HIV and Mental Health

In this issue, we examine the intersection of HIV disease and mental health problems. As a nurse who spent 15 years working in mental health and HIV/AIDS, understanding the mental health needs of persons living with HIV is of particular concern to me.

In her article, Dr. Judith Rabkin notes that depression is the most commonly reported psychiatric problem among people with HIV and that its incidence is higher among those living with HIV. Indeed, Dr. Stephen Karpiak notes that ACRIA’s study of HIV in 1,000 NYC residents over 50 found that the number of people reporting symptoms of depression was 13 times higher than in the general population.

Recognizing that stigma is a major issue for those facing mental health problems, not to mention the stigma associated with being HIV positive, we also greatly appreciate those who have chosen to speak out and share their “Personal Perspectives” with our readers.

Lastly, in keeping with our effort to reach as many persons and communities as possible, this issue of Update is the first to be fully bilingual (English-Spanish).  

Daniel Tietz, Editor-in-Chief

HIV and Mood Disorders

Everyone feels sad or discouraged sometimes. Emotions such as grief and unhappiness are a normal part of life, especially when a person is experiencing high levels of stress or dealing with major losses and life readjustments. Events occur in most lives that are upsetting or stressful, but one may be unhappy without necessarily being clinically depressed. The distinction between “ordinary unhappiness” and clinical depressive disorders depends on the duration and severity of the low mood and the occurrence of related problems, such as loss of interest in most or all activities, changes in appetite/weight or sleep, low energy, persistent thoughts about death, guilty feelings, and other symptoms. The extent to which a depressed mood interferes with work, relationships, and recreation is also considered in distinguishing between sadness and clinical depression.

In this article, the term “depression” refers to clinical disorders, not everyday sadness.

Depression is a common disorder, affecting people of all ages, races and walks of life. Psychiatrists distinguish between major depression, which has many symptoms occurring together, minor depression, characterized by low mood and/or loss of interest but fewer associated symptoms; and dysthymia, which refers to a more chronic and often milder depression that is present on most days for at least two years without a period of well-being of at least (continued on page 3)
Transacin (NGX-4010) for Peripheral Neuropathy
People with HIV who have peripheral neuropathy will use either Transacin (capsaicin) patches or placebo patches for 30 or 60 minutes a day for 3 months. Participants must be 18 or older and have had pain in both feet for at least 2 months.

Pregabalin for Peripheral Neuropathy
People with HIV who have peripheral neuropathy will take either pregabalin (Lyrica) or a placebo (dummy pill) for 3 months. Participants must be 18 or older and have had pain in their hands or feet for at least 3 months.

IMPACT: Reyataz Resistance
People who have developed resistance to Reyataz will come in for one day of blood tests to study the I50L mutation.

For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at ext. 124.

DUET: TMC 114 & 125 for Drug-Resistant HIV (closed to enrollment)
People who are resistant to PIs and NNRTIs will take TMC125 (a new NNRTI) or a placebo (dummy pill). Everyone will also take TMC114 (a new PI) with Norvir and other anti-HIV drugs. Participants must be 18 or older and have a viral load over 5,000.

TH9507 for Lipodystrophy (closed to enrollment)
People who have excess abdominal fat and who are taking anti-HIV drugs will take either TH9507 (an experimental growth hormone releasing factor) or a placebo for 26 weeks.

Maraviroc for Drug-Resistant HIV (closed to enrollment)
People who have taken anti-HIV drugs from three of the four classes of drugs will either take maraviroc (an experimental HIV attachment inhibitor) or placebo with an optimized regimen of anti-HIV drugs for 11 months.

Editor's Notes
- All material in ACRIA Update is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- ACRIA Update refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.
HIV and Mood Disorders

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two months. Rates of depression in the general population have been studied worldwide for many years. A reasonable estimate of those who have experienced major depression in the past year is about 4 or 5%, and about 2% for dysthymia (Narrow, 2002; Waraich 2004). (Minor depression was not evaluated in these population studies.)

Among people with HIV/AIDS, depression is the most common psychiatric disorder (not including substance use disorders), but most HIV+ people are not depressed most of the time. While rates of depression vary depending on how depression is defined and how it is measured, the consensus is that rates of major depression are elevated in the context of HIV/AIDS, with estimates using diagnostic criteria ranging from 5% to 20%, depending on the measures used and the groups being studied (Evans et al. 2005). These estimates usually do not include “minor” depression, which has fewer symptoms but still manifests as persistent sadness with diminished ability to experience pleasure and satisfaction.

Some evidence suggests that HIV+ women have higher rates of major depression and dysthymia than men with HIV, as do those with current substance use disorders. However, women in general and non-HIV drug users also have elevated rates of depression, so HIV/AIDS may not be the major cause of this increased incidence. Much higher rates have been reported when self-report symptom scales or diagnostic screens are used to identify depression, but as a rule these measures are not intended by themselves to establish a diagnosis.

On the other hand, several factors may complicate the diagnosis of depression in a person who is HIV+, because of the overlap between symptoms of depression (like insomnia and loss of appetite), and symptoms of HIV itself or medication side effects. A good diagnostician needs to be familiar with both the standard criteria for depression and the clinical presentation of HIV and the possible adverse effects of medications.

When trying to sort out the relationship of HIV and depression, the age when depression is first experienced needs to be considered. In our psychiatric research program, in which we have seen over 1,200 HIV+ adults in the past 15 years, 60-80% reported that their first episode of depression occurred long before they discovered their HIV status. For example, among gay men, adolescence and the process of coming out may be the period when depression is first experienced. Other factors that put people at risk for depression independent of HIV status are a family history of depression (perhaps reflecting a genetic predisposition) and abuse of alcohol or recreational drugs.

“People who are depressed are less likely to take their HIV medications or keep medical appointments regularly than those who are not…”

Depression is generally one of psychiatry’s success stories: Many antidepressant medications and several kinds of time-limited psychotherapy such as cognitive behavioral therapy have been shown to be effective. For milder depression, support groups often can be helpful, but for major depression, antidepressant medication with or without psychotherapy is the standard of care. Research has shown that HIV+ depressed patients respond as well and as often to such treatments as do people without HIV/AIDS.

Untreated depression is costly. Quality of life is diminished, relationships with family and friends may be impaired, and work may be disrupted. For HIV+ people, there are additional costs: Depression repeatedly has been associated with poorer adherence to medical care. People who are depressed are less likely to take their HIV medications or keep medical appointments regularly than those who are not, and are more likely to neglect nutrition and pay less attention to their overall health, so that HIV disease progression may be a consequence. It may be difficult to tell one’s doctor or care provider about feeling depressed, but it is important to do so or to seek evaluation and treatment elsewhere. (If someone does not know where treatment is available in New York City, there is a citywide service for referrals that can be reached at 1-800-LIFENET.)

Bipolar Disorder

This condition includes episodes of both depression and mania, and is sometimes called manic-depressive disorder. Mania is characterized by periods of abnormally elevated or irritable mood, greatly decreased need for sleep, racing thoughts, distractibility, and uncharacteristic risk-taking behavior. Such periods of abnormal mood must last at least one week (or less if hospitalization is required), to meet the diagnostic definition. The diagnosis needs to be made when the person is not high on recreational drugs, since drug use can confuse the diagnostic picture. Bipolar disorder appears to have a fairly strong genetic component and occurs in about 1% of the general population. It often first appears in the early 20s but may start in adolescence. Bipolar II disorder (hypomania) is a milder form with episodes of shorter duration.

Bipolar disorder most often precedes HIV infection in people with both conditions. Sometimes, however, “secondary” mania may develop because of HIV brain involvement in advanced AIDS, often associated with significant cognitive impairment (Ferrando & Wapenyi, 2002). Fortunately, secondary mania is far less common since the advent of antiretroviral therapy. In other cases, new-onset mania

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may be precipitated by medications such as corticosteroids (e.g., prednisone), which may be prescribed for various medical conditions including asthma. Corticosteroid-induced mania may be managed by lowering the dose or tapering off if that is medically feasible, or by prescribing a mood stabilizer.

