

Prisoners of Pain

Why are Millions of Suffering Americans Being Denied the Prescription Drug Relief They Need?

Barry Yeoman; [AARP The Magazine](#); September – October, 2005

[Identifier: <http://www.doctordeluca.com/Library/WOD/PrisonersOfPain05.htm>]

[Related resources: <http://www.doctordeluca.com/Library/LibPages/WODjournalism-lib.htm>]

[Source: http://www.aarpmagazine.org/health/prisoners_pain.html]

[For Additional Pain Advocacy Resources see: [The Pain Relief Network](#), "Standing up for patients in pain and the doctors who treat them"]

Deborah Hamalainen was feeling more and more agitated by the minute. Waiting to see her neurologist, she was silently rehearsing a confrontation that had been building for months. She planned to look the doctor directly in the eyes and demand that he treat the chronic pain that had invaded her life.

In the two decades since doctors diagnosed her with multiple sclerosis, Hamalainen learned to tolerate numb extremities, tingling sensations, even the weakness that causes her left foot to drag. And it wasn't like her to be confrontational. "I'm much happier in denial," admits the soft-spoken 52-year-old sculptor.

Some physicians fear that if they deliver humane pain care, they'll face prosecution by the DEA.

The symptoms she couldn't ignore, though, were the intense shooting pains that raced across her shoulder blades and down her limbs. By the time she arrived for this doctor's appointment, they were a 24-hour presence. Hamalainen barely slept anymore. Rolling over was an ordeal. When the Medford, New Jersey, resident awoke, stiff and exhausted, she braced her shoulders so they wouldn't move as she rose. Sometimes, her husband had to pull her upright from the bed.

Every three months for three years, Hamalainen saw this neurologist. Each time, she mentioned the pain. Each time, the doctor deftly changed the subject. Each time, she left in pain.

But this time would be different.

Hamalainen waited quietly as nurses wandered in and out of the examination room, taking her vital signs. Finally, she lost it. "My pain is real," she said frantically to one of the nurses. "I need relief. Why does he keep refusing to talk to me about it? What do I have to do?"

The nurse turned to her conspiratorially and lowered her voice. "I should not tell you this," she said. "But he doesn't want to treat your pain because the treatment that works is opioids, and he's afraid to prescribe them."

With that conversation, Hamalainen joined legions of patients who are the victims of a troubling and all-too-common medical practice: the undertreatment of significant and debilitating pain. An estimated 75 million Americans suffer from chronic pain, according to the American Medical Association, and numerous studies have shown that patients often don't receive the medication that could provide relief. Undertreatment runs as high as 50 percent among advanced-stage cancer patients and 85 percent among older Americans living in long-term care facilities.

Much of this suffering is preventable. Experts do know how to reduce pain safely. In particular, physicians now know that opioid analgesics—medicines such as morphine and oxycodone—provide relief for a wide spectrum of pain problems, with relatively few side effects when taken as prescribed. "We can't cure everybody who is in pain, but we can make almost everyone feel better," says Scott Fishman, chief of the division of pain medicine at the University of California, Davis, and president of the American Academy of Pain Medicine. "Becoming a prisoner of pain is not an inevitability."

Additional Resources:

For more on pain-management issues, visit the website of the [Pain Relief Network](#).

The problem is that the most effective medications cause skittishness among many physicians. Poor medical-school training has left them unaware of the tools at their disposal and even the importance of treating pain. Many harbor the false impression that opioids frequently lead to addiction or unmanageable side effects, even when used correctly for a legitimate medical need.

Worse, some physicians fear that if they deliver humane pain care, they'll face prosecution by the federal Drug Enforcement Administration (DEA) or state medical boards. In recent years, a number of respected doctors have been investigated and even prosecuted after prescribing large amounts of opioids. The result, according to experts, is an environment that scares doctors away from practicing good medicine.

"I've had prominent physicians call me up and say, 'I have patients doing well, taking opioids for otherwise treatable pain, but I'm going to stop writing prescriptions because I don't want the DEA coming into my office and putting handcuffs on me,' " says James Campbell, a neurosurgeon at Johns Hopkins University. "Five years ago, we were actually doing a better job at handling pain patients. Now we've seen a backslide, and patients are definitely the victims. They're suffering."

On his first day as a licensed physician, Russell Portenoy had a troubling experience that would influence the course of his career. At the New York City hospital where he was interning, a nurse summoned him to a room where a cancer patient was moaning with

abdominal pain. Portenoy knew the woman would benefit from opioids, but he was new at doctoring, so he first phoned the resident in charge to clear his decision.

"I have a patient here. She's 60 years old, she's got metastatic ovarian cancer, and she's in bad pain," Portenoy told his supervisor.

"What do you want to do?" the resident asked.

"Well, I thought we should give her some pain medicine."

"What do you want to give her?"

"Morphine."

