

The Quality of Mercy

Effective pain treatments already exist. Why aren't doctors using them?

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Abstract:

New understandings of pain are being reached and treatments are beginning to be more effective as an alternative to suicide in severe cases.

IT TOOK DAVID BOGAN A DECADE TO BUILD A GOOD LIFE AND ONLY A FEW SECONDS to have it destroyed. A financial adviser in Deptford, N.J., Bogan owned a sailboat, a Porsche, and his own home. But one morning in 1995, as he was driving to his mother's memorial service, a car plowed into him from behind and changed all that. A back injury from the accident led to surgery. He woke from the anesthesia with the sensation that his right leg was burning up.

The face of Bogan, now 35, bears the marks of two years of constant pain from nerve damage in his back. "I can't shower because the water feels like molten lava," he says. "Every time someone turns on a ceiling fan, it feels like razor blades are cutting through my legs." He has been to 20 doctors in search of relief. He has drained his savings and sold his possessions to pay medical bills, and his friends, weary of trying to coax him out to dinner or a movie, are gone. Last December, when he began fantasizing about jumping off the Benjamin Franklin Bridge over the Delaware River, Bogan checked himself into Mensana Clinic, near Baltimore, which specializes in diagnosing and treating pain. By night, he watches old movies to distract himself. By day, he fights off suicidal thoughts as his current doctor searches for ways to stop the pain. Bogan says, "I'm dying."

To his doctor, Nelson Hendler, treating a patient like Bogan is humbling. Bogan is intelligent, articulate, profoundly depressed, and prepared to kill himself if no one can release him from his suffering. In the eyes of right-to-die proponents, cases like Bogan's serve as powerful arguments for legalizing physician-assisted suicide.

Indeed, pain is one of the principal reasons the sick ask for their doctors' help in dying. And the fear of an agonizing death underlies the support of more than 50 percent of Americans for legalizing physician-assisted suicide. Pain, says Dr. Mitchell Max, director of the Pain Research Clinic at the National Institute of Dental Research, "is the reason Jack Kevorkian has been so successful."

Pain specialists like Max might agree that legalized suicide is the answer--except that they know better. The best antidote to Kevorkian's appeal, in their opinion, is better treatment for pain. And that treatment already is available. Medicine at this very moment

has the means to relieve the agonies of the majority of dying patients. It could ameliorate the suffering of many people enchained by chronic pain. Even more effective treatments are on the way. Scientists have traced pain's path from the site of disease and injury to the brain. This knowledge is beginning to yield experimental drugs that eventually will relieve suffering even better than current therapies, with fewer side effects.

What is lacking is not the way to treat pain effectively but the will to do it. For a quarter of a century, pain specialists have been warning with increasing stridency that pain is undertreated in America. But a wide array of social forces continue to thwart efforts to improve treatment. Narcotics are the most powerful painkillers available, but doctors are afraid to prescribe them out of fear they will be prosecuted by overzealous law enforcers, or that they will turn their patients into addicts. Patients, too, are leary of the drugs. And living with pain in stoic silence still is seen as a sign of moral strength, while taking drugs to relieve it is often viewed as weak or evil. "We are pharmacological Calvinists," says Dr. Steven Hyman, director of the National Institute of Mental Health.

Staggering cost.

Thirty-four million people in this country suffer from chronic pain. Each year, millions of people seek relief at hospitals or pain clinics. The cost to the nation is staggering. Back pain, migraines, and arthritis alone rack up medical charges amounting to \$40 billion annually. And pain results in one quarter of all sick days taken, or 50 million in lost workdays a year.

The biggest obstacle to patients receiving adequate treatment, however, may not be cost, but ignorance. "The techniques for pain relief aren't particularly sophisticated," says Dr. Ira Byock, a pain specialist and author of *Dying Well* (Riverhead Books, 1997). But doctors don't know much about them. Only a fraction of medical residency programs require a course in pain management. Even fewer teach palliative medicine, which involves caring for the pain, psychological distress, and fears of dying patients and their families. Consequently, when most doctors begin practicing medicine, pain is not even in their awareness. A recent study found that half of hospital patients who were in substantial pain were never even asked by their doctors and nurses how much they hurt. After an experimental treatment for melanoma, says Anita Semjen, of Cabin John, Md., the burning pain in her right foot became unbearable. "My foot was dark red and swollen, and my thigh was 30 inches around." Yet, her doctors offered few painkillers at first.