**Depression and Fatigue**

Fatigue is more common than depression among people with HIV; estimates of prevalence cluster around 40%. Fatigue is usually defined as a lack of energy, tiredness, lethargy, inability to feel rested that is not due to insomnia, and low stamina. In contrast to depression, the person with fatigue is interested in doing things and can list activities he or she wants to engage in, but lacks the energy to do them. The substantial overlap between fatigue and depression is to some extent circular by definition, in that fatigue is one of the nine criteria for the diagnosis of major or minor depression, and fatigue is also associated with problems such as poor concentration, which is another criterion for diagnosing major depression. There may be a reverse causal direction as well. When fatigue restricts activities and pleasant events, limits social interactions, interferes with work, and leads to long days alone, depressed mood is a likely consequence.

Fatigue may be due to a variety of medical conditions, such as anemia, low thyroid hormone or low testosterone, or it may be related to HIV medications. When depression is not the obvious cause, fatigue may be treated with testosterone supplementation for men, or stimulant medications such as Ritalin (methylphenidate) or Dextedrine (dextroamphetamine), although the latter are seldom appropriate for those with a history of drug addiction. One promising but as yet unproven medication is Provigil (modafinil), which appears not to cause euphoria or to have addictive potential. Our group is currently studying its effectiveness in a short-term clinical trial for the treatment of fatigue in HIV+ adults.

**Depression and Hepatitis C**

It is estimated that about 300,000 HIV+ patients in the United States, or about 30% of people with HIV, are co-infected with hepatitis C (HCV). Among patients with chronic HCV infection, fatigue is the most common initial symptom (Crone et al, 2004). Although depression also has been reported, this may be secondary to intravenous drug use, which is the most common source of HCV infection and trials (e.g. Laguno et al, 2004; Torriani et al, 2004). Most patients with HCV treatment-induced depression respond well to antidepressants, allowing them to complete treatment which otherwise may be prematurely discontinued (Hauser 2002).

Hepatologists may be reluctant to begin HCV treatment in patients who are already depressed or who have other psychiatric disorders, and this contributes to undertreatment of HCV. Rather than declining to treat depressed patients, psychiatric consultation and antidepressant treatment are recommended and then, after depressive symptoms have lessened (usually after several weeks), HCV treatment can be started.

**Depression and Substance Use:**

**Crystal Meth**

Although the immediate effect of crystal methamphetamine (MA) is euphoria and heightened energy, depression follows swiftly after the drug effects wear off. In fact, depression is both a precursor and a consequence of chronic MA use. A history of depression is more common among gay and bisexual men than heterosexual men, among people with HIV/AIDS than HIV- people, and also among MA abusers, most of whom in New York City are gay men with or without HIV infection, than nonusers.

Depression is particularly prevalent during acute withdrawal, but has been found in high rates even 2-5 years after drug treatment despite significant reductions in MA abuse (Rawson et al, 2002). In a prospective study of 162 gay male MA abusers who participated in a 16-week treatment study, 29% reported at least moderate depressive symptoms at study entry, with significant decreases in symptoms within the first week and through the end of treatment among both HIV+ and HIV- participants, associated with cessation of MA use (Peck et al, 2005).

Acute withdrawal, which occurs within 24 hours after the last use, may resemble a major depressive disorder with loss of interest, depressed mood, fatigue, and sui-
suicidal thoughts. Other serious psychiatric effects of prolonged MA use include paranoia, auditory, visual or tactile hallucinations, irritability, and aggressiveness. Cognitive problems, including impaired concentration and memory, are common and may last for months (Jones, 2005). HIV+ men with hepatitis C who abuse MA have particularly high rates of cognitive impairment.

Overall, use of methamphetamine, past or current, is a significant risk factor for depression; while drug treatment may alleviate depressive symptoms, more focused treatment may be needed.

What Next?
In order to treat depression, it first needs to be identified. With some exceptions, doctors don’t ask, and patients don’t tell. In HIV settings, both doctors and patients are busy with lab results, prescription renewals, and discussion of medical status, which are their essential tasks. Providers could, however, greatly facilitate discussion of depressed mood and related problems like substance use by asking directly about mood. A simple question such as, “Have you been feeling depressed lately?” can open a conversation, and indicate that the topic is acceptable to address. If appropriate, such a discussion can lead to referral for care if the provider does not feel comfortable prescribing antidepressant medication.

Depression screening is recommended at all initial treatment visits, and at least annually thereafter or at any visit if the doctor notices a change in the patient’s mood and appearance.

The majority of depressed patients in the United States are treated by their primary providers, not psychiatrists, and increasing numbers of HIV providers prescribe marketed antidepressants to patients with uncomplicated depression. Referral to a psychiatrist is indicated for patients with bipolar disorder or additional psychiatric conditions, including anxiety or psychotic disorders. Psychiatric referral is always needed for patients with severe depression, and for those who express active suicidal thoughts and plans. In addition, if the patient has not responded to one or two antidepressants of adequate length (8 or more weeks) and dose levels, and the patient is actually taking the antidepressant as prescribed, a psychiatric referral may be needed. Once an effective medication regimen has been established and the patient has responded, the primary provider can take over medication prescription in many cases.

Fortunately, increasing numbers of New York City HIV clinics have psychiatrists on site several days a week or full time, which greatly facilitates both treatment access and collaboration between primary provider and psychiatrist. In this respect, clinic patients have an advantage over those who see their HIV physicians in private offices. In addition, Medicaid covers all antidepressant medications, while an increasing number of private insurance companies do not.

Future research concerning depression treatment in HIV/AIDS would best be conducted on-site in HIV clinics, rather than in academic medical centers that may select for more motivated patients who take the time and trouble to travel to participate in studies. In addition, time-limited forms of psychotherapies, whether individual or group, that can be conducted in clinic settings also warrant study, since antidepressant medication may not always be needed or acceptable to some patients.

Finally, it is not only the responsibility of the care provider to ask about problems with depression. People with HIV and their friends and family should recognize that persistent low, sad, or “blue” mood, accompanied by other signs of depression such as loss of appetite, insomnia, guilty feelings, or recurrent thoughts of death, are signals to seek professional evaluation and treatment.

Since care providers do not see their patients in everyday situations and surroundings, friends and family can often be the first to spot changes in mood, and can play a vital role in alerting both provider and patient that there may be a problem.

(versión en Español en www.acria.org)

Judith Rabkin is a clinical psychology researcher at Columbia University.
In 1987, my partner and I had the conversation about what would happen if we tested HIV positive. We decided that we would take care of each other if one or the other became ill. We had been together since college, when he was 19 and I was 22. We got tested and both came back positive. He died in 1993 after a long struggle with different complications. We had been together 14 years.

I was left without company and with no one to take care of – all of a sudden I was alone in the apartment that we shared. Soon, I began to have suicidal thoughts and just couldn’t find anything worth living for. Although my health had never declined severely, I wasn’t feeling the same as I had felt when my partner was living. Moreover, I was feeling guilty that I had survived – I was a few years older and we had always joked that I would probably be the first to die of old age. It didn’t happen that way.

Although I never attempted suicide I came very close to following through with my thoughts. When he passed away I was feeling physically better and stronger than when I was diagnosed; I had been exercising and was able to build muscle mass. The HIV meds that we were both taking worked well for me. But they never did much for him – he improved very little and had continuous bouts with opportunistic infections leading to frequent hospitalizations. After he passed away I felt there was nothing worth living for; although I can’t really say I wanted to die. I became a loner. Most of our friends had moved or had passed on, so I did everything alone and really didn’t socialize. My sister lived relatively close to me and would stop by almost every day to check up on me, and she made every effort to include me in her family activities. But I still felt alone, so at her insistence I made an appointment to see a therapist who diagnosed me with depression. (My doctor had also referred me to see a therapist or a psychiatrist, but I never followed through, telling him that I was feeling better.) I knew I was depressed – that wasn’t difficult to see – but what I didn’t know is how much better I would feel after beginning treatment.

