Pain Killer Pain

HIVers have more than almost anyone else. But a revolution in understanding and treating it should soon spell relief-as long as the feds don't take away the meds.

June 1, 2002 By Lark Lands, PhD

"Imagine that just having cool sheets brush against your legs in bed is enough to send scalding pain through your body and leave you gasping for breath," says South Jersey HIVer Kathryn Hartley. "That's what living with chronic pain is like. For years, I was miserable and exhausted all the time, and nothing seemed to help.

Richard Jermyn, DO, the pain specialist who finally successfully treated Hartley, believes that the best-kept secret in AIDS is the excruciating pain in which so many HIVers are imprisoned. "Yes, people are living longer with HIV, but they're living in pain," says Jermyn, a physiatric physician who is the founder and director of the Comprehensive Pain Center at the University of Medicine and Dentistry of New Jersey. It's the only center in the U.S. dedicated exclusively to the treatment of HIV pain, and could serve as a model for what is sorely needed nationwide.

Over the last few years, science has made a quantum leap in the understanding of pain and how best to manage it -- but too many AIDS physicians remain in the dark about the many HIV varieties. "AIDS-related pain exists and it is often severe," says Jermyn. Even worse, he says, "it is often neglected and never even properly diagnosed." According to the Philadelphia-based Eastern Cooperative Oncology Group, 85 percent of hurting PWAs are undertreated, a rate twice that for under-treatment of cancer pain -- even though the two diseases have similar pain prevalence. A Sloan-Kettering study showed that the rates of pain rise from 30 percent in early-stage HIV to 50 percent during AIDS, as high as 60 percent among those hospitalized and up to 70 percent in hospice settings.

One reason that pain so often goes untreated is that it is tricky to diagnose, its symptoms are subjective and modern medicine's methods of measuring it remain crude. There are no diagnostic pain tests, no machines that confirm that nerve cells are firing off pain signals. Top-flight pain researchers use decidedly low-tech assessments: your reaction to nylon fibers pressed into your skin, how quickly you detect heat in a glass plate, or whether you respond differently when pricked in different places.

So physicians must rely on their patients' word, probing with simple questions: Where does it hurt? When does the pain occur? How long does it last? Is it constant? Does it prevent normal life activities? Does it affect your sleep or mood? Does anything make it better or worse? What words

describe the pain? Keeping a pain diary that notes all of the above can help physicians not only make sense of what hurts but justify prescription medications for pain relief -- an increasing necessity in the face of painkiller crackdowns.

Hartley's diagnosis was neuropathy, the nerve damage that is the most common cause of AIDS-related pain, occurring in 30 percent of HIVers. The pain is characterized by burning, numbness and a pins-and-needle sensation often (but not always) in the hands or feet. Its possible causes are many: HIV itself, toxicity from HIV meds, other drugs or alcohol, nutritional deficiencies such as folate and B12, chemotherapy, and treatment for opportunistic infections (OIs), including phenytoin (Dilantin) for seizures and epilepsy or isoniazid (INH) for TB.

The specifics on how HIVers' nerves get damaged are only dimly understood. But it is clear that suppressing viral load -- and, hopefully, improving immune function -- as much as possible helps prevent problems. "You decrease the chances of secondary infections that could attack the nerves, and you stop HIV from causing nerve damage," Jermyn says. "That just leaves us with side effects of meds."

Another frequent cause of HIV pain is myopathy -- muscle damage from either the virus or nucleoside analogs such as AZT, often indicated by elevated blood levels of creatinine phosphokinase (CPK). Myopathy shows up as weakness, muscle aches and difficulty getting up from a chair or out of bed. OIs can also cause various incarnations of pain in the abdomen, mouth, skin and joints. For example, abdominal pain in AIDS is reported in up to 25 percent of patients. Headaches occur in 40 percent due to vascular tension and HAART. When T-cell counts fall below 200, more ominous causes of headache such as encephalitis, central nervous system infection and lymphoma may be the culprits.