There was silence on the other end of the line. It was 1980: even physicians who endorsed opioids for terminally ill patients believed that morphine was too potent and too dangerous. Finally, the resident said, "Look, you're the doctor. You want to give her morphine, give her morphine." After further consultation, Portenoy wrote an order for a 3 mg injection, less than one third of what he would likely give her today. He never checked back to see if the medication worked.

The patient was still on Portenoy's mind the following year when he decided to specialize in pain medicine. "I'd given somebody with severe cancer pain a dose that didn't have a prayer of providing any benefit," he says. "My hope is that there was such a profound placebo effect that she didn't scream the rest of the night."

Portenoy joined a coterie of pioneers who encouraged their colleagues to become bolder in treating patients' suffering. They argued that pain is more than a symptom; it's a disease by itself that can trigger a cascade of other health problems—from a weakened immune system to obesity—if left untended.

At Memorial Sloan-Kettering Cancer Center, where he launched his career as a researcher and pain physician, Portenoy initially concentrated on cancer pain. Eventually he discovered that opioid medicines—routinely prescribed in advanced-cancer cases—also worked for patients without terminal illnesses. They relieved the symptoms without fogging patients' brains or turning them into addicts. The only major ongoing side effect, constipation, was manageable with other drugs. But when Portenoy shared the news in a 1986 journal article, he received excoriating criticism from his colleagues.

Slowly, time has proven Portenoy correct. In 1996 two leading professional groups declared opioids "an essential part of a pain-management plan." Five years later, the DEA and 21 health organizations agreed that opioids are often "the most effective way to treat pain and often the only treatment option that provides significant relief."

Across the United States, hospitals are starting to take the issue seriously, creating programs specializing in pain management. Portenoy's own department, at New York

City's Beth Israel Medical Center, has 14 physicians, a team of researchers, and training programs for doctors and others. Using opioids and other therapies, these programs have restored normalcy to many lives.

"It's a miracle," says 55-year-old Michele Ferreri, a Staten Island, New York, woman who suffers from a painful nerve condition that appeared in the aftermath of shingles. Once unable to get out of bed because of her burning headaches, she started taking extended-release morphine and other medications after seeing Portenoy at Beth Israel. Now she lives an active life, taking her mother shopping, doing laundry, and attending social functions with her husband, a hospital CEO. "I can smile now," she says. "I can smile and greet people."

Until recently, there was no legal incentive for doctors to take pain seriously. That's starting to change. In 2001 a California jury awarded \$1.5 million to the family of a lung-cancer patient who lay undermedicated and dying in a hospital near San Francisco. (The award was later reduced in keeping with state law.) Two years later, the California Medical Board reprimanded a physician in a similar case involving a nursing home. These decisions "sound a resounding wake-up call to all health care providers that failure to treat pain attentively will result in accountability," says Kathryn Tucker, attorney for Compassion & Choices, which litigated the cases.

But the wake-up call hasn't stirred everyone. Millions of Americans still don't receive the therapy they need. "The odds of your getting good pain management are, at best, 50-50," says UC Davis bioethicist Ben Rich.

Studies bear Rich out. One survey of Oregon families, published in 2004, showed that almost half of terminally ill patients were in significant pain or distress during the last week of their lives. In a study of nursing homes in 11 states, Brown University researchers found that two thirds of the residents initially found to be in daily pain were still suffering two to six months later.

But even when treatment is available, patients often reject it because of widely held misconceptions. Popular media play up addiction—be it on the TV series *ER*, where Noah Wyle portrayed a young physician addicted to prescription painkillers, or in tabloid newspapers, which devoted voluminous ink to Rush Limbaugh's struggle with pain pills in late 2003. Indeed, Limbaugh's alleged drug of choice, OxyContin (a form of oxycodone), has become popular among rural drug abusers, who chew the pills to destroy their time-release mechanism and get a heroinlike rush.

In reality, for those using opioids as prescribed, the likelihood of addiction is extremely low, according to research. "It's really an unwarranted fear," says Christine Miaskowski, former president of the American Pain Society. Many patients do become physiologically dependent—meaning they'd go through withdrawal syndrome if they quit cold turkey—

but this is a normal condition that can be managed by tapering down the dosage. It's not the same as addiction, which requires psychological dependence. Experts say patients with a history of drug abuse can safely use opioids too, as long as they are carefully monitored by their physicians to avoid a recurrence of their abusive behaviors.

These reassurances don't convince everyone. "There is a just-say-no-to-drugs attitude in the United States," says Diane Meier, a geriatric and palliative-care specialist at New York City's Mount Sinai Medical Center. "Even my own family will say, 'I don't want to be doped up on those drugs.' "

Patients aren't alone in their misinformation. Physicians, trained to suspect there's an abuser lurking behind every painkiller request—and, to be fair, there sometimes is—still confuse addiction with physical dependence. The facts don't dissuade them: although Ferreri has become functional on morphine, her family doctor still "talks to my husband all the time about the amount of medication I'm on, how dangerous it is. He really makes me feel that I'm a drug addict."

