Lessons in Pain Relief — A Personal Postgraduate Experience

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When I chaired an Institute of Medicine (IOM) committee on “Relieving Pain in America” and then coauthored a Perspective article about the vast human toll and financial burden imposed by chronic pain, I believed I understood the impact of chronic pain. Not only did I have experience caring for children with life-threatening and frequently painful disorders, I also had relatives with chronic pain syndromes and had witnessed the limitations of the medical care system. But it wasn’t until my own year-long journey with chronic pain that I received a higher-level education on the topic.

I was loading a suitcase onto an airport conveyor belt, when an unexpected twist led to my first twinge of back pain. I assumed it would be self-limited, especially since I was in good physical shape: for the past several decades, I’d been running one to three marathons a year and working at demanding jobs, most recently as a medical school dean. I felt impervious to stress and was almost always optimistic. Chronic pain changed all that.

Two weeks later, I had another sudden onset of lower back pain and spasm. Unlike anything I’d ever experienced, it soon became localized to the left mid-buttock area. At that point, I sought medical guidance. In the year that followed, I became immersed in trying to assess the widely varying skills, strengths, biases, and deficits of various specialists and care providers. Complicating this variation was the limited evidence base regarding back and musculoskeletal pain. I was surprised by how quickly providers leapt to a default diagnosis that lay within their own comfort zone, even before gathering all the facts or performing a physical examination. Disk herniation was first on everyone’s list — understandably, given its prevalence.

When, after nearly 5 months, interventions including twice-daily physical therapy, acupuncture, deep tissue massage, and efforts to improve my posture had not alleviated my pain, I seemed to be moving out of the self-limiting clinical course generally associated with disk problems.

The patients with chronic pain who prove most challenging to clinicians are those whose physical evaluation, imaging, and other studies are negative or unrevealing. I was one of those patients. Despite symptoms that became more constant and incapacitating, two spine MRIs (6 months apart), an MRI of the pelvis, and one of the hip failed to reveal a clear source. The pain migrated from the lateral buttock to the left ischial tuberosity and was not relieved by sitting, standing, walking, or lying down. One examiner noted a substantial loss of left hamstring strength. After 7 months, I began having radiating pain in the left leg, albeit not below the knee. As time went on and my symptoms and limitations worsened, various clinicians offered suggestions, which often differed from each other. Some clinicians wondered whether the pain was becoming “functional.” Others strongly believed that it was probably neuropathic in origin, but without a defined trigger or site to explain it or to treat. I began having symptoms of clinical depression that contrasted starkly with my usual personality.

After 10 months of unremitting pain, many negative exams, and several ineffective injections of steroids and anesthetics into putative sites of nerve entrapment, efforts were made to refine the diagnostic assessment of the sciatic nerve, from its exit from the spine down to the leg. This was not a standard examination, but had it not been performed, the likely origin of my pain might still be undetermined. It proved diagnostic in defining a high branch of the left sciatic nerve that went through the body of the piriformis muscle. This branch innervated the hamstring muscle and helped to explain why a third of its strength had been lost; this finding was further verified by EMG and nerve-conduction studies. Presumably, it was a congenital aberration with which I had lived successfully for more than six decades. Although there is much debate about the “piriformis syndrome,” in my case the sciatic entrapment was now well defined. The cascade of events following my initial injury was probably exacerbated by the stretching and pelvic anteversion efforts made to improve my posture — an unintended consequence.

The diagnosis was further confirmed by surgery, which appears to have been successful. Though it was a fairly major procedure, the relief from nerve entrapment and neuropathic pain was noticeable within days. Unfortunately, I proved highly sensitive to opiates...
and had two episodes of respiratory depression within days after surgery that required naloxone reversal and intensive care — a response that was not readily predictable and that underscores one of the dangers of using opiates for pain control.

While working with the IOM committee on pain relief, I learned a great deal about the facts, figures, and impact of chronic pain in the United States. But over the past year, I've learned new and very personal lessons about how chronic pain can negatively transform one’s life force.

Previously, I had sometimes wondered whether the chronic pain that patients reported was as incapacitating as they claimed. I now know that it can become debilitating. It can take over one's life, sap one's energy, and negate or neutralize joy and well-being.

Although the question of whether depression antedates or is secondary to chronic pain is still debated, I learned that the sense of loss and the uncertainty that accompanies it can trigger manifestations of clinical depression that also require medical attention. These symptoms can rapidly reverse when the pain is relieved.

I learned that the experience of pain is highly individual, and that ways of measuring it, defining its triggers or causes, and addressing it are limited and subjective. Even sophisticated diagnostic studies lack the sensitivity to delineate subtle anatomical or physiological aberrations. I was fortunate to have an imaging study that defined the cause of my pain, but it is not one that's generally offered, and I could easily have been one of those patients who is told that a cause cannot be defined, nor a solution delineated.

I am confident that the various physician specialists I encountered were eager to help me, but many spent surprisingly little time and diligence thinking beyond the boundaries of their fields of expertise. Fortunately, I had an exceptional primary care physician who was able to coordinate, process, and lead — but that is often not the case for patients with chronic pain.

My experience underscores how much additional knowledge is needed to better define the causes and manifestations of pain, to calibrate its intensity more objectively, and to treat it more successfully and safely. I had a hard time calibrating my own pain on the traditional 1-to-10 scale, especially in the immediate post-operative period but also more generally. That difficulty has implications for the way pain is treated. And although we are all cognizant of the deaths that occur with opioid use and abuse, my experience raises the question of how much we know about the pharmacogenomics of these drugs and how well they are being monitored in clinical settings.

The IOM report laid out recommendations covering pain as a public health challenge, the care of people with pain, and the education and research challenges. The committee affirmed that “addressing the nation’s enormous burden of pain will require a cultural transformation in the way pain is understood, assessed, and treated.” My experience with chronic pain as a physician and as a patient underscores this conclusion and brings greater urgency to the implementation of the IOM committee’s recommendations for relieving pain in America.

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