Jermyn believes that far too many HIVers suffer needlessly because a comprehensive workup is never done. "We saw a patient yesterday who had been referred for right-shoulder care," he says. "He had seen three different orthopedic physicians who had done nothing but refer him for physical therapy." When Jermyn examined him, he found that the nerves coming down from the young man's neck to his arm were compressed, resulting in numbness in his arm and paralyzed shoulder muscles. He says, "I knew when I saw this that it was most likely lymphoma that was compressing the nerves, and a biopsy confirmed it."

Down the line, we are likely to have better diagnostic approaches to pain. Researchers have only recently begun to use MRI and PET scans to image the cells that pain activates in the brain. The current technology is too primitive to pinpoint exactly where in the cell sensation of pain originates, but it can ID the approximate areas of the brain where pain is processed. Although this science is young, the scans have already shown that the same areas of the brain are producing both physical sensations and emotions. Of course, chronic pain and depression go hand in hand. That's partly because of biochemical changes that cause the serotonin supply (a feel-good brain chemical) to be rapidly used up in pain sufferers. Ultimately, such imaging may be able to identify who is really hurting, and how bad.

Such technology would be welcomed with open arms by doctors who want to do the right thing but hesitate to prescribe opiates -- the most effective treatment -- for fear they might lead to addiction and abuse. HIV specialist Larry Lyle, DO, of San Diego says, “We finally have standards for treating pain, but many of us have concerns about what following these guidelines might do, especially with our many patients who have a history of addiction.”

Scandals of overprescription, such as the recent OxyContin (a.k.a. hillbilly heroin) fiasco, have led the legal establishment and, in turn, the medical profession to quash painkiller use. As a result, legitimate patients are in danger of becoming corollary casualties in the U.S.’s long war on drugs. States first tried to curb opioids and other addictive, but medically useful drugs in the ’70s with the “Schedule II Narcotics” classification by enacting stronger penalties for overprescribing; some even required reporting prescriptions for government tracking. By the mid-’90s, a survey found that only 60 percent of California’s docs were authorized to write “Schedule II Narcotics” scripts and only 40 percent actually did.

It wasn’t until 1985 that chronic-pain negligence became a hot-button issue for doctors and the public. A groundbreaking New England Journal of Medicine article by Kathleen Foley, MD, drew attention to the lack of adequate care. By 2000, about half of the states had endorsed requirements for pain treatment. Large health-care centers created pain clinics -- none specifically for HIVers -- which led to an increased access to stronger, more appropriate drugs.

The first national standards requiring pain assessment and control in all hospitals and nursing homes were implemented by the Joint Commission on Accreditation of Healthcare Organizations in January 2001 as a result of research by the University of Wisconsin-Madison Medical School and the American Pain Society, establishing that pain was poorly managed throughout the U.S. health-care system. These standards recognize that unrelieved pain has adverse physical and psychological effects -- people have a right to pain management.

The HIVers at New Jersey’s Comprehensive Pain Center are treated by a team of specialists in physical medicine, including not only docs but nurses and other support personnel. The treatment approach includes a top-to-bottom assessment; pain medications, using the WHO guidelines; psychiatric services focused on emotional problems, including depression and sleep disorders that the pain-wracked tend to develop; physical therapy, including the use of TENS (electrical stimulation of nerve fibers to block pain and activate release of endorphins), electroacupuncture machines and aquatic therapy; nutrition counseling; podiatry; training in breathing techniques and biofeedback as ways to reduce pain; intensive pain, spiritual and addiction counseling.

For his part, Jermyn has no patience with the still-roiling debates over painkiller abuse. “An addict is someone who inappropriately takes drugs to get high,” he says. “Many studies have shown that drugs used for the appropriate treatment of pain do not create addiction. They may cause physiological dependence, but that just means that when you no longer need the med, you have to step it down slowly. There is no long-term harm.” Unfortunately, many HIVers with drug habits are still denied painkillers even when their suffering is abundantly obvious.

Many Pain Center clients are former drug users but are still prescribed necessary pain meds -- followed by strict monitoring. Jermyn says, “It’s ironic that physicians are afraid to treat pain in those with addiction history. I say that if you don’t treat them, you’ll send them back to the streets to get their drugs.” Initially, people are instructed that they must do more, not less, on the meds. That’s because with pain relief should come the improved ability to function that will allow a greater range of activities and improved interactions with family and friends.

