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Page N-6

THERE ARE WAYS TO MANAGE

JOURNAL ILLUSTRATION BY TOM MURPHY

New attitudes, techniques and medicines can soothe the hurt

BY VICTORIA L. WILCOX
SPECIAL TO THE JOURNAL

After a root canal in 1996, Susan Harkins's mouth felt as if someone was putting "a hot poker underneath the teeth." It has felt that way ever since.

The procedure damaged some nerves, saddling her with pain that typically rates a "5" on a 1-to-10 scale. A few times a day, it spikes to an "8."

Despite her injury, the Barrington resident still works as a welfare eligibility technician for the Rhode Island Department of Human Services. At times, she has retreated to the bathroom to cry. Yet, she smiles when she sees people, not wanting to drive them away with complaining.

Before pain became her constant, overbearing companion, Harkins considered herself a "life-of-the-party kind of person." Now, she avoids socializing. She has changed so much her husband asked, "Where did my girl go?"

In pursuit of relief, Harkins, 56, has seen 14 doctors, including specialists in Boston and Pittsburgh. She has tried prescription pills, custom-blended creams, and custom-made dental appliances. She has even asked doctors to cut a nerve.

Like Harkins, many Americans live with chronic pain, a major cause of disability. Pain becomes chronic when it outlives the usual recovery period for an illness or injury, or lasts more than six months, even if it waxes and wanes. Often, it stems from back problems, arthritis, fibromyalgia, headaches, or nervous system disorders such as diabetic neuropathy. Harkins's pain goes by the name of atypical trigeminal neuralgia.

Dr. Daniel Carr, Saltonstall Professor of Pain Research at Tufts-New England Medical Center, calls pain the top reason people seek medical care. Yet, "For many years the importance of pain has been belittled," he says.

Although proper treatment can prevent needless disability and distress, people with unrelenting pain face many hurdles to finding relief. For instance, while Harkins thinks some doctors took her pain seriously, others did not. She says, "When it comes to pain, people don't understand."

Recently, the Endometriosis Association surveyed women with chronic pelvic pain. Many said their obstetrician or gynecologist accused them of exaggerating.

SEE **PAIN, N-3**

Inside: Chronic-pain clinic gets results. **Page N-3**

Pain

Continued from N-1

Carr gives other examples of the belittling that occurs. Health-care providers might say, "Just give it a few more months." They might blame patients for doing too much or too little, or for not following the medical regimen.

In fact, a recent article in a medical journal made a striking admission. It said, "We as medical professionals have put the blame on our patients when we don't understand" what ails them. Many health-care providers feel ill-prepared to treat pain, having received little training in it.

Patients fret that health-care providers will mistake them for slackers or drug seekers. Carr notes that only a "very small" percentage of patients masquerade as pain sufferers. Dr. Peter Baziotis, an anesthesiologist who directs the Center for Pain Management at Memorial Hospital of Rhode Island, agrees. He says most patients "want to get better, they want to get back to work, and they want to get back to their lives."

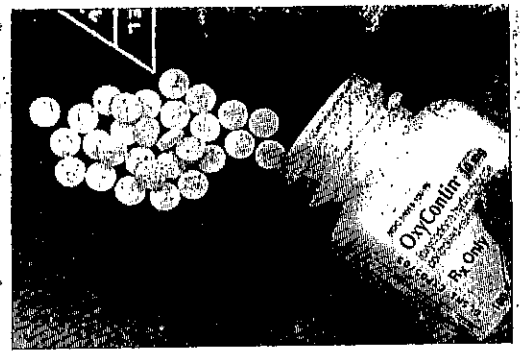
Pain's subjectiveness poses a challenge for health-care providers. Two people exposed to the same stimulus will report different pain levels. Providers cannot order a blood test to measure pain.

Even so, research is starting to document changes in the nervous systems of chronic pain sufferers. For instance, a recent study found that people with fibromyalgia had amplified pain signals in certain areas of the brain. Another found signs of abnormal pain-processing pathways in patients with low back pain.

FOR MANY PEOPLE, medications quiet the hurt. However, Carr says that managed care hinders providers' efforts to match patients with the best medication. If studies show that two drugs yield equivalent results, a health-maintenance organization may include only one in its preferred formulary. Yet, in a given patient, one drug may work better than the other.

Opiates, such as morphine or the long-acting OxyContin, can subdue fierce pain, but providers and patients vary in their attitudes toward them. Some providers think more patients would benefit from them, Carr says. Others, fearing possible addiction with long-term use, try to wean as many people as possible off of them.