It wasn’t until I needed to take protease inhibitors, because my viral load began to shoot up and my CD4 cells were slowly decreasing, that some signs of the disease began to show, especially the terrible “L word” for people living with HIV: lipodystrophy. This happened around 1997. Moreover, signs of aging were also beginning to show. I began to feel depressed again; it seemed like the anti-depression medications I had been taking were not working any more.

I had already begun to socialize and make new friends, participating in social activities, going to the gym and joining some sports leagues. But even so, I began to feel tired again, and lonely – sometimes I would randomly cry, just feeling terrible and sorry for myself. I didn’t know if it was the aging that was bothering me or the signs of lipodystrophy. I never sought out another relationship, but had continued to enjoy sex, and now even that was gone. In not wanting to get into another relationship I mostly ventured out to public sex places, but now I became aware that nobody paid any attention to me, and the erotic games going on around me proceeded undisturbed. I felt like I no longer existed and I wasn’t young anymore. I began to think again that the best thing for me would be to die, although I never acted on the idea. I immediately recognized the symptoms and spoke with my doctor and therapist. I am now taking another anti-depressant and feeling emotionally well.

I know that aging, lipodystrophy and the sense of loneliness leads me to feel the way I do. Every once in a while I feel down, but not enough to make me want to give up. I’ve built new support systems aside from my family which has always been there for me, and continue to see my HIV specialist who I have a good relationship with. I also continue to see my therapist. I understand that I not only have HIV and depression but I have also aged, and all three play a part in the way I feel every day. It’s taking one day at a time and dealing with all three issues that keeps me going.
Depression in Older Adults with HIV

By Stephen Karpiak, PhD

In ACRIA’s 2006 study of HIV in 1,000 New York City residents over the age of 50 (ROAH: Research on Older Adults with HIV), it was found that the number of people reporting significant symptoms of depression was 13 times higher than that found in the city’s general population. As this older population steadily increases and ages (in NYC 30% of all people living with HIV are over 50 and 70% are over 40), there is a critical need to address this treatable disease. Why are there such high levels of depression in older people with HIV? And more important, why is the health care system not more responsive to this medical need? While many illnesses are common to both HIV and aging, the lack of focus on the management of depression is disturbing.

The impact of depression on the immune system has been well established. Stress and depression can have harmful effects on cellular immunity, including those aspects of the immune system affected by HIV. According to Leserman (2003), elevated symptoms of depression are associated with faster progression to AIDS. Another study found that depressive symptoms, especially in the presence of severe stress, are associated with decreases in CD4 cell count and declines in lymphocytes (Kopinsky, 2004). Moreover, it has been theorized that cortisol, which is elevated during periods of stress, may affect HIV viral replication, as well as certain immune system responses. Some studies show that severe life stress, if combined with high glucocorticoid activity, can lower circulating lymphocyte populations, which may then alter the immune system’s defense against infections (Petitto et al. 2000).

The precise relationships between stressors, depression, and the immune system remains a puzzle, but understanding the role of psychosocial factors on HIV disease progression may aid in the development of new interventions to better manage HIV. There is a psychosocial-immune dynamic that affects health and that is the basis for such complementary therapies as relaxation, massage, visualization, and meditation. And since the incidence of depression increases with age, along with a decrease in the response of the immune system, it is clear that the treatment of depression can lead to better management of HIV as well as all of the illnesses of aging.

Since depression rates increase with age, the management of depression in the older adult HIV population becomes even more of a priority in order to maximize immune function, which decreases with age. What are the barriers to treatment? Older adults are less likely than younger people to seek treatment for depression. Often there is a failure to recognize the symptoms of depression, and there may be a perception that being depressed is simply a characteristic of aging rather than an illness. Further, people can be depressed without feeling sad. Rather, the depressive disorder in the aging population may be expressed more by agitation and irritability, and in physical terms such as vague complaints of aches and pains or gastrointestinal upset.

Older adults may continue to regard depression as shameful or a sign of weakness that should not be acknowledged – even to physicians. Physicians, in turn, often fail to ask the questions that will identify and diagnose depression in their patients. And there is too often the belief that nothing can be done for older people with ample reason to be depressed. That attitude seems to be why depression is given short shrift by those who care for people living with HIV: “You should be depressed.”

Older HIV-positive adults who are depressed are more likely to have financial problems, have fewer people to turn to for support, lack critical HIV-related information, live alone, have thoughts of suicide, and experience greater levels of stigma related to HIV and aging as compared to older adults with HIV who are not depressed. Depression may interfere with adherence to treatment, doctor visits, participation in social activities, and personal relationships.

In ROAH, depression symptoms were measured by the Center for Epidemiologic Studies Depression Scale (CES-D). This is one of the primary standardized tools used to assess depression. People with scores below 16 are not considered depressed; scores between 16 and 27 indicate moderate levels of depression and would typically correspond with a clinical depression diagnosis; and scores of 28 and above indicate severe levels of depression. ROAH participants’ scores ranged from 0 to 52. The mean CES-D score was 20.3: 36% of the participants were not depressed (scored less than 16), while 38% were moderately depressed (scored 16-27), and 26% could be categorized as severely depressed (scored 28+).

ROAH found no differences between males and females, but there were significant differences between the ethnic groups, with Latinos having higher levels of depression than Blacks. The White group’s score placed them between Latinos and Blacks. The aging HIV-positive adults in ROAH experienced significant levels of depression, at a rate almost 13 times higher than the...
Depression in Older Adults with HIV  
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general New York City population. Regardless of the measure used, other studies have also shown that older adults with HIV are more likely to experience symptoms of depression than younger HIV-positive people and older HIV-negative adults.

There is no single evident reason why these numbers are so high. ROAH participants are receiving care, with access to myriad support modalities for the management of depressive disorders. One reason may be the difficulty in diagnosing depression when symptoms are not typical or are easily confused with a physical ailment. Too often, treating physicians are focused on HIV and see depressive symptoms as an expected reaction of a person living with HIV. The mental health needs of this growing group of adults can be overlooked. In the era of effective antiretroviral medications, it is important for health care providers to be prepared to assess and treat the physical and mental health conditions that aging adults present. In fact, the co-occurrence of HIV and depression is a formula for continued distress of the immune system. The effectiveness of ARV treatment also may have caused health care providers to view depression as a less significant illness, assigning it a low priority and treating it less aggressively.

Substance use is a contributing factor to the high rates of depression in the older adult population living with HIV. The use of substances to self-treat depression are common. In addition, the stigma of HIV combines with the stigma of depression to make seeking help for depression even more of a challenge. The ROAH study found that 54% of the older adults studied use illicit substances or alcohol on a regular basis. This can precipitate depression, increase the magnitude of the depression, or mask symptoms so the depression is not identified by care providers. Add to these factors our findings that 70% of ROAH participants live alone, many are disconnected from their biological families, and few have spouses or partners, and the high incidence of depression is not surprising.

In the ROAH study, 42% of respondents said the emotional support they had received was inadequate to their needs. This pattern of unmet need is similar to studies that examined diverse groups of older adults. However, the magnitude of need – particularly the need for emotional support – is higher for older adults with HIV than for other older New Yorkers. Taken together, the findings from ROAH describe a population at risk. These older adults may not be able to obtain the needed support to age successfully. The high levels of unmet need for emotional support and significant evidence of loneliness reflect a certain distance from loved ones, either physically or emotionally. One of the possible causes for this estrangement is the powerful stigma related both to HIV/AIDS and to aging. Add to this the large numbers of people with untreated depression and the need to provide directed guidance for the management of the emotional needs of this population becomes clear.

Treatment is needed. More important, effective sustained treatment is needed. And as with HIV, adherence to treatment regimens for depression is critical. This can become a challenging management task for both clients and care providers as older adults also begin to need treatments for coronary conditions, arthritis, osteoporosis, CNS and PNS pathologies, and other illnesses associated with aging. Many studies report that individuals with depression are less adherent when taking their anti-HIV medications. Since non-adherence ranks as one of the strongest predictors of progression to AIDS, it would seem that targeting depression would reduce that progression. A small difference in adherence can significantly affect whether a person avoids progressing to an AIDS diagnosis (Bangsberg, 2001).