"They thought I was overreacting," she says. According to recent surveys, the majority of AIDS patients endure severe pain--that is, pain that ranks above an 8 on a scale of 0 to 10, with 10 being "get me the gun" agony, as one doctor put it. More than half the AIDS patients who rated their pain as severe were prescribed drugs that experts consider barely adequate for moderate pain, according to one 1996 survey. A quarter of them were given no pain medication at all.

Many people suffer longer than necessary because the source of their pain has never been properly diagnosed, and if doctors don't know the cause of the pain, they can't treat it. In two studies involving 180 patients in chronic pain, Hendler found that about half were diagnosed incorrectly. Many, he said, were told that they had "sprained" backs, a

diagnosis that Hendler says is "garbage. You can't have a [back] sprain that lasts five years."

Patients themselves contribute to their own misery by suffering in silence, rather than complaining. "A patient says, 'I feel better.' But when you ask why they're not working, they say, 'I hurt too much,'" says Dr. John Loeser, director of the Multidisciplinary Pain Center at the University of Washington, in Seattle. In a recent survey, many AIDS patients said they didn't tell the doctor about their pain because they didn't want to be a burden. Others were afraid of being labeled as "bad" or troublesome patients.

Safe and effective.

The conviction that pain should be endured without complaint, and without resorting to the "crutch" of drugs, helps explain the reluctance of both doctors and patients to use narcotics, even though they are potent, safe, and effective weapons against pain. Also known as opioids because they originally derived from the opium poppy, narcotics like morphine, methadone, and codeine are routinely given to patients in acute, temporary pain--after a car wreck or major surgery, for example. They can blunt even the most savage pain in 90 to 95 percent of terminal cancer patients, according to a decade of work by pain specialists Drs. Kathleen Foley and Russell Portenoy of Memorial Sloan-Kettering Cancer Research Center.

Morphine is the only drug that makes cancer bearable for Lisa Steinberg, a 41-year-old Bethesda, Md., podiatrist who has survived long beyond the nine months her surgeon predicted when she was diagnosed with late-stage breast cancer in 1993. Unable to walk, and in excruciating pain from tumors that had spread to her pelvic bones, Steinberg had a morphine pump implanted in her abdomen last August. The device, called an intrathecal pump, is about the size and shape of a hockey puck. It delivers a slow, steady stream of morphine directly into her spinal column, allowing Steinberg to walk again and to resume her life.

Yet many patients balk at using narcotics, even when pain is severe. "Patients are terrified of these drugs," says Portenoy. Some worry that taking narcotics early in the course of their illness will leave them with nothing stronger when the pain gets really bad. But for most people, there is no upper limit to narcotics' capacity to dull pain: As the pain mounts, so can the dose. Others fret that narcotics will cloud their minds or leave them completely sedated. One Washington, D.C., man, who did not wish his name to be used, saw his mother suffer horribly from abdominal cancer because she resisted taking the morphine prescribed by her oncologist. "She was afraid she would be knocked out by the drugs," the man says. Yet in many cases, a skillful doctor can combine opioids with other drugs and analgesics to dull the pain without dulling the mind. It is usually at the very end that high doses are needed and the patient is kept sedated much of the time. Doctors have their own concerns about prescribing narcotics. State and federal drug enforcement agencies routinely monitor narcotic prescriptions, and they arrest more than 200 doctors and pharmacists a year on charges of giving them out too freely (box, Page 64). To avoid notice, most doctors refuse to prescribe refills; others give their patients doses that are too low to alleviate the pain.

In recent years, more physicians have become willing to employ narcotics at the end of life, though most are still not very skilled at doing so. But few doctors will even consider using the drugs to treat people who live in chronic pain, that is, pain that is not caused by cancer and lasts longer than a few months. A recent survey of 204 people with chronic pain found that most had sought help from an average of 10 physicians, yet only half had received drugs that reduced their agony. Chronic-pain patients who receive workers' compensation find the least compassion from healers. Suspecting them of being malingerers out for an easy buck, many hospitals and pain clinics turn such patients away at the door.

Millions of addicts?

No one disputes that some cases of chronic pain are very difficult to treat. But pain specialists who, like Foley and Portenoy, even dare to suggest that narcotics provide a merciful and safe relief for chronic pain, meet with vehement opposition. The biggest objection, raised frequently by opponents, is that such patients may use narcotics for years, raising the specter of millions of addicts.

