Chronic-pain patients must cope with chronic lack of physician understanding

Brian Goldman, MD

This article, written by CMAJ *contributing editor Dr. Brian Goldman, is the first of a three-part series on the enigma of chronic pain. In preparing the series Goldman crisscrossed North America twice in search of state-of-the-art approaches to persistent pain. He concluded that physicians' efforts fall far short of what patients, and doctors themselves, expect from other areas of medicine. Interviews with patients who live with constant pain painted a picture of modern physicians at their worst — inept, inconsiderate, sometimes arrogant. The first part of Goldman's series is adapted from a radio documentary he produced recently for a CBC program,* Ideas.

Do no harm. Most of us readily recognize that aphorism, written by Hippocrates more than 2000 years ago. I heard it often at medical school and during residency training, and today it still guides most physicians. Or at least it is supposed to; one area where it doesn't is the treatment of chronic pain. Consider these examples:

- A 22-year-old man experienced a sudden onset of pain in his left hip. When the results of x-rays and blood tests were inconclusive, his doctor suggested the pain was in his mind. Eventually, it was determined that the pain was caused by an osteogenic sarcoma. It recently caused his death.
- Chronic pain developed in the neck and shoulder of a 49-year-old woman after she fell in her kitchen. More than a dozen specialists failed to diagnose the source, and some suggested she see a psychiatrist.
- Chronic, spasmodic pain developed in a 45-year-old woman, a paraplegic since a motorcycle accident 23 years earlier. When she asked her doctors for help, she was accused of being a drug seeker.

Cases like these are not rare, probably because physicians view acute and chronic pain differently. We respond quickly and compassionately when the pain is acute, but become puzzled and frustrated when it is chronic.

"Some of the doctors you meet are unbelievably cold," Sheila Cherry, the paraplegic accused of being a drug seeker, said during an interview at the Memorial Sloan-Kettering Cancer Center in New York City. "If they can't cure you then they don't want to help you."

Cherry's motorcycle accident broke her back and severed her spinal cord. It took 2 years and several operations to recover from her injuries, but after the acute pain abated she was fine, save for an occasional muscle spasm.

Years later she married Tom Cherry, a New Jersey electrician, and before her pain reappeared the couple led an active life. She worked in a government office and they travelled widely — 3 years ago they went white-water rafting in New Zealand.

Two years ago the pain became much worse. The muscle spasms, which now occur up to 60 times a day, vary in sensation from a mild charley horse to a violent grabbing that awakens her from a sound sleep. "The pain became so bad the first thing I'd do when I woke up was cry," she recalls. "It was so bad it hurt to move."

Initially she consulted her general internist in New Jersey and was referred to local specialists. They conducted a battery of tests, but none pinpointed the pain's source. Her doctors speculated that it was related to the original spinal cord injury, but there was no hard evidence. Cherry says the doctors who first saw her 2 years ago weren't prepared to deal with chronic pain.

"If someone's sick, they operate or give them a pill, they get better, and that's the end