Worse, some physicians simply don't understand the importance of treating pain at all. Miaskowski, a professor in the physiological nursing department at the University of California, San Francisco, recently completed a study of cancer patients. "We had one patient whose primary care physician told her, 'Don't take your pain medicine. Let the pain kill the cancer.' " Was this advice offered years before recent advances in pain management? No, she says. "This was 2001."

There's another, more ominous reason some doctors don't treat pain aggressively: they don't want to end up like Arizona physician Jeri Hassman.

Hassman, a physical medicine and rehabilitation specialist licensed in 1986, opened a solo practice in 1999 to focus on nonsurgical treatments for injured patients. Working with physical therapists and chiropractors, she developed a comprehensive program that includes massage, electrical stimulation, muscle injections, and even posture lessons. She also prescribed painkillers. "Medications are important," she says. "If you decrease pain, you get better compliance with exercise and other rehabilitation." Until 2002, she says, "I wasn't afraid of prescribing strong pain medicines alongside the available therapies."

Then, in May of that year, federal agents stormed her Tucson office in full view of her patients. They spent eight hours questioning her staff, seizing patient files and appointment logs, and copying the hard drives off her computers. According to a government brief, the DEA had been contacted by pharmacists "concerned about the large amounts of narcotic drugs that were being prescribed for Dr. Hassman's patients, plus the frequency with which they were returning for refills." The druggists were also concerned that some medicines had fallen into the hands of nonpatients, the brief said.

Hassman was arrested and charged with 320 counts of illegally distributing narcotics and 41 counts of health care fraud.

Just before the case was scheduled for trial, federal prosecutors offered Hassman a plea agreement, allowing her to plead guilty to four counts of failing to report prescription abuse. Unwilling to risk a jury trial, Hassman accepted the offer. She was sentenced to two years' probation and agreed to surrender her DEA license to prescribe controlled substances.

Hassman was relatively lucky. This April, Virginia pain specialist William Hurwitz was sentenced to 25 years in prison for drug trafficking after prescribing large doses of painkillers such as OxyContin, morphine, and methadone to his patients. One of his patients died after taking a very high dose of morphine. DEA officials likened Hurwitz to a heroin dealer. Others, though, testified that Hurwitz provided them with the only effective relief they had ever received for debilitating pain.

Though the DEA wouldn't comment for this article, it has previously insisted that it only goes after bad apples. "Our focus is not on pain doctors. Our focus is on people who divert drugs," agency official Patricia Good said during a 2004 teleconference. But physician groups and patient advocates point to a growing list of respected pain doctors who have been prosecuted by the DEA and by state medical boards. They say that while the DEA has a legitimate interest in preventing the diversion of harmful drugs, the agency's adversarial zeal has grown in the past four or five years.

For its part, the DEA notes that it arrests fewer than 100 doctors a year on drug-diversion charges—hardly a full-scale attack on the profession. The numbers hardly matter, though, because the arrests, and the publicity surrounding them, have created a chilling effect. "Every time a physician picks up a newspaper or hears an account of some physician who has been accused of inappropriately prescribing controlled substances, it reinforces the proposition bad things can happen to you when you attempt to manage patients' pain aggressively but appropriately," says bioethicist Ben Rich. "Doctors don't say, 'I'll be more judicious and that won't happen to me.' Their reaction is, 'I don't need this.' "

It took Deborah Hamalainen another year, plus the encouragement of a friend, to find effective treatment for her pain. Early one morning, the two women took an 80-mile bus trip to New York City, then took a taxi downtown to Beth Israel Medical Center. There, Hamalainen met with pain specialist Russell Portenoy, who found her story credible. Portenoy explained to Hamalainen that he couldn't cure her multiple sclerosis, but he could control her symptoms. "The goal is to focus on the pain itself, to get you comfortable, and to help you function," he told her.

After monitoring several medications for side effects, Portenoy and Hamalainen settled on fentanyl, a synthetic opioid delivered through an adhesive patch worn on her lower back. She uses oxycodone as a "rescue" drug when the fentanyl isn't effective.

As Portenoy predicted, the medicine hasn't eliminated the source of Hamalainen's pain. In fact, the multiple sclerosis has progressed. She's been losing feeling in her hands and feet, dropping objects, and tripping. She relies on a pair of canes to get around. Still, with the pain under control, Hamalainen has been able to return to her art. She recently had a mixed-media exhibition at the gallery where she used to work. In one sculpture, she took old canes—including the ones her father used after he lost a leg to diabetes—and smashed them with an ax, then enclosed them in a clear plastic exhibition box.

When the pain was at its worst, Hamalainen contemplated suicide. Now, with opioids to relieve the symptoms, Hamalainen can envision a productive artistic future. "Being able to be creative again has been thrilling," she says. "It's like having a new life."

**Barry Yeoman last wrote for AARP The Magazine about eminent domain, entitled:
"Whose House Is It Anyway?" (AARP Magazine; May & June 2005).**

[END]

Addiction, Pain, & Public Health website - www.doctordeluca.com/