But at the heart of this debate is confusion about what constitutes addiction and what is simply physical dependence. Most people who take morphine for more than a few days become physically dependent, suffering temporary withdrawal symptoms--nausea, muscle cramps, chills--if they stop taking it abruptly, without tapering the dose. But few exhibit the classic signs of addiction: a compulsive craving for the drug's euphoric or calming effects, and continued abuse of the drug even when to do so is obviously self-destructive.

In three studies involving nearly 25,000 cancer patients, Portenoy found that only seven became addicted to the narcotics they were taking. In part, this is because new formulations of the drugs, such as oral morphine, or narcotics delivered through a skin patch, are absorbed into the bloodstream slowly and consequently don't provide the heady rush that many addicts crave. Other studies suggest that morphine is "eaten up" by the bodies of people who are in pain, so that there is literally none left over to make them high. "If we called this drug by another name, if morphine didn't have a stigma, we wouldn't be fighting about it," says Foley.

For many patients who suffer from chronic pain, the complete refusal of most doctors to prescribe the only drugs that offer relief seems patronizing, if not downright cruel. Without adequate treatment, many consider suicide: It's a form of relief they do have access to, and at bad moments it can seem preferable to a life of persistent agony. "Nobody brought a gun today," jokes one man during a group session at the Mensana Clinic.

Faced with the desperation of their patients, a few doctors, particularly those at top pain clinics, have changed their minds about the use of narcotics for chronic pain. "Twenty years ago, I was strongly against the use of narcotics for chronic-pain patients," says Hendler. "My feeling, like most doctors, was there was potential for addiction. But Foley and Portenoy slowly and surely convinced me."

Still, pain specialists look forward to the day when there will be new and better pain-fighting drugs that allow them to rely less heavily on narcotics. To find such drugs, researchers have been delving into basic science, teasing apart the complex biology that underlies pain sensation.

The reason morphine works so well is that it taps into the body's own pain relief system. A painful impulse first travels from a broken finger, say, up the arm along a nerve leading into the spinal cord. There, a group of chemicals, called neurotransmitters, carry the information over a gap, or synapse, to a second nerve, which will ferry the message up the spine to the brain. One class of these neurotransmitters is chemically similar to morphine. Like opioid drugs, these neurotransmitters, also called opioids, serve to blunt the pain signal as it moves from one neuron to the next.

Pain alert.

In addition to the opioids, a slew of other neurotransmitters adjust the volume of pain intensity up or down before the brain ever finds out that something is wrong. Scientists still don't know exactly how this complicated process works. They do know that the nervous system has at least 15 different types of "receptors," each of which responds to one class of neurotransmitters. The presence of the right neurotransmitter tells a receptor to activate the nerve cell, changing the message it sends in some way. For example, the recently discovered "NMDA" receptor prompts nerve cells to be hypersensitive to pain, so that even a light touch can make a person scream.

NMDA and other pain enhancers may explain why morphine doesn't ease every patient's suffering. Researchers have recently found that the body sometimes responds to morphine by revving up pain enhancers like the NMDA system, which might be the body's effort to get the all-important pain message through to the brain. This may account for why many people need increasing doses of narcotics over time to obtain the same analgesic effect. And narcotics offer little relief for about half the people suffering from nerve damage, which often accompanies illnesses such as shingles, diabetes, cancer, AIDS, and some injuries like the one Bogan received. Researchers are not entirely sure why this is so, but they think it may occur because damaged nerves have fewer opioid receptors than healthy nerves, leaving no place for morphine molecules to dock.

In searching for better ways to treat pain, scientists have gained a greater appreciation of its utility. Pain is literally a lifesaver, alerting the brain to physical harm. "Pain is the body's smoke alarm," says Robert Coghill, a neurophysiologist at the National Institutes of Health. Victims of congenital analgesia, a rare condition that leaves them unable to feel pain, hurt themselves without knowing it, bending their joints to the point of tearing ligaments, or walking on a damaged bone until it breaks. They usually die by the time they are in their 30s from injuries they never felt, their bodies scarred from head to toe. Because pain is so vital, the brain gives it priority over information coming in from other senses. New brain imaging techniques like Positron Emission Tomography, or PET scanning, which give researchers a window on the brain's activity during pain, are showing that brain centers involved in everything from emotions, to movement, to attention "light up" in response to incoming pain signals. Such findings repudiate the notion that people in severe pain should "learn to live with it," says Hyman. "They can't.