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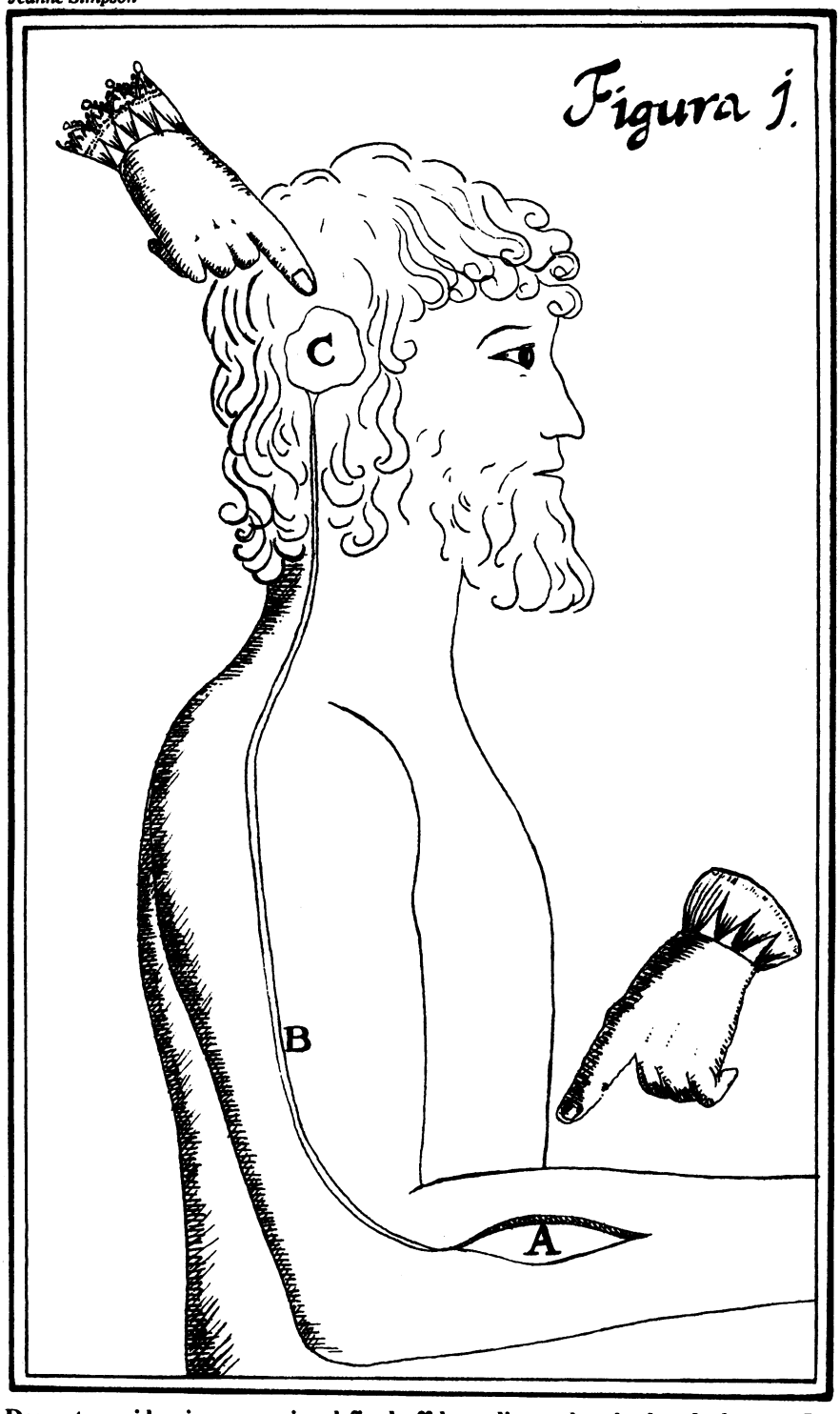
Jeanne Simpson



Descartes said pain was a signal fired off by a diseased or broken body part. It then travelled through "pain channels" to the brain.

of it," says Cherry. "They seem to get almost annoyed when they have to deal with long-term pain. I got the impression that they either think I'm putting on an act or that I'm doing this to get drugs. I'm not looking for sympathy; what I was looking for was a little empathy."

She says physicians cannot identify with that need.

I crossed the continent more than once to determine why patients like Cherry receive so little help. I discovered that the reasons are both numerous and complex, but first in line is ignorance.

"There is essentially no organized curriculum in medical schools, in pharmacy schools, in nursing schools or in any of the paraprofessional schools that relates directly to the assessment and treatment of chronic pain," says Cherry's pain specialist, Dr. Russell Portenoy of Memorial Sloan-Kettering Cancer Center and the Cornell University Medical College in New York City.

"For the longest time pain was viewed only as a symptom of an underlying disease and the interest was in identifying that and curing it if possible, thereby relieving the pain. It's only in the last 20 years or so that people have begun to understand that chronic pain itself is the disease and that it can persist in the absence of an organic cause."

Dr. Chit-Chan Gunn of Vancouver, who specializes in diagnosing and treating myofascial pain, is also a consultant to the Multidisciplinary Pain Service at the University of Washington Medical Center in Seattle.

"The university is about to have its first professor of pain," he told *CMAJ*. "We have professors of surgery, dermatology, obgyn, but no professor of pain. And since pain is usually the presenting complaint, you'd expect it would be first on the list. It isn't."

Physicians have not always thought that pain is primarily a symptom of underlying disease. However, 300 years ago French philosopher-mathematician René Descartes changed the way doctors view it, and his influence continues to this day. In 1664 Descartes proposed that pain is a signal fired off by a diseased or broken body part. According to his model, the signal travels through "pain channels" to the brain. The brain contributes a sense of awareness of the pain, but does nothing to control or modify the signal or experience of pain.

