MENTAL HEALTH MATTERS

We found substantial and consistent evidence that chronic depression, stressful events, and trauma may negatively affect HIV disease progression.1

—Jane Leserman, University of North Carolina, Chapel Hill

Diagnosis and treatment of mental health issues are essential to the physical health and quality of life of people living with HIV/AIDS (PLWHA). Psychiatric disorders are a barrier to medical care and adherence to medications, and several studies have found that depression, stress, and trauma can lead to disease progression and increased mortality.2–5 The power of mental health treatment to reduce depression and anxiety, improve adherence and HIV health outcomes and, in turn, reduce the likelihood of death from AIDS-related causes speaks to the vital role of mental health care in the web of HIV care.6–9

The HIV Costs and Services Utilization Study (HCSUS) found that nearly 50 percent of adults being treated for HIV also have symptoms of a psychiatric disorder—prevalence that is 4 to 8 times higher than in the general population. Nineteen percent of patients studied showed signs of substance abuse, and 13 percent had co-occurring mental illness and substance abuse disorders.10

In approximately one-half of people living with HIV/AIDS who have depression, the depression is both undiagnosed and untreated.11

A significant percentage of patients who commit suicide see their primary care clinician in the month before their suicide.12

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A more recent study of more than 1,000 PLWHA in North Carolina found even higher rates: 60 percent of study participants reported symptoms of mental illness, 32 percent reported substance use problems, and nearly 25 percent identified both symptoms of mental illness and substance use problems. High rates of depression and anxiety have been identified in PLWHA regardless of race, gender, or sexual orientation.

People with serious mental illness are particularly vulnerable to HIV infection as a result of the higher prevalence among this group of a variety of factors, including poverty, homelessness, high-risk sexual activities, drug abuse, sexual abuse, and social marginalization. Estimates of HIV infection rates among people with mental illness vary widely from 3 percent to 23 percent; the average is about 7 percent. Their health outcomes remain poor.

**DIAGNOSING and TREATING DEPRESSION**

Major depression is the most common mental health disorder among PLWHA; estimates are that about 60 percent of PLWHA will have a depressive episode at some time during their illness. Strong evidence indicates that HIV infection is associated with greater risk of major depressive disorder, although a review of research also found that most PLWHA appear to be psychologically resilient.

One challenge in linking patients with depression to care is the attitude of providers. “Too often, we see providers not using medications to treat depression because they are putting themselves in their patients’ shoes and the depression makes sense to them,” says David Haltiwanger, clinical psychologist at Chase-Brexton Health Services, a Ryan White HIV/AIDS Program grantee in Baltimore. “It is crucial that patients be medicated based on their symptoms for depression, not on the reason for depression.”

Recent research reflects the tremendous importance of identifying and treating depression in PLWHA. A retrospective study of more than 3,000 patients found strong evidence that depression without treatment using the

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**DIRECTOR’S LETTER**

We know that improving health care means more than meeting physical needs. For people living with HIV/AIDS (PLWHA), who have higher rates of depression and substance abuse than the general public, treating mental health disorders is especially critical.

Depression rates for HIV-positive people are as high as 60 percent; yet, one-half of all PLWHA with depression go undiagnosed and untreated. We’ve got the means to do better. Screening tools like HRSA’s *Client Diagnostic Questionnaire* can help detect potential signs of risk, such as social isolation and alcohol dependence. By closely monitoring patients at critical times, such as at the start of antiretroviral treatment, we can aid them at the onset of mental health issues. Because the sooner we see warning signs, the sooner we can act.

Let’s remember, too, that treatment regimens only go so far in treating mental illness—relationships matter, too. By providing support groups and strengthening patient-provider bonds, we can boost retention for people at risk, improving patients’ bodies and minds in the process.

Deborah Parham Hopson
HRSA Associate Administrator for HIV/AIDS

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**HRSA CARE Action**

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**Photographs**
Cover: Clients at the Tarzana Treatment Center, Los Angeles County, CA. Pp. 3-4: Clients at the Native American Health Center, San Francisco, CA. Photographs © See Change.

Additional copies are available from the HRSA Information Center, 1.888.ASK.HRSA, and may be downloaded at www.hab.hrsa.gov.