The level of untreated depression in the older adult HIV population is alarmingly large, highlighting the real needs of the growing and aging HIV population. Competent care must acknowledge that we treat not merely a virus, but an entire person, especially as a social being. Medical care and services must be patient-centered. There are rigorous follow-up standards used when a person begins HAART; similar follow-ups are critical when treating depression.

The impact of treating depression extends far beyond managing HIV. The successful management of depression improves an individual’s ability to engage in social and community support networks. This is particularly important for the older adult with HIV who has been isolated and marginalized by their service providers and their communities, who are without the social support networks that are vital to people as they age. Care for those with HIV needs to be examined so that it is inclusive of all health and social needs.

*(Given) the findings in ROAH that 70% of older adults with HIV live alone, many are disconnected from their biological families, and few have spouses or partners, the high incidence of depression is not surprising.*

Stephen Karpiak is ACRIA’s Associate Director for Research

*(Versión en Español en www.acria.org)*
Perspectiva Personal:

Entendiendo la importancia de mi vida y salud

by Judith

Llegué a los Estados Unidos hace cuatro años atrás, cuando tenía 25, con el padre de mi segunda criatura. Cuando le dije que estaba embarazada, me golpeó, el quería hacerme perder mi embarazo. Finalmente lo dejé-mejor dicho, me escapé- cuando una vecina me dijo que lo veía golpeando a mi criatura cada vez que yo salía de la casa.

Me mudé a Nueva York, pero al poco tiempo de haber llegado, pensé en regresar a México. No me entia bien deseaba estar cerca de mi madre y no conocía a nadie en Nueva York. Me fui a hacer un exámen médico de cuidados de embarazo, y unos días antes de mi vuelo de regreso a México fui al médico por mis resultados. Me dijeron que era VIH positiva.

Entonces fue que me acordé que el padre de mi criatura se enfermaba frecuentemente: le venían escalofríos y sudaba. Ahora que sé más de la enfermedad se que habían muchas cosas que lo pudieron haber llevado a infectarse: usaba drogas y alcohol que probablemente lo llevaron a tener muchas parejas sexuales – por lo menos yo sospechaba que el había tenido muchas parejas sexuales. Una vez hasta le dije en broma, ¿Crees que tienes SIDA? Se molestó mucho y me dijo ¡Estás loca! ¿Cómo puedes decir esas cosas? Yo creo que el sabía que tenía el virus pero no quería usar protección.

Cuando descubri que era VIH positiva, lo llamé para dejarle saber que se debería hacer una prueba del VIH, pero no quiso y me dijo que era unicamente mi problema. Unos meses después, su madre me dijo que el estaba sólo y no tenía nadie que cuidase de el. Su madre me dijo que el lamentaba la manera que me había tratado y que quería que regresara con él. Desde ese entonces he evitado tener comunicación con su familia y no se como estará o si alguna vez se hizo la prueba del VIH.

No estaba segura lo que significaba ser VIH positiva o sus consecuencias – solo sabía que era una enfermedad seria y que muchos morían. Sentí que mi vida se derrumbaba alrededor mío. Sabía que podría recibir mejor atención médica en los Estados Unidos. Mas aún no podría explicarle mi situación a mi familia. Sabía que solo los entrístecería. Casi inmediatamente empecé a tomar medicamentos que previnieron que mi hija naciera con el VIH.

El año pasado me deprimí: me sentía sola y triste, lloraba constantemente y sin motivos. No tenía energía y me irritaba mucho. No me sentía bien sobre mi misma y cuidaba de mis hijas pero solo con gran esfuerzo. También había perdido el apetito y estaba perdiendo peso rápidamente. Los médicos pensaban que se debía al virus, pero yo no entendía porque lloraba y me sentía como si mi vida no tenía valor alguno. Entonces mi madre se enfermó pero no podía regresar a México para cuidar de ella. Si regresaba a México se haría difícil que regresara a los Estados Unidos y no tendría mis medicamentos.

Mas aún si regresaba, ¿Cómo le explicaría mi enfermedad a mi familia? Ellos no sabían nada sobre mi virus (si, ahora lo llamó “mi virus”). Habían muchas razones por las cuales evitaba decirles algo- estaban tan lejos y evitaba preocuparlos. Pero me estaban presionando para que regresara a cuidar de mi madre. Me sentía sin control y sin poder tener ningún efecto. También empecé a sentir que todos los suenos que tenía para mi familia y mis hijas no se harían realidad. Después de meses de sentirme así y no poder atender a mi madre, sentía que mi vida no tenía propósito, y no tenía ninguna otra salida que quitarme la vida. Intenté suicidarme con Tylenol y fui hospitalizada- lo único que logré con ese intento fue dañar mis riñones. Mientras estuve hospitalizada mi hija mayor me fue a ver y me dijo que no quería verme morir y que no sabría que hacer sin mi. Cuando vi a mi hija me di cuenta que tan deprimida estaba, hasta el punto de querer quitarme la vida. Me prescribieron medicamentos antidepresivos, pero no sabía porque los necesitaba. Cuando dejé de tomarlos por una semana me volví a sentir deprimida, y fui internada nuevamente en el hospital por cuatro días. Desde entonces no he dejado de tomar mis medicamentos y entiendo lo importante que son para mi para no sentirme deprimida nuevamente.

Siento que mi depression se demoró en presentarse después de que fui diagnosticada (casi dos años mas tarde) porque no tuve tiempo de pensar en mi enfermedad. Estaba tratando de sobrevivir, de criar a mis hijas y de acostumbrarme a vivir en un país diferente y distante a mi familia. Cuando empecé a pensar en mi enfermedad, sobre lo que me pasó con el padre de mi hija, y el no tener a nadie con quien hablar sobre lo que me estaba pasando, me sentí mal. Generalmente me guardaba mis problemas y no los compartía con nadie. Ahora tomo medicamentos para la depresión regularmente, voy a grupos de apoyo y de información, hablo con consejeros, educadores y mis compañeros del grupo. Hasta el compartir un poco de mi vida ahora me ayuda a lidiar con mis problemas. Mas aún – mi virus está indetectable – no estoy tomando medicamentos para el VIH porque no los necesito ahora. Y entiendo la importancia de tener apoyo, y la importancia de mi vida y mi salud.

Transcrita por Sarah Swofford

(English translation available at www.acria.org)
### Psychiatric and HIV Meds Interaction Table

Many medications, including psychiatric meds, interact with HIV drugs. These interactions can affect the levels of the HIV drug, the psych drug, or both. Be sure your doctor knows all drugs you are taking, including ones you buy without a prescription.

- **X** = do not take these drugs together
- **○** = no interaction, drugs may be taken together
- **▼** = use together with caution; a dose adjustment may be necessary

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<th>SSRTIs</th>
<th>Tricyclic Antidepressants</th>
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<th>MAO Inhibitors</th>
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<th>Valium (flurazepam)</th>
<th>Dainum (lorazepam)</th>
<th>Ativan Temesta Tavor (lorazepam)</th>
<th>Versed Hypnovel Dormicum (midazolam)</th>
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<th>Halcion Novodorm Songar (triazolam)</th>
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Perspectiva Personal: **Depresión después de 15 años**

*by Terecita*

He sido VIH positiva por 15 años. Tengo 46 años con dos adolescentes y soy originalmente del Ecuador. Puedo decir que 1990 fue un año marcado por alegrías y tristezas porque me casé, me embaracé y mi esposo se enfermó y fue diagnosticado con SIDA. Yo también fui diagnosticada con VIH después de haber dado a luz a mi hijo. En 1991 mi esposo falleció dejándome con una enfermedad de la cual aún no tenía mucho conocimiento. El dejó una viuda con un hijo de casi un año de edad y una hija que tenía tres años de edad.