The new textbooks on pain will tell you that the failure to treat can cause serious harm to the body. Pain causes the release of hormones like cortisol that can suppress the immune response. Worse, the failure to adequately treat pain may turn temporary discomfort into chronic suffering. Most pain meds actually slow the firing of nerves that would otherwise be transmitting the pain signal -- the electrochemical impulse transmitted along the nerve pathways that sends the message “Ouch!” to the brain.

“When a nerve is injured, the brain is bombarded with pain signals. After a while, the brain says, ’Enough,’ and resets its thermostat so the switch just stays on. From then on, there’s always pain,” Jermyn says. If you treat pain aggressively early on, he says, you’ll always have better control of that switch. “If you don’t properly treat it, or if you wait too long, you greatly increase the chances of a transition into chronic pain,” he says.

The Pain Center’s multi-pronged attack on pain costs a bundle, and private insurance or Medicaid covers only a fraction of the bill, leaving the clinic heavily dependent on federal and state grants for survival. From the progress the patients experience, the results appear to be worth the cost and effort. “I can honestly say that everyone gets some help,” Jermyn says. “The contract that incoming patients sign says that if after four months they are not getting better, we will refer them back to their primary physician. But we never have to.”

Jermyn may toot his own horn, but he needn’t bother -- there’s a chorus of people in recovery from pain eager to back him up. “He’s my Superman, he saved my life,” Hartley says. “It’s been a lot of work, but I’m mostly pain free now. And who wants to live in pain?” She barely pauses before answering her own question. “Nobody,” she says fervently.

Step Right Up To Pain Relief

The World Health Organization’s four-step approach is the last word in drug treatment of pain. Now watch your step!

- Step 1: For mild pain, try acetaminophen or a non-steroidal anti-inflammatory drug (NSAID) such as aspirin, naproxen, sulindac or ibuprofen. When one brand of NSAID doesn’t work, another might. Long-term use can cause gastrointestinal bleeding.

- Step 2: Try a weak opiate derivative such as codeine, hydrocodone or oxycodone alone or along

with acetaminophen or an NSAID.

- Step 3: Try a stronger opiate such as hydromorphone, transdermal fentanyl patches, levorphanol, morphine sulfate (intravenous), sustained-release morphine sulfate (oral) or meperidine -- at the minimum daily dose that affords relief.

- Step 4: Add adjuvant therapies to boost the effectiveness of other drugs. The antiseizure med gabapentine (Neurontin) is effective for neuropathic pain. Other boosters include antihistamines, butyrophenones, psychostimulants, amine precursors and selective serotonin re-uptake inhibitors.

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Sites For Sore Eyes

The Web has no home specifically for HIVers in pain, but these six top sites are only a click -- and an ouch -- away.

Pain.com
www.pain.com
Truly, as its tagline trumpets, a "world of information on pain," this site offers links to resources, societies, publications, news, studies and a drug-interaction checker. Also handy is "Ask the Pain Doctor," with archived Q&As and a by-subject file.

The American Pain Foundation
www.painfoundation.org
Newly revamped, this site includes chat boards, info center and tales from people in pain. A section on opioids and alternative meds rounds out the suffering salve.

American Academy of Pain Management
www.painmanage.org
This A-to-Z site includes pages for patients and doctors, an open forum and links galore. Surf the National Pain Data Bank for news of specific treatments.

Dee's Pain Management Page
www.web-shack.com/dee
Nurse Dee has dedicated her site to the old saw misery loves company. Chock-full of data and a fully functioning forum, this delightful site puts a personal touch on pain management.

International Association for the Study of Pain
www.iasp-pain.org

Top dog in pain, IASP is a nonprofit for research and care. The site is geared toward pain-management pros, but cutting-edge info on treatments and trends makes it a must.

-- Adam Bible

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http://beta.docker.poz.com/article/Pain-Killer-Pain-860-8929