global effect, which was seen in those who had never used HAART. This latter effect may be attributable to the promise of extended survival and the better quality of life that HAART offers (that is, just knowing that HAART is available may give people with HIV a more positive outlook on their lives).

On the Horizon

As new treatment regimens increase the life span of people with HIV, greater attention is being paid to optimizing the mental health of this population. Based on the findings of HCSUS, ongoing studies are further examining factors that influence the mental health, substance use, and sexual risk behaviors of persons with HIV. Other studies seek ways to improve adherence to the difficult treatment regimens so integral to improved survival.

Finally, given the multiplicity of problems faced by people with HIV who also have mental illness, substance abuse, or co-occurring disorders, studies are examining the role of specialized programs in the treatment of these individuals. For example, people with co-occurring disorders need more-complex treatments and support services than those with only one or neither disorder. And the identification of a link between substance abuse and unsafe sex has led to the successful implementation of substance abuse prevention programs aimed at reducing unsafe sex among MSM. ■

This Highlight summarizes RAND Health research reported in the following publications:

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