In the 19th century physiologists replaced the pain-channel concept with the nervous system, but Descartes' theory remained in vogue. Lately, pain specialists have gained a nascent awareness of the true nature of pain, but many unanswered questions remain:

- Why do some people tolerate it better than others?
- What roles do culture and learning play in the perception and the experience of pain?
- Why do some people with injuries experience chronic pain, but others with identical injuries do not?

Despite growing awareness about the nature of pain, the Cartesian model still holds firm in physicians' minds, probably because it is both simple and seductive. It teaches doctors not to treat pain itself, but to regard it as a clue that indicates the presence of disease or a broken body part. Physicians who accept this model are banking that if they heal the broken part, the pain will go away.

Although it might work well for a Colles' fracture, the model does not for causalgia, or shingles, or phantom limb pain. "Physicians are, to a large degree, trapped in the legacy of Descartes, who told us that there was a mind and a body and those were separate things," says Dr. John Loeser, professor of neurosurgery and anesthesiology at the University of Washington Medical Center, and director of its Multidisciplinary Pain Service. "The Cartesian dualism is a very dangerous trap in the treatment of patients with chronic pain and the sooner we can get people to throw it away, the better."

The implications the "search for the broken body part" have for patients in chronic pain are enormous. In their search for broken parts, doctors and patients spend enormous amounts of time and money on investigations and consultations.

Loeser says patients search for broken parts, too. "Their physicians are looking for a broken part, so the patient's behaviour is reinforced repeatedly by a health care system that recycles them through all this diagnostic assessment and workup over and over and over again. Everybody looks at the human body as if it was like an automobile, that if it doesn't work right there's got to be a broken part."

Kay Bartlett, an *Associated Press* reporter, is still searching for her broken part. She's the 49-year-old woman mentioned earlier who began suffering chronic neck and shoulder pain after falling in her kitchen. Since then she's consulted an internist, several orthopedic surgeons, a neurosurgeon, physiotherapists, physiatrists, acupuncturists and several masseurs. Although none has found a cause or cure for her chronic pain, they've been generous with advice.

"[Some say] it's muscle damage, some say nerve damage, some fibromyalgia — those are the main three," she said in an interview in her New York apartment. "It's a conflict of wear the collar, don't wear the collar. Use ice, use heat. Stay in bed and rest, be active. At this point I've taken control of my own case."

Bartlett's search for a broken part didn't end there. Several months after our interview she consulted another New York specialist, who diagnosed her condition as "spasmodic torticollis." As an experiment, he is injecting the affected muscle with *Clostridium botulinum* toxin. She estimates that she has spent at least $25 000 on consultations, computed tomographs, magnetic resonance images and other tests. Like Cherry, she found that most doctors are unsympathetic.

"Specialists are interested in fascinating cases, famous people," she says. "They're not interested in plain old neck injuries, whiplash. They do not realize how debilitating it is, how depressing it is, and how it affects the rest of your health and life."

In the world of mind-body dualism, doctors and patients tend to categorize symptoms as physical or psychological; they find it difficult to conceive that symptoms arise from both physiology and psychology. In the late 1950s, chronic pain was labelled a psychiatric disease; Dr. Harold Merskey, professor of psychiatry at the University of Western Ontario in London, was one of the first psychiatrists to focus on it. At the time, many doctors were fascinated with the possibility that much disease may be caused by the mind's influence on the body. For example, asthma was widely believed to be caused by personality characteristics or emotional adaptation. Why not pain?

"It began with a lack of knowledge about mechanisms of pain," Merskey says. "Yet, here are these patients with lots of pain. Why can't we find out what's wrong with them?"

For a decade or so Merskey and his colleagues treated chronic-pain patients with the traditional tools of psychiatry, such as insight-oriented and supportive psychotherapy, but they were successful only occasionally. On the other hand, psychiatrists had a great deal of success using drugs, such as the antidepressant amitriptyline. Slowly, physicians such as Merskey concluded that psychiatrists were on the wrong track.

"It's not just the fault of psychiatrists," he says. "Our role in the treatment of pain was thrust upon us by other specialists. We all misread the situation. The specialists said, 'We don't see a broken bone, so there's nothing wrong with you.' Because of this, chronic pain was offered to us."

