Blame It on Your Hormones

If you're tired, you're cranky and you've lost your love jones, Lark Lands know just what the doctor hasn't ordered.

November 1, 1999 By Lark Lands, PhD

White linen tablecloths, floral centerpieces, delicate china and a hundred women politely finishing their desserts in the ballroom of a Miami hotel: The scene last July could have been a national convention of the Ladies Who Lunch. But when a speaker stepped up to the podium, all conversation ceased. A hundred pairs of eyes swiveled as the physician began to talk, and women abruptly dropped their silver spoons to scribble notes. A different sort of hunger had overtaken the well-fed crowd.

Sheri Kaplan, a woman with HIV and the event's organizer, says, "We called this conference 'What's Happening to Our Bodies?' because that's what women are desperate to find out. We're suffering from all kinds of symptoms—sleep loss, fatigue, severe PMS and other menstrual irregularities, hot flashes, vaginal dryness or pain, depression, skin changes and loss of sex drive. And our doctors mostly ignore the problems because, hey, it's not something 'important' like our viral load."

Across the country, in a health educator's office in Phoenix, men come by almost daily with similar, undiagnosed complaints. Body Positive's Mark Hoffman listens again and again to the same list: fatigue, depression, muscle loss and, the most distressing to many, impotence and loss of sex drive. Again and again he asks the same question: Has your doctor run hormone level tests?

Research has shown that almost the entire raft of symptoms described by the men in Phoenix and the women in Miami can stem from one common problem in HIV disease: sex hormone abnormalities.

Produced by the glands, hormones are chemical messengers that relay signals to every organ in the body and thus affect countless aspects of the body's functioning. The sex hormones—so called because they affect sexual and reproductive function, as well as body composition and mood—include progesterone in women, and estrogens and testosterone in both men and women. Testosterone is produced by the testicles and adrenal glands, estrogens primarily by the ovaries and testicles, and progesterone primarily by the ovaries.

Studies of testosterone levels in HIV positive men have found that up to half may have abnormally

low levels, and that clinical signs of the problem are present in a third (in the case of impotence) to two-thirds (lack of libido) of those with advanced disease. Although there has been no accurate assessment of testosterone insufficiency in HIV positive women overall, a study by Harvard's Steven Grinspoon, MD, found that two-thirds of women showing signs of AIDS wasting had abnormally low levels.

The causes of lowered testosterone in PWAs have long been debated, but it appears to result from altered signaling from the central nervous system and, in some men, testicle dysfunction. As for the female hormones (progesterone and estrogens), the incidence of problems related to abnormal production—such as early menopause, which hits some HIV positive women even in their 20s—is so high it indicates that women's ovaries may be affected in HIV disease. One study found that nearly 60 percent of HIV positive women interviewed had experienced irregular periods or vaginal spotting, and that incidence rose with disease progression.

Jon Kaiser, MD, a physician with a large HIV practice in San Francisco and author of *Healing HIV*, says that a crucial part of medical care for both men and women with HIV is to monitor all major hormones and, when levels are low, to supplement them. "Scientists know that hormone signaling affects many aspects of immune function, making optimal levels crucial in PWAs," he says. "And years of clinical observations make it clear that hormone changes can create symptoms that detract from quality of life. So this one step—optimizing hormone levels—can enhance longevity and quality of life, help to ensure optimal immune system function and prevent many life-degrading symptoms."

One of those who attended the Miami conference, Claudia Mello of Pompano Beach, Florida, wishes her doctor had known that long ago. Soon after learning she was positive in 1986, Mello developed vaginal burning that caused searing pain. For more than 10 years, no one was able to diagnose the problem or find an effective treatment. She also suffered from anxiety and depression. "I had to struggle to be happy," she recalls. In addition, she says, her skin felt coarse and dry, and waking up at 4 o'clock most nights left her fatigued. During her periods, she experienced miserable cramps, bloating and fevers. And sex drive? "It had been so long since I felt a thing that I couldn't figure out why anyone would even want to have sex," Mello says.

Although these symptoms could have come straight out of a hormone textbook, one physician after another ran cultures to find the source of the vaginal pain. Finding no infectious cause, they had no real suggestions. In fact, it's not uncommon for HIV doctors to be stumped by the symptoms of hormone deficiency. In the complex field of AIDS, doctors and researchers have focused on treating the virus and opportunistic infections. For those with large HIV practices, it's hard enough to keep up with those. On the question of hormones, doctors may have to depend on a long ago endocrinology course in med school. One Miami conference participant asked her physician to run hormone tests but, she said, "He only ran them because I asked him to, and then he admitted that he didn't know how to interpret them. So I was left trying to figure out what they might mean."