This publication lists non-Federal resources to provide additional information to consumers. The views and content in those resources have not been formally approved by the U.S. Department of Health and Human Services (HHS). Listing of the resources is not an endorsement by HHS or its components.
class of antidepressant medications known as selective serotonin reuptake inhibitors (SSRIs) decreased the odds of both achieving adherence to highly active antiretroviral therapy (HAART) and lowering viral load.\textsuperscript{19}

Conversely, patients with depression who were prescribed and adhered to SSRIs had HAART adherence rates and viral loads similar to those of patients without depression. In addition, among patients with depression, those taking SSRIs showed significantly greater increases in CD4 T-cell counts than did patients not taking SSRIs. Especially noteworthy, the evidence indicated that the improvements in viral load among patients on SSRIs were not solely attributable to HAART adherence, implying that depression itself may affect viral control.\textsuperscript{20}

### DEPRESSION vs. DEMORALIZATION

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<thead>
<tr>
<th>DEPRESSED*</th>
<th>DEMORALIZED*</th>
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<tr>
<td>Persistent inability to experience pleasure from normally pleasurable life events</td>
<td>Characterized by a “welling up of grief”</td>
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<tr>
<td>Cannot be distracted by and enjoy pleasant activities</td>
<td>Can be distracted by and enjoy pleasant activities</td>
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<tr>
<td>Feel worst in the morning; mood improves during the day</td>
<td>Feel best in the morning; mood worsens during the day</td>
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<tr>
<td>Difficulty staying asleep</td>
<td>Difficulty falling asleep</td>
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Although the high prevalence of depression among PLWHA is well documented, clinicians at Johns Hopkins University’s Moore Clinic describe an equally prevalent condition among their patients known as demoralization.\textsuperscript{21} Common among people with physical and mental illness, demoralization is characterized by existential despair, hopelessness, helplessness, and loss of meaning and purpose in life.\textsuperscript{22}

Although it shares many of the symptoms of depression, demoralization has key differences that affect its symptoms and the course of treatment; correct diagnosis is made trickier because the two disorders can coexist. Unlike depression, demoralization is not a brain disease but an adjustment disorder caused by recent events or ongoing life circumstances.

According to the Hopkins team, clients with major depression respond well to antidepressants, whereas those with demoralization may not. Clients who are demoralized, however, do respond well to psychotherapy, support groups, encouragement, drop-in centers, education, and time.\textsuperscript{23}

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\*Note: These are generalized statements; patient symptoms may vary.

FINDING PEOPLE WHO NEED SUPPORT

Before PLWHA can be linked to the mental health care they need, those who have mental health issues must be identified. Two screening tools developed specifically for PLWHA are aimed at working efficiently in busy clinical or support service settings.

One tool is the HIV/AIDS Bureau’s Client Diagnostic Questionnaire (CDQ). The CDQ was developed through the Special Projects of National Significance Program for use in various service sites, including medical clinics, multiservice community organizations, and homeless shelters. The questionnaire, which takes 15 to 20 minutes to complete, can be administered by staff with no mental health training. It screens for depression, anxiety disorder, and psychosis as well as for alcohol and drug abuse or dependence.

The baseline assessment indicates PLWHA who need either further assessment or direct referral to treatment by a clinician. Research on the CDQ’s effectiveness found that it identified 90 percent of clients with clinically significant mental health needs. Ordering information for the free CDQ and the related training manual is available at http://hab.hrsa.gov/tools/topics/cdq.htm.

Another useful tool is a 16-question form known as the Substance Abuse and Mental Illness Symptoms Screener (SAMISS), which has proved its effectiveness as a frontline screening tool. The questions take less than 15 minutes to administer, so patients who screen positive are also advised to undergo a confirmatory psychiatric evaluation. English- and Spanish-language versions of the SAMISS, together with the answer keys, can be downloaded at www.dshs.state.tx.us/hivstd/qm/documents.shtml.

Data from the HCSUS also identified certain characteristics that may predict a greater likelihood of mental health issues. An analysis of a subsample from the HCSUS found that those most likely to screen positive for mental illness were

- Under age 35,
- Lived alone or with a nonromantic partner,
- Unemployed or disabled,
- Experienced more HIV-related symptoms, or
- Used illicit drugs other than marijuana.

Severity of HIV disease did not play a role in the findings, although women in the study who showed signs of mental illness were more likely to have advanced disease or need income assistance.

More recent data from the North Carolina study echoed the association between younger age and mental illness and also found that mental illness rates were higher among Whites and patients with higher viral loads.