Today, doctors don't generally believe that chronic pain is a psychiatric disorder, but many

think it has a strong psychological component. Loeser, for instance, points to an epidemic of chronic low-back pain in the United States, where it accounts for greater economic losses than cancer and heart disease combined.

"I think chronic pain is a stress disorder that has become an epidemic because of the difficulties people have in coping with the modern world," he speculates. "The way people manifest their difficulties is culturally determined.

"It's acceptable in our society to claim that you can't function because of an illness, in this case chronic pain. So, what we're looking at predominantly is the realization that many people's lives are not happy, not fulfilling, and that many jobs are not pleasant or challenging. People are not motivated to be contributors."

Pain specialists at the University of Washington have taken Loeser's philosophy to its logical conclusion — they don't treat pain, but its behavioural consequences. The program, which uses behaviour modification to discourage patients from focusing on pain, was developed by Dr. Wilbert Fordyce, professor of rehabilitation medicine at the university's school of medicine.

Patients are admitted to hospital for a gruelling 3-week program involving intensive physiotherapy, group therapy and withdrawal from analgesics and other medications. "We encourage families to not respond when the patient focuses on his or her pain and talks about it," said Fordyce. "When the person is talking about something else, then you respond. You're letting your social feedback or attention be contingent upon engaging in a behaviour that is helpful and useful. And you avoid letting your attention be contingent upon emitting or expressing pain behaviours."

The Seattle program succeeds in getting most patients back to work, but does it take away their pain? Some researchers consider it a denial of the patient's chief complaint. "You do not, for the most part, change the pain they have," says Ronald Melzack, a professor of psychology at McGill University and a pain researcher. "You're teaching them how to live with their pain, but you have not got down to that basic problem — the pain that needles away at them."

Bartlett did not need to be cajoled back to work. Despite constant severe pain she continues as a reporter, but now works out of her apartment; a computer links her with the office. "My company offered a disability pension and I've rejected it," she says. "I want to work till I drop. I want to get better."

Chronic-pain sufferers aren't the only ones to believe that doctors have a problem dealing with them. "I have worked with colleagues who, as far as I'm concerned, were callous," says Melzack. "That, I think, is unfair and unprofessional — you certainly expect a lot more of the people in the healing arts.

"I have seen physicians who've distanced themselves so far that they are not able to understand the extent and awfulness of the suffering. It seems to me that if you're going to have a physician who really is concerned about the patient's pain and wants to do his very best to treat it, he must also feel considerable empathy and sympathy for the patient."

Dr. Bruce Pomeranz, a neurophysiologist at the University of Toronto and an expert on acupuncture and endorphins, carries Melzack's assessment further — he believes physicians blame chronic-pain patients when treatment fails. "It's not done consciously, but if a method fails it's human nature not to blame yourself. Man has always wanted to conquer nature and doctors want to conquer death. If a treatment fails they feel like a failure and most people can't cope with that. It takes a courageous doctor to admit that he doesn't have answers."

"I don't see it as a lack of sympathy," Portenoy adds. "Physicians become frustrated by their lack of knowledge. That can lead to a withdrawal from the patient, an aloofness, because the constant complaints can't be dealt with."

There are no easy solutions to these attitudinal problems. Pain specialists say medical students should receive more training in chronic-pain management. "Unfortunately, the wheels move slowly," says Melzack. "It's going to be a long time before medical students get proper training about chronic pain and what it can do."

Altering medical school curricula won't help physicians already in practice, so Melzack thinks clinics that specialize in chronic-pain treatment are one way to meet the current need. "The great breakthrough in the pain clinic is that it will have a team of people who might be able to help," he concludes.

In this age of cost containment, pain clinics are unlikely to be a high-priority item. The situation in Alberta, where there are no clinics, is typical — only a handful of physicians is available to meet the needs of more than 2 million people. "We have a tremendous waiting list," says Dr. Helen Hays, an Edmonton-based family physician who specializes in palliative care. "There is no backup."

As yet, chronic pain is not a major issue for medical researchers, and its treatment is not as "sexy" an item as magnetic resonance imaging or laser endoscopy. With scarce funding, it is likely to stay that way.

[In the next issue of *CMAJ*, Dr. Brian Goldman will look at the widespread use, and misuse, of analgesics in the treatment of chronic pain.]