Hormone problems are confusing, since many of their symptoms can also stem from other causes,

including infections and HIV itself. This poses a major stumbling block to diagnosis. The advice given by endocrinologists is to look for patterns, rather than individual symptoms. For example, fatigue alone has a variety of possible causes. But fatigue combined with depression, muscle wasting and loss of sex drive points clearly toward testosterone deficiency. And fatigue seen in a woman also suffering from vaginal dryness and hot flashes should signal the possibility of menopause or perimenopause (premenopausal symptoms)—both caused by decreased female hormones—since fatigue can be triggered by nighttime hot flashes that interrupt restful dream sleep.

Diagnosis tends to be especially slow for women with hormone trouble, since, in many HIV practices, women are still a small minority. At that same Miami conference, one participant said, “So many of us are seeing doctors who haven’t dealt with women on a regular basis. They know HIV, but they don’t know women and they sure don’t know our hormones.”

Kaiser agrees that doctors fall short when it comes to hormone problems: “Physicians should seriously suspect hormone deficiencies when they see muscle loss, depression or anxiety, loss of sex drive, impotence, fatigue, worsened premenstrual symptoms, or problems that could signal menopause, like hot flashes or insomnia.” He urges anyone with such symptoms to ask his or her doctor to check on hormone levels.

That’s exactly what Body Positive’s Hoffman had to do. HIV positive since at least 1983, by 1990 Hoffman began experiencing fatigue, lost muscle mass and total lack of libido. “I was so weak that climbing a flight of stairs left me huffing and puffing and sore,” he says. “My chronic fatigue made it impossible for me to work full time. And I had simply accepted that sex would never again be a possibility for me.”

Then, around 1994, he attended an AIDS conference where he heard a description of the symptoms of low testosterone. It took some persuasion to talk his doctor into running hormone tests, but in December 1994 he finally had his numbers: 158 nanograms per deciliter (ng/dl) for total testosterone and 33 ng/dl for free testosterone, both of which are below normal.

Hoffman first tried a testosterone patch. But he had a hard time keeping it attached to his scrotum (as the early patches required), which resulted in inadequate absorption. His total testosterone never went above 340, still too low to reverse his symptoms. Finally, in the spring of 1996, he learned of a testosterone cream available from compounding pharmacies (which create meds to doctors’ specifications).

Since these creams are created on demand, the precise amount of hormone they contain can be adjusted based on an individual’s specific needs. And since they deliver small daily amounts of hormone, they more closely approximate the workings of a healthy body than twice monthly injections possibly could. (If there’s no compounding pharmacy in your area, the Women’s International Pharmacy has a wealth of info on hormone therapy, and it does mail order. Doctors can call in prescriptions to 800.279.5708.) Most experts now recommend transdermal (skin-absorbed) testosterone replacement over injections, whether in the form of creams, gels or the

new Testoderm TTS patch, a model that can be applied on the upper torso and seldom causes skin irritation seen with earlier versions.

Within 10 days of beginning his twice-daily use of the cream, Hoffman experienced his first full erection in years. “Using the testosterone cream gave me back a full life,” he says. “I began to sleep better. My energy improved so much that I could work full time again. I was able to join the local gym, where workouts restored my muscle mass.” And he grins when he adds, “I feel the fittest I ever have, even at the ripe old age of 49.”

Once she finally got her hormones tested and treated, Claudia Mello experienced a turnaround as profound. Although the hormone tests she had asked for came back with normal readings, they were on the low end of the range, so her acupuncturist suggested hormone replacement therapy (HRT). She started a daily application of triple-estrogen (tri-est) cream, with progesterone cream for the last half of each menstrual cycle, and calls the results “nothing short of miraculous.”

Her longstanding depression vanished almost immediately. She no longer wakes up during the night, and getting enough sleep has greatly improved her energy. Her skin became more youthful-looking, and her premenstrual symptoms lessened. After two months, the vaginal burning almost completely disappeared. And her sex drive? She laughs and says, “Well, let’s just say that I’ve become very interested in the pilot who lives across the street.” For Mello, adding testosterone wasn’t necessary, but for many women, a combination of male and female hormones works best. If test results show that a woman’s testosterone is low, the small amount of testosterone that she requires can also be delivered in cream form.

In addition to the benefits Mello saw, HRT can wipe out hot flashes and restore vaginal lubrication. It may also provide longterm protection against osteoporosis, Alzheimer’s, colon cancer and heart disease—now a worrisome specter in those with lipodystrophy.