People working with or supporting PLWHA should be on the lookout for other signs of mental health
difficulties, such as missed appointments or abruptly changing or stopping medications. Specific triggers that may lead to mental distress include the following:

- Learning of one’s HIV-positive status
- Disclosure of one’s HIV status to family and friends
- Introduction of medication
- Occurrence of any physical illness
- Recognition of new symptoms or progression of disease (e.g., a major drop in CD4 cells, an increase in viral load)
- Necessity of hospitalization (particularly the first hospitalization)
- Death of a significant other or anniversaries of loved ones’ deaths
- Holidays
- Diagnosis of AIDS
- Changes in major aspects of lifestyle (e.g., job loss, end of relationship, relocation)
- Need to make end-of-life and permanency planning decisions.30,31

ADDRESSING MENTAL HEALTH ISSUES SUPPORTS ADHERENCE

The experiences of the Medication Support Team (MST) at Chase-Brexton illustrate the impact of mental health issues on the initiation of and adherence to HAART. MST Coordinator Tracey Salaam recounts the experience of a patient who confronted severe anxiety as he prepared to begin therapy. A mental health patient for many years, the patient had been HIV positive for 3 months when his primary care doctors recommended HAART. “Mentally, he could understand why it was so important, but he had so much anxiety about treatment and his concerns that it would throw him off the stability he had attained in his mental health,” said Salaam.

Chase-Brexton’s multidisciplinary MST works closely with patients to ensure that they are ready and equipped to begin treatment. Salaam met with this patient at least six times over 3 months to address his anxiety, but he was still not ready. In addition to Salaam, the patient’s therapist and psychiatrist were involved, but no one ever pushed the patient to begin HAART.

With a strong support team in place, the patient did eventually begin treatment, although not without anxiety. He spent 15 minutes on the sidewalk in front of the building sweating profusely before his appointments. The prep work paid off, however—the patient has now been on treatment for 18 months and has an undetectable viral load. Salaam attributes the patient’s success in part to his ability to sustain a regimented medication routine, a skill that came from years of taking medications to stabilize his mental health.

According to Haltiwanger, the patient’s anxiety about medication was not uncommon. “The medication regimen can be very stressful,” he says. “Our patients may be asking themselves, ‘Am I taking the medications correctly?’ and ‘What will my results show?’ and those issues can cause tremendous anxiety.”

One strategy Chase-Brexton uses to provide support is “Club Med”—a biweekly support group led by a health and behavioral psychologist. At group meetings, participants fill their pillboxes, support one another in their efforts to be adherent, and discuss issues they are confronting. “We focus on the benefits of HIV medications and strategies to stay healthy. We also talk about anything and everything they want, and some of the topics that come up are addictions, depression, loneliness, stress management, and suicide,” says Salaam.

These kinds of struggles are real. One member with a history of drug addiction was clean when she started on HAART. When it became obvious that she was abusing drugs again, Salaam, her case manager, her primary care provider, and staff at the local methadone clinic talked with her about the importance of maintaining her medication regimen. When the patient was 2 weeks late picking up her medications and had relapsed on heroin, the team decided that it was in her best interest to stop the medications. “She was on a very fragile regimen and risked developing drug resistance in a short window,” said Salaam. “We are here to support her now and when she is ready to resume treatment.”

“The medication regimen can be very stressful. Our patients may be asking themselves, ‘Am I taking the medications correctly?’ and ‘What will my results show?’”
## MOOD DISORDERS

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Description</th>
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<tbody>
<tr>
<td>Major depression</td>
<td>A disabling condition characterized by a persistent sad mood; a diminished sense of well-being; and feelings of guilt, anxiety, or self-loathing. Symptoms interfere with a person's ability to work, sleep, study, eat, and enjoy once-pleasurable activities, and they prevent normal functioning.</td>
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<tr>
<td>Dysthymia</td>
<td>Chronic, mild depression that can prevent normal functioning and persists for at least 2 years in adults or 1 year in children.</td>
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<tr>
<td>Bipolar disorder</td>
<td>Dramatic mood swings from overly &quot;high,&quot; irritable, or both to sad and hopeless, and then back again, often with periods of normal mood in between. The periods of highs and lows are called episodes of mania and depression, respectively.</td>
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## ANXIETY DISORDERS

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<th>Description</th>
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<tr>
<td>Generalized anxiety disorder</td>
<td>Chronic anxiety, exaggerated worry, and tension accompanied by a variety of physical symptoms.</td>
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<tr>
<td>Panic disorder</td>
<td>Unexpected and repeated episodes of intense fear accompanied by physical symptoms that may include chest pain, heart palpitations, shortness of breath, dizziness, or abdominal distress.</td>
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<tr>
<td>Posttraumatic stress disorder</td>
<td>Persistent frightening thoughts and memories of a terrifying event or ordeal in which grave physical harm occurred or was threatened. Symptoms include sleep problems and feelings of detachment or numbness.</td>
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## OTHER