No me di tiempo para llorar o pesar su muerte. Estaba demasiada ocupada cuidando de mis hijos. Aunque difícil de creer, también estaba cuidando de la mujer que posiblemente había infectado a mi esposo – o al revés – no se ahora pero eso ya no es importante para mí. Ella me lo confessó después de la muerte de mi esposo, durante un momento que estábamos solas las dos. No le podía guardar rencor, las cosas ya habían pasado y las cartas estaban echadas para ambas. Nos apoyábamos mutuamente hasta que ella decidió regresar al Ecuador, donde ella falleció.

Después de muchos años de estar viviendo con “mi virus” había empezado a sentirme triste y deprimida. A veces lograba sonreír, pero eran pocas y contadas las veces. Pienso que se debe principalmente a mi esposo pero me pregunto, “¿Por qué ahora después de tantos años de su muerte es que me está golpeando tan fuerte?” En parte creo que el estar cuidando de mis hijos me mantuvo ocupada, pero ahora que ya han crecido y que ha habido tiempo para pensar en el y otras cosas que me ponen triste-parece que el tener más tiempo para mí misma no ha sido tan bueno para mí.

Desde que empecé a sentirme triste, se me hacía difícil hacer mis tareas diarias y a veces no me motivaba para hacer cosas que tenía que hacer. A veces sentía dificultades para ir a mis citas médicas y me tenía que empujar para hacerlo. Senti que mi depresión no era tan fuerte-había escuchado de personas que se descuidaban y que tenían pensamientos para suicidarse- pero aún así sabía que necesitaba ayuda. Así que busqué ayuda antes de sentirme demasiado mal. Hablé con mi médico, él recomendó que viera a un psicólogo, y fui diagnosticada con depresión.

Ahora tomo medicamento para la depresión con mis medicamentos para el VIH. Aún no se si los medicamentos para la depresión están funcionando porque no los he venido tomando por mucho tiempo, pero pienso que ahora sonrio más que antes. No estoy segura si me sentí mejor de la manera que me sentía, pero hay días que me siento mejor que otros. Voy a mi grupo de apoyo, continuo viendo al psicólogo, aprendo más sobre el virus y mi enfermedad. Ahora entiendo que mi vida no ha terminado. Puedo conversar con mis compañeros de grupo y con un profesional de salud mental que me ayuda a sentirme mejor antes de que no tuviera a nadie con quien conversar. Desde que me he sentido mejor salgo a bailar con mi novio (si, ahora tengo un novio). El poder bailar, mantenerme activa y pasar tiempo con él aleja mis pensamientos de cosas tristes.

También sé que en el pasado el ser madre y cuidar de mis hijos tomaba una gran parte de mi tiempo, y no me permitían pensar sobre lo que sentía. Ahora que mis hijos ya están grandes me duele que ya no necesiten de mí tanto, pero sé que es un proceso natural – los hijos crecen, se independizan, y forman su propia familia. Creo también que este proceso me ha permitido pensar mucho en la muerte de personas queridas a mí, y la muerte de mi esposo. El tiempo adicional que tengo me ha llevado a pensar sobre mi vida pero también me ha permitido lidiar con situaciones dolorosas del pasado que no fueron resueltas.

En Junio, serán quince años desde que mi esposo falleció. Tendré una misa en su honor, y parece increíble que después de tantos años me entristezca tanto su muerte, pero así es la depresión. Tomo las cosas día a día. Lo amaba mucho y no le guardo rencor y lo recuerdo con mucho cariño. Entiendo que debo de dejar de lado los recuerdos y perdonar. Yo continúo tomando mis medicamentos, voy a mis grupos, y trato de hacer tantas actividades que me sienta capaz de hacer.

Transcrita por Sarah Swofford
**Personal Perspective: Depression after 15 years**

by Terecita

I’ve been HIV positive for 15 years. I’m 46 years old with two teenage children and am originally from Ecuador. I could say that 1990 was a year marked by happiness and sadness because I married, became pregnant, and my husband became ill and was diagnosed with AIDS. I was also diagnosed with HIV after I gave birth to my son. In 1991 my husband passed away, leaving me with an illness of which I still didn’t know much. He also left a widow with a son who was almost a year old and a daughter who was three years old.

I didn’t allow myself to mourn his death; I was too busy taking care of my children. And, hard to believe, I was also taking care of the woman who possibly infected my husband – or vice versa – but that is not important to me any more. She told me herself after my husband’s death, during a moment when we found ourselves alone. I couldn’t have rancor, things had already happened and the deck of cards had been dealt for both of us. We would support each other until she decided to return to Ecuador, where she passed on.

But after many years living with “my virus” I began feeling sad and depressed. Sometimes I’m able to smile, but those times are few and far between. I feel it is mainly because of my husband but ask myself, “Why is it that after so many years my husband’s death is now hitting me so hard?” Partly it’s because I had been taking care of my children and was kept busy, but now they are older and when I feel alone I begin to think about him and things that sadden me – it seems that having more time for myself has not been a positive situation for me.

Since I’ve been feeling sad, it’s hard for me to complete my daily chores and I can’t find motivation to do what I need to do. I even had a hard time going to my medical appointments and had to push myself to do it. I felt my depression wasn’t that severe – I had heard of people who really let themselves go and who had suicidal thoughts – but I knew I needed help. So I sought help out early. I spoke to my doctor, who recommended that I see a therapist, and I was diagnosed with depression.

In June, it will be 15 years since my husband died. I’ll have a mass said for him. I still think about him, and it’s unbelievable that after so many years I still become saddened by something that happened such a long time ago, but that is how depression is. I take things day by day. I loved him very much and I don’t have any rancor, but remember him with love. I understand that I need to leave aside those painful memories and forgive. As for me, I continue to take my medications, attend my groups, and fill my time up with as many new activities as I can.

English translation by Luis Scaccabarozzi
La depresión en mujeres VIH positivas by Sarah Swofford and Kialing Perez, MD

De acuerdo al Instituto Nacional de Salud (NIH, por sus siglas en inglés), las mujeres tienen mayores posibilidades de sufrir de depresión. Algunas estudios realizados por el NIH muestran una proporción de dos mujeres por cada hombre, sin importar la raza, etnia, y/o estatus económico. Los estudios no han podido claramente determinar aún el motivo de la diferencia entre los géneros sexuales pero se cree que las experiencias de muchas mujeres que son únicas en las vidas de las mujeres son determinantes, tales como los factores sociales y biológicos. Un motivo principal que frecuentemente es citado en la bibliografía es el peso de las muchas responsabilidades de la mujer de tener que cuidar de la salud del resto de la familia. La falta de recursos económicos, educación, y apoyo social también parecen ser factores que contribuyen a la más alta incidencia de depresión en la mujer.

Las mujeres VIH positivas que también sufren de depresión tienen una carga de salud aumentada. La investigación enfocada a las mujeres hace falta en muchas áreas de estudio y desafortunadamente los estudios de VIH y salud mental que específicamente se relacionan a mujeres no son la excepción. Sin embargo, la pequeña cantidad de investigación disponible sobre éste tema sugiere que las mujeres VIH positivas están en mayor riesgo de sufrir de síntomas depresivos. Adicionalmente, los estudios han encontrado una conexión entre la salud mental de las mujeres VIH positivas y la manera que progresa la enfermedad. Se ha demostrado que las mujeres VIH positivas con depresión mayor acuden a sus citas médicas con menos regularidad, son menos adherentes a su tratamiento, son más propensas de progresar más rápidamente a SIDA, y tienen una más alta mortalidad relacionada al SIDA. Un mejor entendimiento de la depresión en mujeres con VIH puede ayudar a disminuir no sólo la progresión de la enfermedad, pero también puede mejorar la adherencia a la terapia antiretroviral de gran actividad (TARGA, HAART por sus siglas en inglés). Los proveedores de salud quienes tratan mujeres VIH positivas deben de considerar el estado de salud mental de sus pacientes, junto con el cuidado de su VIH.