But for anyone considering replacement therapy, a few cautions are in order. Hormones may interact with your HIV or OI drugs, so make sure every drug you’re taking is considered when hormones are being prescribed, and report any odd new symptoms.

For women, additional cautions apply. Studies indicate that replacing female sex hormones could increase the risk of breast, uterine or ovarian cancer, a particular concern for women with HIV, whose compromised immunity may already put them at increased risk for cancer. (Those searching for alternatives to HRT may consider a daily intake of soy, which contains natural estrogens. Nutrients may reduce menstrual or menopausal symptoms: Try vitamin E for hot flashes or swollen breasts; magnesium for cramps or irritability; and B complex and calcium for bloating or moodiness. Acupuncture may also provide relief.)

And giving testosterone in the wrong forms can create serious problems for men and women. Because of its particular chemical composition, oral testosterone can cause liver toxicity. In men, longterm use of injectable testosterone can shut down the testicles’ own hormone production, cause testicles to atrophy, or result in erratic hormone levels—too high for several days after the

injection and too low a week or so later. Mark Hellerstein, MD, PhD, of the University of California at Berkeley, warns that this up-and-down pattern not only achieves less than optimal clinical results, but can create feelings of dependence on the shots and drug-seeking behavior. Too much testosterone can cause aggression and, in women, masculinization—darker facial hair, a deeper voice and a swollen, itchy clitoris—so dosing must be carefully monitored. Kaiser recommends follow-up hormone level tests after one or two months on replacement therapy, with semi-annual monitoring from then on.

Hormone tests have become Mark Hoffman's cause célebre. He tells the story of a client who confided that, due to his impotence, he couldn't have sex with his wife. This had created serious marital discord. At Hoffman's urging, his client asked for the test. Days later he received a call, telling him to come to his doctor's office immediately because his testosterone levels were dangerously low: total testosterone at 16 and no free testosterone. Now, Hoffman says, "His marriage is back to normal. He calls me a miracle worker."

But Hoffman still finds that at least two-thirds of the people he sees with obvious symptoms of hormone insufficiency go untested. He worries that too many doctors give low priority to

Hormone Testing

Hormone levels can be checked through simple blood tests. But Jon Kaiser, MD, warns that finding out your levels are in the "normal" range may not be enough: "The optimal range is where you're at your peak of health. And a rule of thumb is that the optimal range is usually the upper half of the so-called normal range."

Testosterone

Optimal ranges for men:
Total testosterone: 500 to 1000 ng/dl
Free testosterone: 100 to 200 ng/dl
Optimal ranges for women:
Total testosterone: 50 to 100 ng/dl
Free testosterone: 1 to 2 ng/dl

Female Hormones

To diagnose perimenopause or menopause, draw blood on days 2 to 4 of the menstrual cycle (day 1 is when a woman begins to bleed) to check for two marker hormones: FSH and estradiol, an estrogen.

FSH: A level of greater than 20 IU (international units) for two months indicates perimenopause; greater than 35 to 40 IU for two months indicates menopause.

Estradiol: A level that is too low or too high (normal levels vary by age) suggests hormonal imbalance or perimenopause.

Hormone Replacement

When tests show a need for hormone supplementation, experts recommend:

For younger women with menstrual irregularities: birth control pills.

For perimenopausal women: progesterone cream, applied topically on thin areas of skin (such as the inner thigh) during days 14 to 28 of the menstrual cycle. The usual dose is 100 mg progesterone (1/4 teaspoon of 10 percent progesterone cream), applied twice a day. If testosterone levels are low, testosterone cream (5 mg testosterone/ gram of cream) can also be used: 1/4 tsp topically, twice a day, for a total daily dose of 10 mg; adjust based on results.

For menopausal women: tri-est gel or cream (contains three estrogens in a concentration of 2.5 mg/gram). The usual dose is 1/4 tsp of cream twice a day, rubbed where the skin is thin. Adjust to relieve symptoms. Progesterone cream should also be used, on the same days and doses as for perimenopausal women. Add testosterone cream if needed.

For hypogonadal men (with insufficient testosterone): 25 mg of testosterone daily via either cream (12.5 mg testosterone/gram of cream; 1/4 tsp rubbed into scrotum twice daily), or gel (12.5 mg testosterone/gram of gel; 1/8 tsp rubbed into scrotum twice daily); adjust based on results. Or use a daily Testoderm TTS transdermal patch.

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