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<tr>
<td>Adjustment disorders</td>
<td>A psychological response from an identifiable stressor or group of stressors that causes significant emotional or behavioral symptoms, including anxiety and depressed mood, but does not meet criteria for more specific disorders.</td>
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<tr>
<td>HIV-associated dementia or AIDS dementia complex</td>
<td>Progressive illness that is the result of HIV's impact on the central nervous system. May affect behavior, cognition, mood, and motor skills. Patients may develop ambulation or gait problems, mania, panic, psychosis, social isolation, or anxiety.</td>
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<tr>
<td>Personality disorders</td>
<td>A group of mental disorders characterized by inflexibility, rigidity, and inability to respond to the changes and demands of life. People with personality disorders tend to have a narrow view of the world and find it difficult to participate in social activities.</td>
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<tr>
<td>Substance abuse</td>
<td>Abuse or dependence on anything that is ingested to produce a high, alter one's senses, or otherwise affect functioning.</td>
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The MST team also pays close attention to the mental health–related side effects of the anti-HIV medications. For example, some medications can exacerbate ADHD and bipolar disorder. “In matching patients up with a medication regimen, it is important to screen for those medications that may impact or trigger their mental health issues as well as [for] those that may interact with antidepressants,” says Salaam. HIV medications and psychiatric medications may interact or be contraindicated and should therefore be chosen with consideration for adverse effects and potential interactions.40,41 (See the online resources box for a guide to interactions.)

**OPENING AVENUES to TREATMENT**

“Look to the client, and see what they identify as helpful,” says Armando Smith, chief program officer of Chicago’s Vital Bridges, in discussing how to work with clients who need mental health treatment but are resistant to getting care. “It is important to both recognize that there are differences in how people view mental health treatment and to help folks understand that seeing a mental health professional is just another tool in the toolbox along with churches, support groups, and friends and family.”

In addition to linking clients to mental health professionals, Vital Bridges, which is a Ryan White HIV/AIDS Program–funded agency that provides support services at five locations in the Chicago area, also uses what Smith calls “low-key” mental health interventions. An art therapy group and a Friday afternoon movie group give clients a chance to gather and be with their peers, to talk about issues they are facing, and interact with a mental health professional in a less traditional setting.

Although the art therapy program was conceived as a structured group, it has found more success as a drop-in program with both regular and occasional participants. It is located next to one of the agency’s grocery programs and meets when the pantry is open. Members may “talk for a minute or 10 minutes or not at all. It’s a break, it’s fun, and it serves a purpose in their lives,” says Smith, who also notes that some participants have now asked to see the therapist individually.

The value of social interactions is echoed by Jeff Levy of Live Oak, also in Chicago. Levy, who has been working with PLWHA for many years, says, “I believe that some of my patients have gotten more from their connection with others through community-based supports than sitting with me for an hour. Many of those I see suffer from isolation [that is] often related to changes in their bodies and their appearance, and they need more ways to connect with other people.” Ideas for decreasing social isolation include strengthening connections with family, participating in 12-step meetings, or joining community groups unrelated to HIV.

Levy identifies the aging PLWHA population, many of whom are long-term survivors, as a growing mental health concern. Age is closely linked to issues of isolation, which may be heightened by the loss of significant others and friends to HIV. A study comparing social networks and social isolation in older and younger PLWHA bore out those concerns. The study found that older adults were more likely to live alone; it also found that 38 percent of older adults and 54 percent of older adults of color were at risk for social isolation, compared with 25 percent of study participants ages 20 to 39.42

Whether old or young, newly diagnosed or long-term survivors, many PLWHA will confront mental health challenges. But as Chase-Brexton’s Haltiwanger notes, an HIV diagnosis can spur psychological health: “It can present an opportunity to repair damaged relationships and improve communication. If patients work with a mental health provider, they can cope with their diagnosis and heal those issues that preceded their diagnosis.”

**ONLINE RESOURCES**

- HIV and Mental Health Clinical Guidelines from the New York State Department of Health AIDS Institute
  www.hivguidelines.org/Content.aspx?pageID=261

- mental health AIDS
  http://mentalhealthaids.samhsa.gov/index.asp

- Mental Health Screening: A Quick Reference Guide for HIV Primary Care Clinicians
  www.hivguidelines.org/Content.aspx?pageID=466

- Mental Illness and Health
  www.aids-etc.org/aidsetc?page=et-30-18

- Psychiatric Medications and HIV Antiretrovirals: A Guide to Interactions for Clinicians
  www.aids-ed.org/aidsetc?page=etres-display&resource=etres-283
3Lesser, 2008.
18Whetten et al, 2005.