"When used appropriately for pain," Baziotis says, "there's not a problem with abuse." Tolerance may develop, however, leading to the need for higher doses to achieve the same relief.



PAINFUL CHOICE: Many doctors do not like to prescribe the powerful painkiller OxyContin because of the potential for abuse.

LOS ANGELES TIMES PHOTO

Patients with raging pain may show signs of "pseudoaddiction." Ronald Thebarge, a clinical assistant professor of psychiatry and human behavior at Brown Medical School, explains, "They're on such a tight leash that they're constantly having to call their doctor and say, 'This isn't working,' or, 'I need more medication.' " Desperate for relief, they seem desperate for drugs.

Fear of crime inflames the controversy. Providers face threats from patients denied opiates. Patients who take often-abused pain relievers, such as OxyContin, don't want anyone to know. They worry about attracting thieves who need to feed their own addiction or hope to make money by selling opiates on the street.

DESPITE these problems, experts sense a sea change occurring in the treatment of chronic pain, perhaps echoing what Carr calls "the rise of consumerism and patient-centered care." Last year, the Joint Commission on Accreditation of Healthcare Organizations added pain control to its criteria for evaluating candidates for accreditation. Advocates are pushing for pain's acceptance as "the fifth vital sign," putting it on par with pulse and blood pressure.

The new thinking views chronic pain not just as a symptom of illness or injury, but, rather, as a disease in itself. Carr says the hallmarks of "chronic pain syndrome" include withdrawal from work, friends, and family; a high risk of depression or anxiety; even an increased risk of suicide. Those afflicted tend to do less, weakening their muscles and sapping their stamina. As the vicious cycle churns, they become more disabled.

Pain often begets more pain, as sufferers adjust the way they do things to avoid hurting, perhaps favoring one side of the body. Harkins feels pain in her neck and shoulders, as her muscles absorb the stress of living with mouth pain. In a cruel twist, persistent pain ramps up the sensitivity of the nervous system, as if, having been blindsided by injury before, it fortifies its defenses against future assaults.

Carr says that John Bonica, the father of modern pain management, "recognized that the proper rehabilitation of someone with chronic pain would rarely be accomplished just by giving them a medicine or injection." Because pain colors every inch of sufferers' lives, they need a multipronged approach. Depending on the problem, this may involve specialists in orthopedics, neurology, neurological surgery, physical therapy, nursing, psychiatry, and psychology, among others. An aggressive approach, experts say, unshackles some people from years of needless pain, gives partial relief to others, and enables still others to thrive despite pain.

PAIN MANAGEMENT should start with a thorough evaluation. The work-up sometimes unearths an overlooked, but treatable, cause of the pain.

Even without any known cause, medical treatments may help. Besides pills, the arsenal includes electrical stimulators, implanted medication pumps, nerve blocks, and injections. Other strategies include behavioral interventions to help people function better and physical therapy to restore strength and flexibility.

While approaches and programs vary, a common theme underlies all: they validate patients' pain as real.

Since 1997, Harkins has been getting help with her pain from the Behavioral Medicine Clinic at Miriam Hospital. Harkins says, "There comes a time when you have to realize this is not going away."

According to Thebarge, who treats Harkins at the clinic, patients learn that, "While I may not be to blame for this, I am responsible for how I proceed from here." Many think that if they cannot do things the way they used to, they cannot do them at all. Some need to find new ways to do things or new activities to enjoy.

Harkins, for example, discovered she enjoys writing poetry and drawing. She has forgotten her burning mouth only once, while drawing till 3 a.m.

Patients must learn to pace their activities. On their better

days, many overdo it, and then spend days recovering. Thebarge tries to break the "cycle of all or none." Harkins has learned to say "no" and to fight the urge to take care of everyone but herself.

On the other hand, patients may need to stop viewing their bodies as fragile. Often, those with low back pain treat their backs like "a glass rod" that will break if they do too much, Carr says. Yet, many can and should exercise.

Harkins learned relaxation techniques at the clinic. When she first tried them, she asked herself, "What am I doing? Is this the '60s?"

No longer skeptical, she now calls them "a saving grace."

Despite advances in pain medicine, Baziotis says some pain clinics in Rhode Island have closed due to poor reimbursements. Carr considers it a false economy to "delay, defer, and deny," since people with uncontrolled pain use health-care services at a high rate.

While Harkins hopes for a cure, she won't sit around waiting for one. She is moving on with her life, smiling through the pain.

Victoria L. Wilcox, a psychologist and consultant for the Neurosurgery Foundation, writes from Greenville.