Pain makes us unhappy. This is hard-wired in the brain." A person in terrible, chronic pain curls into a ball of misery, his brain unable to pay attention to anything else.

This new understanding of how pain signals dominate the brain has solved a lot of mysteries. For example, scientists now know that pain literally rewires the brain and the nervous system, so that a pain can spread to parts of the body far from the original injury--something chronic patients know all too well but doctors have been slow to acknowledge. Recent studies show that when pain signals from a particular area of the body arrive in the spinal cord, neurons "recruit" neighboring nerve cells to respond as if they were receiving pain signals as well. In the lab, Coghill studies pain by injecting chili-pepper extract into the feet of volunteers. Although the extract penetrates only a tiny distance into the foot, he has observed that it can send searing pain shooting halfway up the subjects' legs. In a condition known as reflex sympathetic dystrophy, this kind of spreading pain never goes away, and sometimes it can eventually take over much of the body. This has taught researchers the importance of getting to pain early, before it leaves lasting impressions in the brain and nervous system. Dr. Charles Berde of Boston Children's Hospital has found one way to do just that. He places tiny capsules of anesthetic at nerve endings during surgery, which stop the patients' pain signals before they even start, and relieve pain for several days.

Such findings are pointing the way to new analgesics that will be able to manipulate the body's own mechanisms for transmitting pain. In recent studies, drugs that block NMDA's action can reduce tolerance to morphine. That means that eventually, patients will be able to get more relief with lower doses of opioids, and to avoid side effects like constipation.

Better chemistry.

In the future, patients will be given drug cocktails, small amounts of four or five compounds that block different pain channels in the body. Several new classes of drugs used in various combinations are already in clinical trials, and a dozen new drugs are likely to reach the clinic within the next few years. And several drugs already in use for other purposes, such as antidepressants and anticonvulsants, are showing promise in treating pain. Researchers are also looking for ways to rid patients of chronic pain while preserving the initial, brief burst of pain that alerts the brain to damage. For example, SNX-111, now in the final stages of clinical trials at Neurex Corp., interferes with a type of neuron dedicated solely to transmitting long-lasting pain.

It will take a while for these new drugs and techniques to reach those who suffer. In the meantime, the ongoing debate over the right to die is offering an opportunity--a chance to reconsider, to educate, to change rigid ways of thinking about pain. In some places, change is already happening. Over the last decade, doctors who specialize in treating terminal cancer patients have broken down some of the legal barriers and misperceptions that have traditionally hindered doctors from prescribing narcotics. And a new awareness of pain is appearing at medical schools and research institutions. Dartmouth Medical School, for example, is drafting a curriculum for teaching pain management and palliative care. And at the National Institutes of Health, a newly convened pain

consortium will coordinate research now performed by far-flung scientific disciplines, and shepherd findings in basic science into commercial development.

Hospitals, too, are beginning to pay attention to pain. At the urging of the American Pain Society, some hospitals have begun to include a description of the patient's pain on the chart that records other vital signs, such as temperature and blood pressure. With a pain chart staring them in the face, nurses and doctors cannot avoid asking patients if they hurt, and they are more likely to take steps to control the pain. The Department of Health and Human Services has issued guidelines instructing hospitals to treat both chronic and acute pain aggressively with strong opioids. Though the guidelines are voluntary, millions of patients now refer to them when talking to their doctors about pain, says Dr. Daniel Carr, a co-author of the guidelines. "It's like raising the ocean an inch," he says. "It doesn't seem like much, but it can lead to massive changes."

Who will pay?

Pain experts are heartened by the signs of improvement. But they worry that the cost-cutting fervor of insurance companies and HMOs will put limits on how much things can change. Treating pain can be expensive. An intrathecal morphine pump like Steinberg's, for example, can cost as much as \$40,000. Doctors say they often have to spend weeks haggling for permission to prescribe pain-relieving drugs, technologies, or surgery, while their patients suffer.

Even more worrisome to pain specialists is the possibility that physician-assisted suicide will be legalized before better strategies for treating pain are in place. In the Netherlands, for example, where physician-assisted suicide and euthanasia were legalized 24 years ago, efforts to improve palliative care at the end of life remain undeveloped. The hospice movement there is more than 20 years behind its counterparts in the United States and Britain, where hospice doctors pioneered the use of narcotics for dying patients.