Algunos estudios han sido realizados tratando de establecer un vínculo entre la depresión y la progresión del VIH en mujeres. Un estudio en el 2005 por el Departamento de Psicología de la Universidad de Pennsylvania (Crueess, DG) encontró que las mujeres que se recuperaban de la depresión tenían aumentos significativos de la actividad de sus células asesinas naturales (un tipo de célula blanca evulvia en la respuesta inmune), Tomando en consideración que el VIH disminuye el número de las células evulvidas en la respuesta inmune, la comcomitante presencia de la depresión puede agravar la salud del sistema inmune.

El Estudio Entre Agencias en Mujeres con VIH (WIHS, por sus siglas en inglés) es el estudio más comprensivo sobre el tema de la depresión en mujeres positivas. Entre 1994 al 2001 se estudiaron 1,716 mujeres positivas en clínicas en Brooklyn, Bronx, Chicago, Los Angeles, San Francisco, y Washington D.C. Encontraron que la incidencia de muerte es 1.7 veces mayor en mujeres con depresión crónica comparada a mujeres sin depresión crónica, después de controlar otros factores incluyendo el conteo de células CD4, la carga viral, y el uso de la terapia antiretroviral de gran actividad (TARGA). Para aquellas mujeres quienes estaban utilizando TARGA tenían una menor incidencia de depresión, pero que las mujeres VIH positivas crónicamente deprimidas que fallecieron de SIDA habían tenido una depresión clínica severa el año antes de sus muertes. Significa que el diagnosticar oportunamente la depresión no solo mejora la adherencia al tratamiento pero también influye en la progresión de la enfermedad por mecanismos que no están claramente entendidos.

Un análisis de las mujeres en el WIHS encontró que las mujeres VIH positivas con desordenes de comportamiento tienen menos probabilidad de iniciar o mantener la adherencia a TARGA. Un estudio publicado en la Revista de la Sociedad Internacional de Neuropsicología en el 2002 determinó que la incidencia de desordenes del comportamiento eran más altos en mujeres VIH positivas que en mujeres negativas. También se encontró que aquellas mujeres que no estaban tomando TARGA tenían una incidencia dos veces mayor de poder tener un impedimento neuropsicológico.

De acuerdo a un estudio por la Universidad de Sao Paulo publicado en la Revista Brasileña de psiquiatría en el 2006, las mujeres con VIH sintomático tienen una mayor incidencia de depresión que las asintomáticas. El mismo artículo menciona la falta de estudios que investiguen el inicio y la progresión de la depresión a lo largo del curso del VIH-SIDA.

Los estudios demuestran que en las mujeres existe una correlación directa entre la depresión y progresión del VIH a SIDA. También se ha observado que la adherencia a TARGA así como el inicio al tratamiento es menos probable en mujeres con depresión crónica. Los servicios de salud mental, los medicamentos antidepresivos y la terapia psicológica son necesidades para mejorar las vidas (y en algunos casos salvar las vidas) de mujeres positivas con depresión. Es de suma importancia que pacientes con VIH y SIDA tengan un tratamiento integral que incluya la evaluación psicológica de los pacientes, no sólo para lograr una mejor adherencia y soporte social, sino también como la evidencia científica sugiere, para mejorar la respuesta inmune que podría estar adicionalmente deteriorada por trastornos de esta naturaleza.

(English translation available at www.acria.org)

Sarah Swofford, Educadora del VIH de ACRIA
Kialing Perez, MD, Médico Internista en su tercer año de rotación en el Hospital Flushing
I was diagnosed with anxiety and panic disorder in 1993. It started with worries about my health, especially since I have been overweight my entire life. I also was unhappy with my job, which had become monotonous and stressful. I began to have muscle pain, I wasn’t sleeping well and would suddenly become dizzy and irritable. My edginess and worries began to increasingly affect the work that I was doing; I began to take time off and still my doctors could not figure out what was happening with me.

Then I had a panic attack at work. It was frightening. I had never felt something like this – for no apparent reason I began to tremble and sweat, and I had chills and dizziness. I felt like my life was in danger and that I needed to get out quickly; to escape. But it only lasted about 15 minutes and by the time the EMT’s arrived at work it was almost over. Many tests were run, even some to see if I had been using drugs, but they found nothing.

I stayed in the hospital for a couple of days in the emergency room, and spoke to a psychiatrist while I was there. I learned that what I was feeling was due to anxiety and panic disorders, and I was prescribed some medications. They helped some, and I managed to get back to work but was unable to function well – I felt overly concerned about simple tasks. I was able to work for about six months but then I felt like I was losing control. I found myself constantly calling my doctors, convinced that I had some disease that had not been diagnosed. As a gay man I began to think it might be HIV, even though I had always been careful and had consistently tested negative.

I attempted to get back to work after I took a short-term disability leave, but was never again able to return fulltime. I was calling my doctor and psychiatrist almost every day. I noticed that at work I had panic attacks with increasing frequency and severity. I then took a long-term disability leave, and have not returned to work since 1993.

In the beginning it was difficult for me because I didn’t know anyone who had a mental disorder. There was also the stigma of having to see a therapist and psychiatrist aside from my usual medical doctor. It took me some time to get used to the idea of having to see doctors that I thought only “crazy” people saw. Of course I now understand that mental disorders happen to many people.

With more time on my hands and with a computer at home I became very savvy about chat rooms and sex sites. I used them throughout the day, not only because I couldn’t sleep but also because I was feeling lonely. I began to meet other men to have sexual encounters, inviting them to my house because I had begun to feel anxious when I went out. I felt less anxious when I had company and it became routine for me to have several sexual encounters a day.

Then in 1999 I became extremely ill. After losing a lot of weight (intentionally), I began to have recurrent respiratory infections. After a serious recurrence, I went to the emergency room where I was told that I had PCP, a pneumonia common in people with AIDS. I remained in the hospital for about four days and learned that I had a viral load that was in the millions and a CD4 count of four. I couldn’t understand how I had become infected. I had always used condoms. I would become anxious thinking about who had infected me and how it could have happened. I was in denial. Psychiatrists needed to be brought in as part of my care team.

In the beginning I thought HIV was a death sentence, and I felt anxious for months. At the insistence of my care providers I began to attend a support group. At first I felt uncomfortable, but met others there who had similar problems to mine. People who had other mental disorders attended the group and seemed to be doing well, not only with their emotional symptoms but also with their HIV. I began to feel that everything would be well, and that I needed to take my HIV medications. I had learned how to handle my mental disorder, so now I needed to learn how to handle my HIV. Every once in a while I still have anxiety attacks but I have developed a strong support system: case manager, therapist, doctor, psychiatrist, and my peers at the support group. I know that sometimes I still get overly concerned about my health but I have also learned to control that and to stop calling my care providers almost every day. I also have the support of my family.

I am currently taking my “pastillas para los locos” (my “crazy pills” as I call them) and my HIV medications. My health is great. My viral load is undetectable, my CD4 count is 280, and I have not had an opportunistic infection since my PCP. I exercise – don’t want to put on the weight again, I still get anxious about that – I meditate, attend my support group, seek out my friends and family, and meet with my care providers regularly.

Having an anxiety disorder pushes me sometimes to make sure that I am on top of my health, so I take all my medications. I prefer to be anxious about taking care of my health while I’m doing well instead of being anxious about not taking my medications and becoming ill again. I still have not managed to return to work, and I’m not sure that I would be able to do that. I take care of my health one day at a time, but understand the importance of taking all my medications. I’ve tried to learn as much as possible about my diseases since my diagnosis, but I know that there is lot more to learn. (Versión en Español en www.acria.org)
Managing a Triple Diagnosis

Within the last decade, the medical and psychiatric communities have begun to recognize a subgroup of people with HIV who suffer from severe persistent mental illness and substance use disorders. In spite of the challenges and barriers to providing quality health care to these patients, the health service community has developed and designed effective health care and supportive service programs for this triply diagnosed population. This article is a review of the different approaches to care and the best practices that have been developed to effectively offer care to this unique population.

