Hitting Below The Belt

Often misdiagnosed and always unnerving, myelopathy may soon have knockout treatments

February 1, 2000 By James Learned

Allen Schoenfeld was mystified when a strange range of symptoms appeared in 1995. “I was having trouble walking,” the Boston PWA recalls. “At first I thought it was HIV fatigue. Then I thought it was due to my [already-diagnosed] neuropathy.” But it took months of increasingly frequent urination and trouble getting an erection before Schoenfeld (not his real name) finally asked his physician what might be wrong. The doc also thought that the motor problems stemmed from neuropathy, but was stumped about the other symptoms. After a two-year barrage of medical tests, Schoenfeld was finally diagnosed with vacuolar myelopathy, a degeneration of the spinal cord that can cause a collection of below-the-belt symptoms. By then he was virtually housebound, every step a struggle.

While only an estimated 10 percent of PWAs have symptoms of myelopathy, autopsies have found the condition in some 55 percent. Yet the disease is rarely recognized, let alone discussed, in the AIDS community. Often typecast by docs as a “late-stage” condition, myelopathy can strike at any time and may be present long before symptoms appear. And misdiagnosis is common. The most frequent error is confusing myelopathy with neuropathy, as in Schoenfeld’s case. The two conditions often occur together, making a correct diagnosis more difficult. David Simpson, MD, director of the Neuro-AIDS Program at Mount Sinai Hospital in New York City, explains, “Leg weakness—as opposed to pain or numbness—is a symptom of myelopathy, not of neuropathy.”

AIDS docs may also attribute difficulty in getting an erection—a primary symptom of myelopathy—to better known causes such as medication side effects, low testosterone or HIV itself. PWAs may blame frequent nighttime urination on increased water intake. And doctors and patients alike may simply be too embarrassed to even bring up such issues.

“Myelopathy is the neurologic condition that we know the least about in HIV,” Simpson says. This much is known: Small holes, or vacuoles, develop in the middle part of the spinal cord—which controls the lower body—and become larger over a period of months or years. Myelin, the protective coating around nerve fibers, is slowly destroyed. As more and more fibers die, the brain’s electronic signals are short-circuited, which blocks communication with the lower body.

The disease’s progress can be as cruel as it is relentless. “A little weakness going up the stairs becomes a complete inability,” says Alessandro Di Rocco, MD, chief of the Division of Neuro-AIDS

at Beth Israel Medical Center in New York City. “Difficulty walking—due to leg and butt weakness or stiffness—becomes having to use a cane, then a walker, next crutches, and finally a wheelchair.” Trouble with urinary and bowel control can become full-fledged incontinence, and in rare cases the person can become paralyzed below the waist.

There is no specific test for myelopathy, so “putting together the symptoms is key,” Di Rocco says. “When you have a certain combination, you often have a pretty simple diagnosis.” But first, other conditions and infections that affect the spinal cord—CMV, toxoplasmosis, HTLV-1, syphilis and lymphoma—must be ruled out. A spinal MRI (magnetic resonance imaging) is recommended to check for tumors or spinal compression. (A spinal tap is usually unnecessary.) The most useful diagnostic tool may be somatosensory evoked potentials (SSEP)—expensive, but covered by insurance. This simple test measures how quickly electrical signals travel from the brain through the spinal cord and which section of the spinal cord, if any, is damaged. Abnormally slow results often show up before symptoms.

The cause of myelopathy remains unclear, although it has no apparent correlation with levels of HIV in either blood or spinal fluid; antiretrovirals that cross into the central nervous system fail to yield improvement. Many studies have shown that a large percentage of HIVers have B-12 deficiency, a known cause of myelopathy in the HIV negative. Although studies of B-12 levels in HIVers with myelopathy have had mixed results, nutrition researchers note that a “normal” blood level often masks a deficiency in the tissues. Di Rocco advises that any HIVer with myelopathy take B-12 supplements (injections or nasal gel are best)—and the earlier, the better.

Di Rocco and other researchers theorize that myelopathy is an indirect effect of HIV infection—a chain of events in which HIV-induced “miscommunication” between cells results in the breakdown of a complex metabolic process that involves B-12, along with the essential amino acid methionine and its derivative S-adenosylmethionine (SAMe), which helps to form and repair myelin.

In a Mount Sinai pilot study, seven out of nine HIVers with myelopathy who took three grams of methionine twice a day for six months showed various degrees of improvement in strength, sexual function and bladder control. A larger, placebo-controlled study is now enrolling at Beth Israel, and a trial using SAMe is under consideration by the federal AIDS Clinical Trials Group. Another treatment being studied at Mount Sinai is intravenous immunoglobulin (IVIg), a solution of bacteria-fighting antibodies that may also act as an anti-inflammatory agent, slowing injury to spinal-cord cells. A small study of IVIg showed promising, though temporary, results.

But even when myelopathy can’t be reversed, medications can help lessen or eliminate some symptoms. You can try methantheline to control urinary frequency, Viagra to resolve sexual dysfunction, and baclofen or dantrolene to diminish stiffness, spasms and cramps in the legs. Physical therapy can also help. And it’s a must to watch for and treat any urinary infection.

Not content to just treat his symptoms, Schoenfeld began taking methionine in December 1997 and experienced better bladder control. He then switched to SAMe (400 milligrams twice a day) when it became commercially available last August. “Two months later, my neurologist was

astounded at the improvement in my tests for strength," he says. "I was able to stop the progression of my condition. I can now walk a few blocks comfortably with crutches." If any of these experimental therapies prove effective, Schoenfeld and other myelopathy-disabled PWAs may well be covering far greater distances.

An excellent article on HIV myelopathy is available from Body Positive at 212.566.7333. For a list of trials for myelopathy (and other HIV-related conditions), call 800.TRIALS.A or visit www.hivatis.org or www.amfar.org/td When purchasing pricey SAMe, look for the words stabilized and enterically coated. SAMe and info about it are available from the nonprofit buyers club DAAIR at 888.951.5433 or www.daair.org.

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