New drugs, new hospital policies, and a growing number of pain specialists may help bring about change. But what will finally persuade doctors and hospitals to alleviate unnecessary suffering is the realization by patients that they don't have to live with pain, and that dying is not the only solution. One day, severe pain could be a thing of the past, even at the end of life. "We're talking about having quality of life even in dying, and not having to spend the last three months of your life in total mismanagement," predicts Harold Slavkin, director of the National Institute of Dental Research. Within a few decades, more and more people will be living well, even into their 90s. They could also be dying well, free of pain.

The circuitous path of pain

The sensation of pain is triggered by signals from nerve endings at the injury site, which are then processed in a feedback loop between the spinal cord and the brain. New drug combinations promise to offer greater relief than current therapies.

Pain spotting.

Nerve endings in (for example) the elbow send pain signals up nerves in the arm to "control centers" in the spinal cord, where they are processed before the message is

relayed to the brain. Pain-inhibiting signals. The brain evaluates the importance of the information coming from the spinal cord and may send back signals telling the spinal cord to mute the body's response to the pain. The end result--ouch! The process of evaluation continues as long as the pain persists. The spinal cord acts as a kind of arbiter of signals coming from the injury site and the brain. Interrupting the pain. Drug combinations of the future will more directly interrupt the chemical communication among the nerves at the spinal cord so they do not send a signal on to the brain or become hyper-sensitive.

BEATING THE PAIN

How to get the help you might need Pain does not have to be a fact of life--or death. Many organizations offer information about support groups, referrals, and new treatments. Below are some resources for the most common types of pain.

GENERAL RESOURCES

The National Chronic Pain Outreach Association (540-997-5004). How to Cope With Chronic Pain by Nelson Hendler, M.D., and Judith Fenton, (Liberty Publishing Co., \$9.95). The Worldwide Congress on Pain Web site [<http://www.pain.com>]. A Child In Pain (Hartley & Marks Publishers Inc., \$14.95) by Leora Kuttner.

MIGRAINE HEADACHES

Severe headaches caused by expansion of blood vessels. PAIN TREATMENT Prescription drugs, including Imitrex and Depakote; also acupuncture and massage. RESOURCES The National Headache Foundation (800-843-2256) and Web site [<http://www.headaches.org>]. Migraine by Oliver Sacks (University of California Press, \$15.95).

TMJ

Temporomandibular joint disorder. A jaw condition caused by muscle spasms and teeth-grinding. PAIN TREATMENT Muscle relaxers, anti-inflammatory drugs, narcotics and, mouth splints. RESOURCES The American Academy of Head, Neck and Facial Pain (800-322-8651). TMJ and Facial Pain Center Web site [<http://www.netset.com/docws/>]. TMJ: Its Many Faces by Wesley Shankland (Anadem Publishing, \$19.95).

SHINGLES

A disease of the skin and nerves caused by the chicken pox virus. PAIN TREATMENT Antiviral drugs can minimize outbreaks. Narcotics and antiseizure drugs may be prescribed. A new anesthetic cream, EMLA, seems effective in dulling skin tenderness. RESOURCES The VZV Research Foundation (800-472-8478). Shingles and PHN (Cross River Press, \$10.95) by Thomas Carl Thomsen.

TERMINAL ILLNESS

Cancer and AIDS can inflict severe pain, especially near the end. PAIN TREATMENT May consist of drug "cocktails" containing a narcotic (to dull pain) and a stimulant (to ward off drowsiness). Many patients also find relief from therapies such as acupuncture and massage. People with terminal illnesses often need help managing depression, anger, and grief, as well. RESOURCES The National Hospice Organization (800-658-8898).

The National Cancer Institute, Cancer Information Service (800-422-6237). The Cancer Pain Page Web site [<http://www.mdacc.tmc.edu/acc>]. Online book Pain in HIV/AIDS [<http://www.roxane.com/Roxane/RPI/AIDSPain/PainBook/index.html>]. Centers for Disease Control and Prevention Web site [<http://www.cdc.gov>] and AIDS Hotline (800-342-2437).

BACK PAIN

Bone, muscle, ligament, tendon, nerve, and joint disorders can lead to chronic back pain.

PAIN TREATMENT Over-the-counter painkillers, prescription anti-inflammatories, exercise, ultrasound, and traction. Surgery and narcotics may also be advised.

RESOURCES Chronic Back Pain: Moving On (Biddle Publishing Co., \$9.95).

WellnessWeb [<http://wellweb.com/index/QBACKPAI.html>].

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