What is a Triple Diagnosis?
The term “triple diagnosis” has been used from the onset of the AIDS epidemic, when intravenous or other injecting drug use was first seen as a major risk factor for HIV. The term arose from the earlier “dual diagnosis,” which referred to a patient with severe persistent mental illness (SPMI) and a substance use disorder (SUD). A triply diagnosed patient also suffers from another medical problem or chronic physical condition. The term was created to describe a new breed of patients with complex medical and other social care needs who required specialized health care services that were virtually nonexistent at the time.

Triply diagnosed patients are overrepresented in many treatment settings because of their unusually severe and chronic symptoms. For instance, a 1994 study (Lyketsos) of 50 randomly chosen people with HIV who accessed Johns Hopkins AIDS Services found that 44% had a diagnosis of current or previous substance use disorder, and 24% had both a primary psychiatric diagnosis and substance use disorder.

Triply diagnosed patients can pose significant barriers to treatment because they may have a tendency to act on strong, impulsive feelings rather than following carefully considered treatment instructions. Their behavior can be driven by the transient, immediate rewards of drug use rather than by future consequences.

Some studies have found that these clients may become easily bored. They tend to “want what they want when they want it”, rather than what they need and when it may be good for them.

Mood disorders, especially major depression, are also found in these patients, with studies estimating a prevalence of 15% to 30%. Diagnosing affective disorders in drug users, however, can be difficult and controversial.

“Triply diagnosed patients can pose significant barriers to treatment because they may have a tendency to act on strong, impulsive feelings rather than following carefully considered treatment instructions.”

The controversy stems from the problem of determining the relationship between drug use and mood disorders. In order to precisely diagnose a drug user with a primary mood disorder, some mental health professionals believe that observation over a period of abstinence in a confined environment is necessary. Others believe that treatment can be started even if the patient is not abstinent. It may also be difficult to determine whether an individual’s symptoms meet the full criteria for major depression. Finally, AIDS itself can lead to changes in mental status or a new psychiatric or cognitive disorder, such as dementia, delirium, cognitive disorders, anxiety, or even psychotic disorders.

Providers should also be aware that active drug users may have difficulty managing potentially addictive psychotropic medications, or may feel the need to sell their medications, which could lead to incarceration. This should not be used as a reason to deny treatment, but mental health practitioners should carefully evaluate and screen for alternatives to psychotropic meds for certain at-risk patients.

Harm Reduction
The harm reduction approach acknowledges that a person may continue to use substances, but employs several strategies to ensure a level of safety for the patient. Methadone maintenance treatment, needle/syringe education and bleach distribution, legal clean needle purchase, and needle exchange programs are examples of harm reduction strategies.

Care providers should become familiar with the “transtheoretical stages of change” in order to evaluate a patient’s readiness to change unhealthy behaviors effectively. During precontemplation, the patient has no intention of changing the behavior. In the contemplation stage, she or he is thinking about change but remains ambivalent. In the preparation stage, the patient has decided to change and is taking initial steps to obtain treatment. During the action phase, the patient is modifying his or her behavior, environment, and circumstances in order to stop the behavior. Finally, in the main tenance phase, the patient works to prevent relapse into old behaviors.

Harm reduction strategies can be employed within the therapeutic alliance that is normally developed in the delivery of health care. To start, a nonjudgmental and empathetic approach is critical when interviewing the patient. Moving from comfortable topics of discussion (employment, family, friends, hobbies) to questions about drug use and sexual behavior is a technique that can be employed during the initial stages of
treatment. Maintaining confidentiality is also a vital part of building a therapeutic alliance, especially when accessing other sources of information such as medical records, family members, friends, and other health care providers.

Harm reduction recognizes patients’ motivation and readiness to become involved in their health care needs. In the event alcohol or other drugs are identified as barriers to safer behaviors, the clinician should counsel the patient to reduce or avoid substance use prior to engaging in sex, or refer him or her to prevention case management for more specialized risk reduction. The provider can often assist the patient in identifying methods for reducing HIV transmission risk, including those that do not require abstaining from alcohol and drug use. Of course, this requires that clinicians discuss substance use, including steroid use, with their patients, and reinforce their understanding of the adverse effects that these drugs can have on the body and the immune system.

**Care of the Triply Diagnosed**

There is no set protocol for working with triply diagnosed patients. As a first step, however, providers need to create a safe environment and supportive structure for the patient in which the necessary drug treatment history can be obtained. Properly worded assessment forms can provide critical answers. These can contain questions concerning the length of time in detoxification, outpatient drug treatment, methadone maintenance programs, AA/NA meetings, and residential drug treatment programs. This information is helpful in ascertaining the client’s perception of which methods of treatment have been successful and which have failed. Questions related to drug craving, loss of control of drug use, withdrawal symptoms, medical complications, and impairment in psychosocial functioning can also be part of the process of building a therapeutic alliance.

Examples of these include:

- Have you ever felt you wanted to cut down on your drinking or drug use?
- Have you ever been criticized about drinking or using?
- Have you ever felt any sense of guilt about your drinking or drug use?
- Have you ever begun drinking or using first thing upon awakening?

These sample questions are potentially less harmful and intrusive when trying to understand the patient’s own perception about their use.

Performing a complete physical examination, including a careful search for physical evidence of drug use, is a necessity. Injection marks, scars, burns, nasal septum erosion or perforation, skin abscesses, cellulitis, and other soft-tissue infections should be part of the examination. In addition, careful evaluation of markers of alcohol use, including hepatosplenomegaly, ascites, and physical trauma, should be considered. For the mental health provider, a careful neurological assessment, including a complete mental status examination, is essential to assess the presence of both substance intoxication and the neuropsychiatric manifestations of AIDS.

Early studies supported a cautious approach when treating the triply diagnosed. These studies argued that the multiple medical problems associated with chronic substance use could affect HIV disease progression. A 1992 study (Selwyn, PA) found that substance users with HIV were at higher risk for developing bacterial infections such as pneumonia, sepsis, soft tissue infections and endocarditis than HIV-negative drug users. A 1994 study (O’Connor, PG) showed that tuberculosis and hepatitis C infection were common in this population. But a surprising number of other studies have shown that continuing substance use does not accelerate HIV disease progression in people who are not taking HIV medications.

In addition, neurological symptoms can surface when HIV infection and substance abuse overlap. For instance, both AIDS dementia and drug intoxication can lead to apathy, disorientation, aggression, and an altered level of consciousness, and drug withdrawal can lead to seizures and symptoms of depression.

Because of these potential complications, some physicians were reluctant to prescribe any treatment until the patient had stopped all substance use and had a psychiatric evaluation. The stigma of mental illness and substance abuse effectively prevented some physicians from prescribing needed medication regimens. Physicians still face difficulty choosing which HIV medications to prescribe when psychotropic medications are also being taken. They may be concerned about potential side effects and adherence difficulties, and triply diagnosed patients may refuse treatment and decide not to adhere to any drug protocols. Despite this level of frustration, recent studies provide some useful recommendations. For instance, ID specialists can consult colleagues or use charts and computer programs to check for potential drug interactions. Physicians should not simply avoid treating patients aggressively out of fear of potential drug interactions.

The continuing medical care of active drug users also presents challenges. A 2002 study (Arici, C) found that active drug users, along with people who had higher CD4 counts, were less likely than others to return for follow-up medical care visits. While there is a common

(continued on next page)
Managing a Triple Diagnosis (continued from previous page)

assumption that substance use is associated with poor antiretroviral medication adherence, studies have found contradictory results on this issue. Certainly, many active users are able to adhere to HIV medications, and substance use alone should not be a reason to deny HIV treatment. High-risk sexual behaviors can also be common in drug users, increasing the risk of STDS for both them and their partners. In addition, the physical symptoms of HIV infection can mirror those of substance abuse and withdrawal, including malaise, fatigue, weight loss, fever, diarrhea, and night sweats.

Coordinating Care

The clinician should assess if the patient is ready for referral to treatment services. For instance, if the client is using injection drugs, the emphasis should be on evaluating his or her knowledge of the risk of acquiring HIV or other infections (such as endocarditis and hepatitis C) through sharing needles and other injection equipment. The clinician should also evaluate each patient’s readiness to change his or her drug injection practices and make referrals to syringe exchange programs, substance abuse treatment programs, relapse prevention programs, or other sources of ongoing support.

Collaboration and coordination of care with a variety of medical, substance use treatment, social service, complementary therapies, chaplaincy, and mental health providers is critical to ensure that appropriate specialty care is provided to triply diagnosed clients. In such instances, providers should find this approach useful to find and share their knowledge about the most appropriate clinical interventions. Managing adherence is profoundly important for the triply diagnosed, as it is for anyone with HIV. Medical and mental health providers should actively discuss with patients adherence to both psychotropic medication and HIV medications. If the clinical site permits, medication monitoring or directly observed therapy may be an option.

Linking to Other Services

Another useful strategy is linking patients to outpatient programs that offer specialty health care services, such as support groups that address the specific social and health needs. Referral to an outpatient or inpatient drug treatment facility should be done carefully, with the provider chosen to address the complex needs of the individual patient. For instance, certain drug treatment programs that use a therapeutic community model may not be effective in addressing the needs of a triply diagnosed person.

Finally, although religion and spirituality often play a significant role in the lives of people with HIV, providers generally do not assess or explore patients’ spiritual beliefs and their impact on their ability to cope with multiple medical and mental health illnesses. Providers should not be afraid to ask questions about a patient’s concept of God, sources of strength and hope, and the significance of religious practices and rituals in their lives.

Although caring for the triply diagnosed continues to be a growing challenge, employing these best practices can be the key to providing care to this medically fragile but complex population. The health care establishment has made significant strides in addressing the needs of the triply diagnosed. But just as the mental health community once developed programs for the dual diagnosed patient, the HIV/AIDS community must now strategize and advocate for the triply diagnosed, who deserve a uniform and replicable model for treatment and care.

(Versión en Español en www.acria.org)

Hans Desnoyers is the Executive Director of Adult Day Health Care at Housing Works in the West Village.

ACRIA at the International AIDS Conference

ACRIA will be well represented at the upcoming XVI International Conference on AIDS, with representatives from both the HIV Health Literacy Program (HHLIP) and our Research Department making presentations.

HHLIP has been invited to present three abstracts:
• “An HIV Health Literacy Model for Providing Non-Governmental Organizations HIV Treatment Education to Minority Communities”
• “Changing Beliefs, Knowledge and Attitudes About Clinical Trials: A Two-Tiered Education Model To Increase Female and Minority Participation in Clinical Trials”
• “Integrating HIV Treatment Education into Existing Programs of Minority Community-Based Organizations (CBOs) Through a Tailored Capacity-Building Program in New York City”

Two poster presentations were also accepted:
• “Implementation of a National Technical Assistance HIV Treatment Integration Program in the United States”
• “A Multi-Level Approach to Culturally and Linguistically Appropriate HIV Treatment Education for Adults in Underserved Communities”

The Research Department will be represented by Research Associates Andrew Shippy and Nicola Di Pietro, who will give poster presentations of the findings from ACRIA’s ROAH study:
• “Will the Social Networks of Aging Adults with HIV/AIDS Provide Adequate Support to Maintain Health?”
• “Diagnostic Dilemma: Depressive Symptomatology in Aging Adults with HIV/AIDS”
• “Sexual Activity and Partnership Status in Older Adults with HIV/AIDS”
• “An Analysis of Modes of HIV Transmission by Gender, Sexual Orientation and Ethnicity in Older Adults with HIV/AIDS”

The Conference will be held in Toronto, Canada, August 13 to 18. Mark Milano will cover the proceedings for ACRIA Update.
**Tietz Testifies**

“The challenge is no longer keeping death at arm’s length for those who are engaged in treatment, but developing new strategies for how best to live with the virus for an entire lifespan,” according to ACRIA’s Executive Director Dan Tietz.

Tietz was testifying before the New York City Council at its June 29 “Oversight—Older Adults and HIV” hearing. The forum was historic in that it marked one of the first times that the importance of this growing segment of the HIV population was officially acknowledged.

“The Council is to be commended for today’s hearing,” said Tietz after his testimony. “It’s a beginning. The challenge remains to translate what is being learned into effective services for positive seniors.”

ACRIA was invited to testify because of the agency’s unique position as a widely recognized authority on HIV and AIDS among older people.

In his testimony, Tietz addressed the policy implications of the rapidly growing number of people facing the physical and social problems that inevitably accompany getting older and at the same time managing their HIV.

“As we enter the second quarter century of this epidemic we know that antiretroviral drugs have brought down death rates,” he said, “but the virus has not been eradicated. In fact the epidemic is growing and aging. And our research suggests that many in the growing ranks of older adults with HIV will find themselves wholly dependent on an already frayed care and services safety net. We urge timely action to preserve and expand that safety net to meet the needs of older adults with HIV.”

**ROAH Rolls Out**

ACRIA’s Research on Older Adults (ROAH) project, the nation’s first comprehensive study addressing the aging HIV/AIDS population will be released at a press conference on July 31.

The HIV-positive population is graying, with the fastest growing segment being individuals over 50 years of age. In New York City, the HIV/AIDS epicenter in the United States, 31% of the almost 100,000 people living with the disease are over age 50. ROAH examines the underserved, unacknowledged, yet substantial HIV-positive population of men and women of all sexual orientations and races in New York City who are growing old with this disease. The study looks both at their unique health needs, i.e., complications that arise from or are exacerbated by their age, and the complex psychological and social issues that affect these older adults.

According to Dr. Stephen Karpiak, ACRIA’s Associate Director for Research and one of the study’s principal investigators, the primary reason for the consistent growth of the number of people over 50 with the virus is the success of anti-HIV drugs that enable infected persons to live longer lives. As people with HIV grow older, however, they face a host of health challenges that are common in older adults but compounded by HIV/AIDS. How these conditions, and the medications used to treat them, will affect them is largely unknown.

This study also examined for the first time the sexual behavior, substance use, and social networks of these older people with HIV, as well as their physical, emotional, and behavioral health. ROAH found that older adults living with HIV are also greatly marginalized and neglected, creating a population of persons over 50 who are living with this disease, yet who lack the social support systems they need and whose healthcare providers may be insensitive to their unique and changing needs.

“The success of anti-HIV drugs makes it probable that that age group will account for the majority of people with HIV within the next decade,” according to Karpiak. “Unfortunately, they face a healthcare system, social support networks, and communities ill-prepared to meet their needs.”

**Community Mapping Initiative Completed**

The Community Mapping Initiative, a project of ACRIA’s HIV Health Literacy Program working closely with our Research Department, has been completed and a report compiled. The program was an effort to “map” HIV-positive people throughout New York City with regard to a variety of factors affecting their access to care, their ability to participate actively in their own care and make informed decisions, and the concrete effects on their care of the availability of community-based treatment education.

The study assessed the HIV health literacy levels and treatment education needs of HIV-positive women of color throughout New York City. The survey was conducted with the cooperation of over 50 NYC ASOs and was done with the assistance of fifteen community members, twelve of whom were women.

The study found that the women surveyed do not experience significant barriers to treatment, but their health literacy levels are not optimal. Knowledge, attitude, and behavior, as studied in this survey, showed areas needing improvement. The majority of subjects failed to answer 20% of the questions that are considered important for their own medical management correctly, less than 50% strongly agree that they want to be involved in decision making regarding their health, and just above 50% strongly or very strongly endorse their relationships with their medical care providers.

The full report, “HIV Health Literacy and Treatment Access: Women of Color in New York City,” is posted on ACRIA’s Website, www.acria.org, as is a brief fact sheet summarizing the findings. The study was underwritten by a grant from the New York City Communities of Color HIV/AIDS Coalition.
Contributions in support of ACRIA’s research initiatives were made in honor of the following individuals:

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